IDEAHL

Improving Digital Empowerment for Active Healthy Living

TASK 2.2 SETTING THE FRAMEWORK

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1. INTRODUCTION

The scope of Task 2.2 Setting the framework is twofold: on the one hand, to formalize the targets and the potential areas of improvement to be reached by the EU (d)HL Strategy outlined when defining the project proposal, in order for it to be comprehensive and inclusive; on the other, to identify eventual additional elements related to health literacy and digital health literacy that seems important to explore during the co-creation process foreseen in Work Package 2 Co-creation of the EU strategy to improve (d)HL.

To this end, the analysis focused on ongoing and recent policies in the European regions. It is important to underline that, during analysis, the term policies have been adopted in its most extensive sense, considering National Action Plans on Health, Regional policies and programs, European or country-based indications and guidelines, European Commission-funded projects, and local initiatives.

The research investigated health promotion, disease prevention, treatment, and self-care as crucial domains of d(HL), by exploring for each of them the following elements: existing policies and initiatives, principal shortcomings and barriers, areas of potential improvement, actors to be involved, types of initiatives to be developed and, finally, their level of implementation.

According to the requirements, this document presents the results of this investigation and incorporates the principal findings from the literature review conducted within the Work Package 1 Map (d)HL research and practices in Europe and beyond, dedicated to mapping (see D1.1 Report on (d)HL). The main results are provided in the close of the document.

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2.THE FOUR DOMAINS

2.1 Health Promotion

Existing policies/ Policy initiatives

Health Literacy and Digital Health Literacy are closely interconnected with the concept of health promotion, as a matter of fact increasing health skills and trust among the general population, patients, and healthcare workers is essential to advance health promotion. Health promotion is not only one of the objectives to which HL and (d)HL policies tend, but it collects a series of initiatives whose policies are substantiated in order to improve the general standard of health, improve knowledge of risk factors and encourage people to adopt healthy lifestyles and behaviours.

In order to develop or enhance and test new models and approaches of (digital) health literacy intervention through the co-creation of an EU (d)HL Strategy, is central to consider the existing policies and related activities to benefit citizens, patients, and communities. To do that it is necessary to act at all levels of society: individual, community, organizational, and system (legislative), thus extending the range of areas of intervention, including the living environment, the workplace, the media, and digital health, according to a holistic approach.

According to The Health Evidence Network synthesis report 57, a total of 19 member states have recognized low health literacy as an issue to focus on and have consequently developed or are in the process of developing policy to address it: Austria, Belgium, Croatia, Czechia, Finland, France, Germany, Ireland, Israel, Italy, Portugal, Romania, Russian Federation, San Marino, Slovenia, Spain, Sweden, Switzerland, and the United Kingdom.

What appears crucial is a stronger political commitment to health literacy and digital health literacy, through the involvement of policymakers, to ensure long-lasting and comprehensive success in the implementation of these strategies. Such a commitment can be achieved through stable governance and stable funding mechanisms within a clear, shared, and actionable framework for improving the level of HL and (d)HL. Policy-makers are recommended to monitor and evaluate the progress of investments and policies to be certain that they are contributing as expected to the achievement of national health goals. It is, therefore, necessary to incorporate robust qualitative and quantitative evaluations into health literacy policies and interventions before and after activity, with evidence of health, social and economic effects at all levels. To this end, better engagement between policymakers and the academic community would be fruitful to collect solid data to inform policies and measure the impact of policy-related activities.

What is recorded is that there are examples of national HL/(d)HL programs, which are often similar or tend in the same direction, but what is missing is precisely a comprehensive and shared framework for the European region. Member states would benefit from the adoption of this framework and the use of its metrics to design effective policies that support the development of a health-literate Europe.

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Main shortcomings/ Barriers

Insufficient health literacy not only impacts the lives of individuals because they are unable to properly take care of their health but also constitutes a social and economic challenge. Understanding the reasons for low levels of health literacy helps us identify what barriers to overcome and obstacles to remove. These motivations are not exclusively attributable to individuals' lack of knowledge or skills, but people's contexts and lifestyles play a significant role.

The analysis shows that our education system does not address these issues, just as the health system seems unable to provide adequate information to support them. In fact, the information coming from the healthcare system is often perceived by users as too complicated. At the same time, research methods also do not seem to be enough intuitive. This can lead to overuse, underuse, or incorrect use, which can not only cause unnecessary harm to the people concerned but also create unnecessary costs for the healthcare system.

Obstacles to policy success include cultural barriers, such as social and economic inequalities, and deep-rooted cultural beliefs, which make it difficult to adopt healthier lifestyles, and/or educational attainment.

According to the WHO document "From Innovation to Implementation - eHealth in the WHO European Region" (2016), one of the barriers that cannot be ignored is the linguistic one. English is known to be the primary language dominating the web, which is especially relevant when we look at disparities in digital health literacy. It seems that ethnicity as a single barrier factor may have less impact than language.

Another issue is the sustainability of these policies, which prove to be effective when they are stable and shared. As a matter of fact, the lack of a structural and fixed budget dedicated to health literacy policies can significantly limit the activities of HL and DHL and their effectiveness. Add to this, it is underlined difficulty obtaining high-quality evidence of those interventions, which reveals a lack of attention in the spheres of evaluation and measurement.

What is useful to keep in mind is that existing barriers can be addressed and overcome through cross-sectoral work, underpinned by institutional processes and structures, including the active involvement of political leadership and community participation and networking.

Areas of improvement

When it comes to health promotion, what requires immediate attention is the shift from a problem-solving-disease perspective to a prevention perspective and the dissemination and correct application of information outside the health context. Health promotion must be supported especially in the living environment and in everyday life, therefore it is necessary to focus on everyday life environments and challenges outside the healthcare system. However, this does not mean that the health system can be side-lined, but that there is a need to improve the information for the users of the system and to make the health system itself more health literate and user-friendly, thus reducing the challenges users face.

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Another area of improvement concerns inequalities in health literacy: transferring health promotion efforts from offline to online and mobile devices does not automatically alleviate these inequalities, even with today's improved access to technology.

Health promotion is also essential to enable people with an immigration background to take care of their own health. Therefore, the health information offered should take into account cultural diversity and language barriers, at the same time health professionals should be aware of this diversity and be able to develop strategies to better address the challenges of limited health literacy. Readability of health-related content found on the internet is still a relevant issue: language and ethnicity should be taken into account, while the use of instant translation services could result in mistakes and misunderstandings. These are important aspects to be addressed for a better adaptation of future DHL interventions.

Another aspect to consider is that, although the Internet is becoming increasingly important for seeking health information, doctors are still the most trusted source of information. This suggests that a combination of instruments, including physician live or online consultation, could be helpful in delivering useful and effective health information using digital information technology. In order to foster the development of health promotion policies and interventions, it is decisive to be able to demonstrate their impacts on the individual, the community, and the health and social system. consequently, one of the areas of focus must be how the benefits can be spread and made known to the community. The measurement and evaluation of the interventions are the keys to strengthening health promotion interventions and also health literacy in a broader sense.

Actors to be involved

Actors can be defined as the people working or living in the sectors, organizations, professions, and societal groups affected by health promotion policies. When we speak about actors involved, therefore, we refer both to those who are the beneficiaries or recipients of the interventions, and to those who take part in the implementation of policy activities. Furthermore, it would be auspicial to involve the stakeholders also in the planning phase of these policies, using the co-design method, because their active participation could assure more effectiveness. For this to happen, it's essential that patients, citizens, learners, school students, and health professionals get involved at an early stage, taking into particular account people in vulnerable groups, such as older people, migrant groups, socioeconomically excluded and children in socioeconomically deprived families, prisoners.

As has already emerged in the course of this document, the centrality of the involvement of institutional subjects and public bodies and organizations - especially those working in the fields of education, health, and social services - is also highlighted.

Another group of actors that it is strategic to be engaged is represented by the media and journalists, who have a crucial role in the communication and dissemination of information.

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Type of initiatives to be developed

What needs to be emphasized first and foremost is the importance of networking for the development and implementation of policies and interventions, reaching out to involve policymakers and institutional actors at the local, national and European levels. There are already networks to support and foster, such as the WHO European Action Network on Health Literacy for Prevention and Control of Noncommunicable Diseases. Collaboration and support within these networks are as crucial as any collaboration working to systematically develop, implement or evaluate health literacy.

In most cases, health literacy and thus health promotion interventions have mainly been addressed within specific healthcare settings or diagnostic groups. However, more integrated and wide-ranging approaches have the potential to better identify needs and improve the response across the lifespan by reducing barriers and improving support systems. it is essential to support the development and implementation of both further national and transnational projects that expand and broaden the variety of contexts, reaching different populations and different stages of life at the same time, and of interventions aimed at health literacy in specific areas of the population that are or are at risk of being marginalized.

Another recurring element, which should continue to be implemented and indeed strengthened, is the use of co-design in the development and implementation of interventions. The use of methods that attempt to actively involve all stakeholders, such as users, employees, collaborators, or other interested parties, can support the creation of context-sensitive initiatives that improve local empowerment and sustainability.

Summarising the main findings and suggestions that could help health promotion, the following points have been identified:

- **Everyday life environment**
  Enable the education system to promote health literacy early in life;
  Promote health literacy in professional life and at the workplace;
  Strengthen health literacy in dealing with consumption and nutrition offers;
  Facilitate the handling of health information in the media;
  Empower communities to strengthen the health literacy of citizens in their living environment.

- **Healthcare System**
  Integrate health literacy as a standard at all levels of the healthcare system;
  Facilitate navigation within the healthcare system, increase transparency, and reduce administrative barriers;
  Create comprehensible, effective communication between health professionals and users
  Facilitate and strengthen patient participation.

- **Life with chronic disease**
  Integrate health literacy into caring for the chronically ill;
  Facilitate and support a health-literate handling of disease progression and its consequences;
  Strengthen the self-management ability of people with chronic disease and their families;
  Promote health literacy for coping with everyday life and chronic disease.

- **Research**
  Develop health literacy research.

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Level of implementation

One of the main relevant studies on the determinant elements for the adoption of “Health promotion” initiatives and their success has been developed in the perimeter of the DEMATEL-Decision Making Trial and Evaluation Laboratory in 2021. The Study has deployed a method of analysis of the main factors that play a role in health promotion implementation. The proposed DEMATEL method constructs a cause-effect model of health promotion, and places forward suggestions and strategies for improvement based on the evaluation of the results. This research compared the original DEMATEL model with a Modified DEMATEL (M-DEMATEL) to identify the success factors of health promotion. The results have shown the connection and the difference between the two methods. The main purpose of this research is not to determine which method is the best method, but instead, to derive the combined effect of both methods.

The final results coming from the study is that the following dimensions should be considered as powerful levers for any kind of health promotion initiatives:

“Leadership” and “Communication channel” are the most two important factors and also influential factors when promoting healthy diet indication, while “Budget” is the most influential factor among all. “Leadership” is the ability to make subordinates obey voluntarily, and the key word is voluntary. As an example, concerning the non-profit organization, the charisma, kindness, and compassion of the leader can drive the behaviour of the volunteers and members. Therefore, leadership is authoritative when followers are willing to obey because they believe the leader’s directions represent followers’ self-interest and also the mission of the organization. Leadership was identified as the most frequently associated factor with health promotion.

In the case of the “Communication channel”, health promotion may benefit from the use of mass media to promote positive health behaviours. Thus, the result implied that health promotion campaigns that combine mass media and communication channels with the distribution of free or reduced-price health-related products are effective in improving healthy behaviours.

It is believed that “Budget” is one of the important factors to operate activity or campaign for any organization. And, budget requirements depend on program focus, available resources, and incentives incorporated into the program and the specific health promotion activity. The majority of non-profit organizations depend largely on the donation of the public. Budget is important and crucial for non-profit organizations because it can be a way to achieve organizational sustainability and provide resources for campaigns and activities.

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2.2 Disease Prevention

Existing policies/ Policy initiatives

In the first place, it is important to point out that there are no policies, guidelines, or recommendations issued at the European level that each country is expected to implement for what concerns the topic of disease prevention and, more generally, with regard to (d)hl. It should be noted, however, that many of the policies initiated at the local level, seem to derive or draw inspiration from general WHO guidelines (such as the 2016 "From Innovation to Implementation - eHealth in the WHO European Region" or the 2019 "Draft WHO European roadmap for implementation of health literacy initiatives through the life course";https://www.who.int/publications/i/item/9789240055353). Such a framework implies that there is no unitary corpus to be considered, but a diverse range of initiatives, guidelines, projects, and policies, sometimes of an extemporaneous nature, issued by individual countries or regions. It is also significant to point out that in analysing policies it is often complex to distinguish the specific domain of disease prevention from other macro spheres linked to the theme of health, in particular health promotion and awareness raising.

These areas in fact lie along a continuum within the broader perimeter of initiatives aimed at educating individuals and communities by adopting a transversal approach. That being said, the (d)hl on disease prevention tends to address a general audience, having specific pathology as the main driver. In this regard, it is interesting to note the establishment of the European Network on Health Literacy for Prevention and Control of Non-Communicable Diseases launched in January 2019 (https://apps.who.int/iris/handle/10665/327056) with the aim of promoting health literacy around the vast topic of non-communicable diseases. The seven member countries of the network- Denmark, Ireland, The Netherlands, Portugal, France, Norway, and Slovakia- have implemented a series of health education initiatives on topics such as the prevention of obesity in children and adolescents, heart disease, rheumatic diseases, diabetes, kidney disease, and disease of the female reproductive system. Of a different slant, is the NHS Long Term Plan promoted by the British government starting in 2019, which targets the main causes of illness and premature death in the country, in order to raise awareness of their prevention: smoking, diabetes, hypertension, and alcohol consumption are the main objects of multiple programs and activities directed to population. Other examples can be found in Spain through initiatives such as Aulas de Salud and Canarias Saludable (Gran Canaria) or Educar en Salud (Valencia), aimed at encouraging education on disease prevention (of a general nature), also through the use of ICT (https://www.redescuelassalud.es/) There are cases, as in Ireland (National Intercultural Health Strategy, 2006, Atelier Roma Men's Training, Diversion and Health Literacy Programme, 2016) and Switzerland (National Programme on Migration and Health 200-13) in which health education and prevention programs are vertically directed to migrants and refugee population.

Initiatives aimed at the valorisation and dissemination of (d)hl can also be found in the Portugal Health Literacy Action Plan (2019-21), although no actions specifically focused on the prevention of the disease can be found. Furthermore, a constellation of activities promoted by the Ministry of Health is to be found in the Italian panorama. It is also possible to detect a good number of project initiatives at a European level on the topic, which however are limited in time and with narrow diffusion among the population. To conclude, there is a quite relevant range of initiatives at the country, regional and local levels that include disease prevention (often through an omni-comprehensive approach to health literacy) among their objectives. Their typology, level of formality, and systematization are extremely variable. In general, they aim to address the prevention of highly differentiated diseases, often targeting a general audience, but with some exceptions such as children, women, and migrants.

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Main shortcomings/Barriers

Initiatives to support (d)hl, also on disease prevention, seem to be relatively widespread across Europe. However, in most cases, they appear to be circumstantial and of a time-limited nature. This observation, although not extendable to all of them, makes it possible to state that, generally speaking, the poor systematization and homogenization of these practices could represent a barrier. Such a situation risks implying that the number of reached citizens remains relatively small and a potential discontinuity in the provision of educational opportunities.

Ensuring continuity and homogeneity would be in fact conducive to more awareness raising, better knowledge, and solid education. A further important element concerns citizens' capacity to reach and understand information about health, including disease prevention. Indeed, inequalities can be detected between people with a higher educational background and those who quit the educational pathway around the age of 15 (Eurobarometer, 2014). Inequalities between those with a higher level of schooling and those with a lower one seems to increase even more in the case of (d)hl. Here, additional difficulties are also related to the capacity to discern which online sources are truly reliable among the large quantity present. Moreover, information found on the web is considered commercially oriented by 40% of the population and, again, scarcely reliable regardless of their schooling level (Flash Eurobarometer report No 404 "European Digital Health Literacy).

According to the survey on digital health literacy developed in April 2011 by The Health on the net Foundation, searching for disease prevention and health-related information on the web finds additional critical issues in the low specificity of search results, their general disorganization, the excessive amount of information, it's in general, ´poor quality, and in the lack of information in the mother tongue of the individual. This last observation suggests that citizens with little or no literacy in the English language (that is predominant on the Web) and/or migrants and refugees, often unfamiliar with the one spoken in the migration country, are more exposed to the risk to face barriers confronted with the rest of the population. Of course, this is extendable also to health literacy that does not pass through the web. Finally, accessibility of information turns out to be a diriment variable, especially with regards to the online one.

Those who do not possess good digital literacy are in fact penalized. Absence or weak digital alphabetization is intended both as a lack of ability to properly use tools and as the absence of familiarity with the internet and its features, with the consequent difficulty or incapacity of orienting, discerning, and understanding. Finally, accessibility is strictly connected to possessing the technological infrastructure that allows access, such as PCs, smartphones, tablets, and, first and foremost, the Internet network connection.

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Areas of improvement

Based on the above, the following can be considered areas of improvement:

• Accessibility of information, in its various declinations;
• Attention to the specificities of certain segments of the population (older adults, migrants, low-literate and other vulnerable population).

Developing programs that take these variables into account could allow more citizens to be approached, ensuring more widespread awareness and knowledge. Systematization of programs aimed at fostering (d)hl and disease prevention can be a key element to ensure this result. Equally relevant seems their diversification according to the target audience. Such improvement could open the door to greater and more effective dissemination, increased quality, and, hopefully, a more significant impact on the population. Communication should also be developed by the target audience, identifying the appropriate channels, the register to be adopted, and the proper way to organize the information. This would facilitate accessibility.

Actors to be involved

A primary role should be played by public institutions which should ensure the systematization and homogenization of initiatives targeting disease prevention (and dhl in general), whose patchy and often extemporaneous nature, as stated above, can be a limitation in terms of incisiveness and effectiveness. In addition, it would be essential to encourage the active participation of individuals and community -including the so-called “hard to reach” and people belonging to the vast range of the “minorities” - in the design and definition of these policies at the local, regional and national level before their enactment. This would not only ensure greater accessibility, but also greater sensitivity, awareness, and responsibility on the part of the citizen, who would no longer be just a user, but would have an active and proactive role. Such circumstances could ensure their stronger effectiveness. Indeed, disease prevention represents a theme that would significantly benefit from the creation of a dialogue between the healthcare institution and the citizen, who is in fact required to enact virtuous behaviours in order to implement it.

Type of initiatives to be developed

The policies developed would first benefit from good coordination between the local, regional, and national dimensions and their actors, so as to be as coherent as possible and potentially equally widespread throughout the territory. Similarly important would be their capacity to reach individuals regardless of their differences and specificities. They should therefore foresee training occasions, courses, and initiatives diversified according to the subject’s specifics. Ad hoc structured consulting materials and communication strategies would also be useful to this scope, adopting differentiated registers and communication channels. Attention to the territory constitutes another important variable: the territorial characteristics (type of population, infrastructures present, organization of services ...) should be accounted to adapt them, making them really accessible. In short, initiatives and policies should leverage common objectives at a macro level, as well as an equally homogeneous territorial diffusion, but paying attention to differentiate both according to the target and to local specificities. To this scope, the creation of alliances with the various agencies of the territory, even of an informal nature, such as associations of citizens, cultural and recreational centres, schools, and other relevant stakeholders, represents another important keystone.

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Level of implementation

Policies oriented towards (d)hl on disease prevention seem to have reached a fair degree of implementation in different European countries. Implementation must be here understood in the sense of dissemination rather than actual advancement and systemization. In fact, it is difficult to state how deep-rooted these policies actually are and how far they represent structured and lasting initiatives. Whether they are policies issued at the state or regional level, guidelines, European commission-funded projects, or local initiatives, it is hard to find accurate information on their actual concretization and their sustainability, partly preventing such evaluation. In this respect, it should be also underlined that no detailed data is generally available with regard to their impact, often lacking an impact assessment, an element that would allow a more accurate evaluation of their level of implementation. Many of the initiatives, particularly those of a very local character, and those linked to projects financed by the European Commission or other fundings, also seem to be of an extemporary nature. It is, therefore, possible to state that the spread of (d)hl, including but not limited to disease prevention, appears to be good, but it is not possible to verify its degree of real development, structuring, and territorial impact.

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2.3 Treatment

Existing policies/Policy initiatives

Information has become easily accessible, more channels, media, and sources are available, and the amount of information increases steadily. At the same time, digitalization changes existing structures of treatment and interaction in the healthcare system. This development continues at a rapid pace and brings new chances but also new challenges. In the context of Health or Digital Health when we talk about treatment, we cannot fail to consider the role of the patient and their caregivers within the whole constellation concerning Health Literacy distributed in global, national, and regional policies, and strategies for health promotion and social determinants of health. According to Sørensen et al., “Health literacy is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course”. One of the WHO objectives to improve access to treatments and interventions is to promote inclusive communication. As written in the report WHO National Health Literacy Demonstration Projects (NHLDPs) address health literacy needs in the European Region, rapid advances in health technologies and treatment options inevitably result in the increased complexity of health systems. This poses a risk for vulnerable people and communities, with lower health literacy, to be left behind due to reduced access, knowledge, and understanding. Vulnerable groups include people who have limited education, a migration background, multiple morbidities, or experience loneliness, among others whose voices are often left unheard.

Main shortcomings/ Barriers

When interventions fail to address the specific needs of these groups and communities, average improvements in population health can conceal widening health inequalities. Therefore, it should always be questioned whether new interventions reach those who are often not considered, in order to prevent the unintentional widening of the health gap. By genuinely and effectively involving all stakeholders, including vulnerable groups, interventions are likely to be more appropriate for a wider number of people and thus support WHO’s mission to leave no one behind.

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Areas of improvement

When considering approved actions in most of the national plans to comprehensively increase access to good treatments, one area of improvement appears the necessity of a change in patient role, preferably by adopting the shared decision-making model. Such a model is based on the collaboration between patients and members of the healthcare professions team and it is characterized by a process of an equal and shared decision on the care pathway. Studies show that shared decision-making can lead to an increase in knowledge, active participation in the treatment process, and an improvement in the communication between physicians and patients, that's why it is fundamental to involve the healthcare system, with its organizations and actors, in the improvement of health literacy and work towards the development of a system that is user-friendly and health literate at all levels. Its aim should be for all users to express their needs, make informed decisions and participate actively in treatment and care because communication problems can have negative effects on the course of treatment. In addition, the German National Action Plan-Health Literacy Promoting health literacy, stated that chronic diseases currently constitute the most diffuse type of disease, creating considerable challenges with regard to health literacy and self-management. At the same time, chronic illnesses require particular skills in terms of dealing with health-relevant information, for example when navigating the healthcare system or making decisions about treatment and care options. In this sense, communication seems a relevant area of improvement to be considered. More specifically it would be important to create comprehensible, effective communication between health professionals and users and improve communication and information in order to make informed decisions also in the advanced stages of illness and at the end of life, to avoid or reduce treatment-related stress and unnecessary suffering, and to maintain a good quality of life. According to IC-HEALTH - Deliverable 1.1 - Report on key factors, drivers, barriers, and trends on digital health literacy it would be important to strengthen Information and Communication Technology for health and well-being (eHealth) as it is becoming a key area with high growth potential and possibilities for innovation in Europe, and which can enhance the quality of care. eHealth has the potential to empower citizens to improve their management of health and disease, improve prevention, enable more accurate diagnosis and treatment and facilitate communication between healthcare professionals and patients. It can also contribute to more equal access to healthcare while facilitating access to health information.

Actors to be involved

The main actors are undoubtedly the sectors, organizations, and socio-health and health professions, as well as citizen interventions, both those who participate in the implementation of policy activities. These actors, together with relevant territorial stakeholders, should be involved in the design and local adaptation of policies through participatory strategies. This is with a view to laying the groundwork for their greater effectiveness. Important at this stage is the involvement of people from vulnerable groups, such as the elderly, migrant groups, socioeconomically excluded and vulnerable groups, children in socioeconomically disadvantaged families, and prisoners.

Equally important is the active presence of institutional actors and public agencies and organizations, primarily those working in the fields of education, health, and social services.

Type of initiatives to be developed

Making people with low health literacy aware of their rights and involving patients in treatment and care is particularly challenging. That's why it is necessary to develop standards in care facilities on how patients' voice can be taken into consideration during each phase of treatment and care ("no decision about me without me"), and at the same time increase support in recognizing patients' rights with respect to service provision.

Level of implementation

There are examples of national HL programs (such as the "NHS Long Term Plan" implemented in 2019 in the United Kingdom, the Scottish health literacy action plans "Making It Easy", promoted in 2014, and "Making It Easier" in 2017, the German "National Action Plan – Health Literacy" developed in 2018 or the "Health Literacy Action Plan" launched in Portugal in 2019) or other forms of national Health strategies that do comprise aspects of HL, (d)HL and attention on how to get access to the best treatment to assist the increasing number of people needing care and the intensity of support they require by - growing visibility and concern about areas of longstanding unmet health need (for example in young people's mental health services); - expanding frontiers of medical science and innovation, introducing new treatment possibilities that a modern health service should rightly be providing (for example, new cell and gene therapies). Also, technology is an important resource to be considered as it's written in the IC-HEALTH project - (Deliverable 1.1-Report on key factors, drivers, barriers, and trends on digital health literacy), using Big Data in health has many potential benefits. It may contribute to, for example, increasing the effectiveness and quality of treatments available for patients, widening possibilities for disease prevention by identifying risk factors at the population, sub-population, and individual levels, improving pharma co-vigilance and patient safety and reducing inefficiency and waste.

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2.4 Self-Care

Existing policies/Policy initiatives

The issue of "self-care" is inherent to the main idea of Health or Digital Health Literacy and is therefore present in all policies and initiatives that have been or are being proposed throughout the European Region in the most recent years. Although some of these policies do not explicitly mention "self-care" it is evidently implied not only as a goal of such policies but also as a means to achieve the intended results. Sometimes the topic is referred to with a slight change of words, such as "self-management", "self-improvement", "self-monitoring" or via a synonym or a periphrasis like "improved awareness", "independence", or "autonomy". Self-care is never solely indicated as the only objective of HL or (d)HL policies but is always paired with a number of other actions that helps build a comprehensive strategy aiming to activate and engage a wider range of stakeholders, from health professionals to caregivers and policy-makers.

Even though most HL and (d)HL policies are expected to descend from general WHO guidelines (such as the 2016 "From Innovation to Implementation - eHealth in the WHO European Region" or the 2019 "Draft WHO European roadmap for implementation of health literacy initiatives through the life course", that so far remained at the draft level) there does not seem to be a univocal and unambiguous body of legislation at the European level that coordinates all member states. Nevertheless, there are examples of national HL programs (such as Scotland's health literacy action plans 2014 "Making It Easy" and 2017 "Making It Easier", Germany's 2018 "National Action Plan – Health Literacy" or Portugal's 2019 "Health Literacy Action Plan") or other forms of national Health strategies that do comprise aspects of HL, (d)HL and attention to the issue of "self-care". One such example is the UK "NHS Long Term Plan" which devotes a specific focus to "supported self-management" and "self-management education" within a broader strategy that foresees integrated support provided by Health professionals. As the national policy documents seem to insert HL within a wider range of issues, smaller and more local public authorities seem to be able to focus more directly on HL and (d)HL as vehicles to promote "self-care". It is the case, for example, of the City of Stoke-on-Trent (UK) that since 2014 has been implementing a number of HL initiatives addressed to school children, hospital patients, health professionals, pharmacies, and so on by involving different local stakeholders in the program such as universities, charitable bodies, foundations, the local NHS branch, GPs, pharmacies, cultural and arts associations, and schools.

There is a plethora of bespoke, precise projects and initiatives that aim or have aimed at promoting "self-care" through citizens' engagement.

Main shortcomings/Barriers

It is often hard to estimate what the costs of launching, implementing, and maintaining HL and (d)HL strategies and actions are, although there is wide consensus in acknowledging that a higher degree of "self-care" will result in smaller financial strain on the National Health Systems. Simultaneously, it will also represent a lighter burden on the economic allowance of people by preventing them from experiencing serious health conditions that might be costly to sustain. With the exception of singular, specific projects and trials that depend on a fixed budget, it is usually not clear how much the implementation of a policy would cost, especially within a broader evaluation model of its efficacy.

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Indeed, what seems to be the biggest shortcoming in the vast majority of European policies, action plans and initiatives is the lack of an appropriate evaluation and monitoring model that could demonstrate whether the foreseen (or deployed) actions will actually generate a positive outcome. Similarly, when such policies do include an evaluation plan, as in Portugal's 2019 Health Literacy Action Plan, it is difficult to identify results and whether an overview and analysis of findings, feedback, and output has taken place (or whether it is being carried out right now). Despite the lack of data in this sense, it seems that, according to WHO's recommendations, there is a need to place a stronger focus on the evaluation of results within a theoretical framework that will subsequently instruct further actions, if required. With regards to "self-care" outcomes (and other sub-topics of HL alike), there appears to be a certain degree of detachment from the eventual national guidelines and the various concrete projects, actions, and initiatives that are carried out at the local level. On the one hand, it is not clear how much of a political commitment is invested in the topic of Health Literacy as an important component of a comprehensive health policy and strategy, particularly in the direction of an increased level of self-care and -management by the public. On the other hand, the distance between the various actors (policy-makers; health professionals; citizens) in the deployment of HL strategies and actions for the enhancement of self-care, and their univocal direction of relationship, with no real exchange of views, does not produce an informed and dialogic discourse that could eliminate the risk of complicating the engagement of the public and its uptake of the proposed solutions.

Lastly, as Health Literacy levels struggle across Europe, many policies and initiatives still dedicate too little attention to the potential role that digital/mobile technologies and social media could play in promoting self-care. This rings particularly through with respect to people in later life that is traditionally the beneficiary group that most drags behind in the use of digital technologies. While there is quite a strong focus on the Health Literacy of children and, simultaneously, while there is a number of policies to stimulate the training in the use of digital technologies, these two often do not seem coordinated within a general comprehensive HL strategy that looks with as much care to older individuals.

Areas of improvement

A lot of attention is recently being put on increasing the simplicity of texts and processes (see for example the New Zealand Plain Language Bill that was approved in October 2022; https://www.parliament.nz/en/pb/bills-and-laws/bills-proposed-laws/document/BILL_115953/plain-language-bill). To simplify language means actually improving the accessibility of contents to the wider public and when it comes to matters of health this implies eliminating exclusive medical jargon and limiting sources of difficulty related to numeracy and literacy. It is important that guidelines, information materials, and initiatives that wish to stimulate self-care are fully comprehensible by the larger portion of beneficiaries.

Other aspects that should be taken into account when designing HL and (d)HL policies directed at promoting "self-care" consist in planning ahead for a thorough scheme of evaluation that considers the actions that are being put into place or that could be implemented according to the set guidelines. To conduct project initiatives along a certain methodology does not bring effective results if these are not monitored and weighted inside a structured vision of what is the impact that is achieved (compared to what was desired), how much it costs to achieve that impact, and what should be done next according to this result. The scrutiny of results is therefore an obligatory passage that needs to inform the subsequent decisions on how to proceed with the path that has been undertaken, or on how to tweak the proposed solutions if they have been unsuccessful.

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It is desirable that the general public be more widely involved in shaping policies and initiatives together with policy- and decision-makers, as well as with health professionals. Too often the HL strategies are based on a training approach that sees a one-directional relationship between the trainer (health professional or other) and the citizens seen as mere recipients of content designed from a “top-down” perspective. Considering they are not only to be considered the objects of “self-care” initiatives but the actual subjects that will have to take the issue into their hands, it seems only appropriate that they are truly empowered in all stages of the process.

Another area of improvement would be to invest more generously in a more comprehensive mobile and social media strategy. With the increasing level of digital alphabetization and the widespread use of mobile devices and social media, with which most people are already familiar, it would make sense to plan a robust action plan that seeks to exploit the pervasiveness of these technologies. Although there is already a lot of investment in the training for digital alphabetization and the improvement of digital skills, this is not usually organically coordinated with HL strategy, while the individual interface of mobile technologies and social media would be the most suitable instrument to promote personalized self-care.

Actors to be involved

The wide variety of policies and initiatives that are currently being deployed around Europe insist on the engagement of several different levels of stakeholders where the one constant is the involvement of citizens as end-users and beneficiaries, particularly considering they are the main actors that need to actively take things into their hands in order to put “self-care” habits into practice. Nevertheless, individuals and communities should be brought into the process at an earlier stage and with a rather more active role that could establish a dialogue with regional and national institutions as well as with health professionals and trainers alike. Indeed, the community dimension, as opposed to the general “nation-wide” policies and to the individual repercussion of these policies, could be the right scope on which to invest by collectivizing responsibility within the limits of a recognizable and relatable group of people that are close to each other, either geographically or for social and cultural reasons. As is the case for the project initiatives developed by the City of Stoke-on-Trent, or by the OEPGK (Österreichische Plattform Gesundheits Kompetenz – the Austrian Health Literacy Alliance; https://oepgk.at/english-summary/), many programs have been developed explicitly around one specific community, rooting the mission of the project in the local identity and for the local wellbeing by tailoring the activities around the people belonging to the same local group.

In order to best capitalize on the engagement of citizens and communities it is important to win the support of and work collaboratively with national, regional, and local partners who can, on the one hand, provide financial and technical assistance, and on the other hand, help reiterate and multiply the effort of engagement directed towards the public. This is particularly true when such partners enjoy a sense of reliability and trust from the public’s perspective. For this reason, it is recommendable that even policies at the national level foresee direct involvement and a strong collaboration with local partners and especially with those who can be trusted and represent “familiar faces” for the local communities such as not-for-profit organizations, foundations, local cultural associations, schools, GPs, etc.

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Type of initiatives to be developed

It is recommendable that general large-scope policies be implemented via a number of projects and initiatives that are coordinated within a wider, comprehensive vision that has set clear objectives and results. The projects that can be observed at the European level, even if implemented locally, often seem to be directed autonomously outside of a coordinated effort that seeks to achieve an impact within the established logical framework. As aforementioned, it is desirable that such projects and initiatives being developed at the closest possible level to citizens and communities, considering the need to stimulate the uptake of “self-care” habits. For this reason, the initiatives should try to involve local partners and stakeholders in the financial and technical investment, by inspiring them to adopt the mission of the wider HL and (d)HL policies. Similarly, these partners and stakeholders should, alongside the citizens themselves, be involved in the initial stages of the process, since its design and in setting the objectives that are pursued and the methodology that will be deployed.

Level of implementation

The current level of implementation of most national frameworks and policies appears to be quite at an early stage due to the lack of clear and explicit results that derive from these policies. As the sample of policies considered in this study comprehends instances that are quite recent in time, it may be that these are still being implemented or need to find a concrete appliance through projects and initiatives, and therefore data coming from results and feedback still needs to be gathered or harmonized in structured reports. Nevertheless, as illustrated earlier on, most often there does not seem to be a clear strategy for the evaluation and monitoring of results and therefore there is uncertainty regarding if, when, and how such data will be available and who will analyse them.

In fact, there are various examples of projects and other kind of initiatives that have been deployed in recent years but they seem to be rather extemporaneous and with no clear or guaranteed outlook of subsequent actions.

Lastly, in recent years the general global attention regarding health might have slightly shifted due to the emergence of the SARS-CoV-2 pandemic that is dragging on well into 2022. This urgent issue appears to have paralyzed the production of new legislative and strategic documents on HL and (d)HL, although it could be said that all health recommendations spread by national and regional governments during the pandemics represent nothing but instances of self-care itself, with respect to the COVID-19 disease.

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3. SETTING THE FRAMEWORK IN A NUTSHELL

Below is an overview of the elements that emerged as transversal to the four domains of d(HL), and which therefore appear to be the key points to be given special attention when conducting the co-creation process.

Existing policies/policy initiatives

A plurality of initiatives and programmes is observed. They significatively differ in terms of focus, extension (local, regional, national), duration and target group;

When observing practices, it is often difficult to distinguish one domain from the other, as formal definitions get blurred when translated into concreteness. d(HL)-oriented actions and initiatives are frequently embedded in broader health-related policies, where (digital) health-literacy is not the sole or the direct objective;

d(HL) is not always explicitly mentioned in policies addressing it. Sometimes themes related to d(HL) are dealt with by explicitly labelling it, others it is not clearly delimited.

Main shortcomings/Barriers

Accessibility appears central in its plural expressions: as comprehensibility of health-related contents, information and services, accessibility to communication channels, accessibility to technology and digital environment. Accessibility is highly impacted from:

- **Educational level:** information is often considered too technical and complex, requiring an educational background that is not in line with the average level of the population;
- **Language barriers:** information is rarely provided in the languages of minorities;
- **Socio-economic conditions:** they can have a multilevel impact on the individual (purchasing power, schooling, marginality in its plural declinations) limiting accessibility to tools, information and services;
- **Cultural aspects:** health-related socio-cultural elements tend to be ignored or scarcely considered in information development and in services planning and delivery;
- **Information,** especially but not only on-line one, is too abundant and poorly organized; this is strictly connected to the problem of
- **Reliability:** citizens find it difficult to discern which source of information is reliable and which is not;
- **Low digital literacy;**
- Overly complex **bureaucracies** and **procedures** for **accessing services** (both digital and traditional).

Although, as mentioned, policies related to d(HL) are present, they lack homogeneity, both at national and European level, often consisting of initiatives of an extemporaneous nature and/ or of limited, discontinuous duration, or of an exclusively local character. While these are not critical aspects per se, they may become so to the extent that missing uniformity and continuity may result in a fragmented and poor impact on the population.

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Areas of improvement

Based on what reported with concern to the main shortcomings and barriers, the following appears as relevant elements to insist on:

Information & Communication, that should be improved by:
- Developing content according to the to target groups in order to make them accessible and understandable;
- Identifying effective communication channels, that can be diversified based on the target.

Organization should go into the direction of:
- Systematising and homogenising policies;
- Reducing administrative barriers, both when planning and delivery on line and traditional services;
- Improving digital literacy and providing educational opportunities.

Actors to be involved

The involvement of citizens, policy makers and key national, regional and local stakeholder/actors seems important in order to develop actions that are in line with population's needs, uniform and consistent in terms of vision and mission and homogeneously spread, but adaptable to territorial specific characteristics.

Types of initiatives to be developed

With regard the initiatives to be developed, they should move from what highlighted when considering the main shortcoming and the areas to be improved.

Based on these findings, they should:

- Sustain and improve digital literacy and education;
- Take into consideration demographical, social, cultural and gender aspects;
- Be based on coordinated and comprehensive vision and action (local, regional, national, EU);
- Simplify procedures and bureaucracies for the access and proper use of traditional and on-line health-related services;
- Develop coordinated and comprehensive vision and guidelines/indications in order to systematise policies and, by so doing, ensure their uniformity, homogeneity and continuity, thus increasing their impact on the population.

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Level of implementation

Health policies directly or indirectly including d(HL)-related interventions, are fairly diffuse at the countries-level. However, their implementation is discontinuous and diverse, both with regards to territorial diffusion and to the duration and continuity;

Interrogating implementation in the sense of impact, no conclusions can be drawn. The majority of initiatives do not include any form of assessment/evaluation, so it is not possible to estimate their actual effects.

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4. ADDITIONAL FINDINGS FROM WP1 D1.1. REPORT ON (D)HL

The mapping of HL and dHL ((d)HL) research and practices in Europe and beyond conducted within Work Package 1 has been structured into three main analytical strands:

1. Mapping of EU (d)HL research to assess the interconnections between (d)HL contribution and health, healthy living, and the well-being of citizens;

2. Mapping of (d)HL practices and identify best practices, and champions;

3. A review of existing monitoring mechanisms and indicators to assess EU (d)HL levels.

Because of its extensiveness and level of depth, a selection of the main results has here been made, isolating evidences related to the analysis of the implemented initiatives and best practices, as more aligned with the scope of the task. In order to have a complete and detailed overview of the entire analysis, and to better grasp its articulation, it is it is highly recommended reading the full version of the produced document D1.1. Report on (d)HL

Findings from the mapping are remarkably consistent and complement and complete the findings of the policy research. In fact, to emerge from the study is the necessity to:

- Implement cross sectoral interventions in order to increase (d)HL;
- Have clear and coherent goals, objectives, strategies for planning and developing policies related to d(HL);
- Define clear roles and responsibilities of the actors that are involved in developing and implementing policies;

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Moreover, to be identified as best practices are those initiatives that include:

- Training;
- Teamwork;
- Plain language/clear communication;
- Contact-based education;
- Contextually relevant information;
- An opportunity to explore varied perspectives;
- Sufficient time to integrate and apply learning;
- Organisational readiness/support;

In addition, visual communication seems well-suited for people with low HL.

The analysis also led to the formulation of a number of recommendations on actions to be deployed and direction to be taken, an extract of which is given here:

- Structure a shared strategy and action plan to guide the improvement of (d)HL in the EU;
- Develop interventions aiming at having an impact on those social determinants that can lead to improve the possibilities of obtaining successful and sustainable results;
- Consider demographical, social, cultural and gender aspects to target interventions towards groups of individuals with inadequate HL;
- Identify evaluation tools that have been developed according to the target group to be used continuously and uniformly across the EU.

5. CONCLUSION

The findings reported in this document show that the most relevant elements on which to focus in order to increase d(HL) tend to be common to all the health-related domains analysed. This evidence emerges from both the research conducted on the implemented policies and from the mapping of the literature. To stand out as a preponderant is undoubtedly the need for uniformity in vision and planning at supranational, hence European, and national level. Consistent and coherent guidelines should be the necessary outcomes of this.

On the other hand, the research highlights the urgency of aligning policies with the characteristics and needs of an extremely composite and diversified population. The capacity to intercept citizens' multiform instances and specificities, hence a flexibility and malleability to target group and context, appears as an equally crucial requirement.

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