

WP4

D4.1 IDEAHL inclusion, ethics & privacy toolkit V.1

Technical References

Deliverable No.	4.1
Dissemination Level	PU ¹
Work Package	WP4
Lead beneficiary	CSPA
Version	V.2
Due date of deliverable	31/12/2022
Actual submission date	29/12/2022

Versions

Version	Person	Partner	Date
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Approved by Coordinator on: 29/12/2022

Approved by Quality Manager on: 29/12/2022

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GLOSSARY / LIST OF ACRONYMS

AI: Artificial intelligence

(d)HL: (Digital) Health Literacy

EHR: Electronic Health Records

EIGE: European Institute for Gender Equality

EU: European Union

GBV: Gender-Based Violence

GDPR: General Data Protection Regulation

GP: General Practitioner

ICT: Information and Communication Technologies

OECD: Organization for Economic Cooperation and Development

SDOH: Social Determinants of Health

SDG: Sustainable Development Goal

STEM: Science, Technology, Engineering or Mathematics

WHO: World Health Organization

WP: Work Package

EXECUTIVE SUMMARY

This deliverable provides an **inclusion, ethics & privacy toolkit (Version 1) for the IDEAHL project**. The deliverable is intended for policy makers and health and care professionals and presents the aims of a toolkit and how the rationale for its design is based on these objectives.

The IDEAHL inclusion, ethics, and privacy toolkit V. 1 sets the basis and key principles for two thematic clusters – **gender and inclusion as well as ethics and privacy** – to be considered for the co-development and pilot of the IDEAHL European Union (EU) (digital) Health Literacy ((d)HL) Strategy and related activities. The toolkit builds and describes the state of the art, the main barriers, and challenges associated with gender and inclusion and ethics and privacy in the field of health and care and (digital) health literacy. This framework will be later considered when drafting the IDEAHL Strategy.

The toolkit content has been developed through the following approaches: literature review, policy review, and stakeholders' consultations on the addressed thematic clusters. On one side, the toolkit presents and discusses implications of gender and inclusion, and ethics and privacy in the health and care context and, more specifically, in relation to (d)HL, which is the focus of the IDEAHL project. These considerations provide the reader with a background and theoretical understanding of the main trends, barriers, and challenges emerged with the rising of digital technologies and the use of the Internet in the health and care sector and in the (d)HL field. On the other side, the toolkit puts forward an initial list of recommendations for policy makers and health and care professionals divided per thematic cluster (see Section 4). These draft recommendations are intended to build the foundations of the first activities of the project related to co-creation and development of the European Union (EU) (d)HL Strategy.

The ultimate purpose of the toolkit is to guide practitioners and policy makers, along with IDEAHL project partners, towards the establishment and promotion of actions and measures for (d)HL that are gender-sensitive and more inclusive and that take into account the needed ethics and privacy components to protect citizens and patients and their data.

1. INTRODUCTION

1.1. DIGITAL HEALTH LITERACY

The Improving Digital Empowerment for Active Healthy Living project – IDEAHL (<https://ideahl.eu/>) aims, as one of its planned tasks, to review the issues of gender and inclusion and ethics and privacy and discuss their implications in relation to (digital) health literacy (hereafter referred as '(d)HL'). To be able to do that, first of all, it is key to **define (d)HL**. There are many different definitions; one all-encompassing descriptions calls it “**the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to address or solve a health problem**” (Birati et al., 2022). (d)HL is not confined to Internet searches on health; rather, it extends to include electronic sources and technologies used by patients and health care professionals such as portals, personal health records, and technology collecting data (Jacquemard et al., 2021).

When considering (d)HL, it is impossible not to recognise its rising importance, given the digitalisation of health systems but also the digital revolution of all aspects of life, reinforced by the aftermath of the COVID-19 pandemic. Nowadays, more than ever, citizens need to have the necessary skills to access and navigate the existing sources and tools of health information, products and services, such as the Internet, mobile applications and also social media. This is needed for their self-empowerment i.e., to reinforce health self-management and, in some cases, for primary access to services, which are now turning digital or depending on the proper use of email, cell phone and other digital tools (Muscat et al., 2022).

At the same time, (d)HL is a complex concept and depends on a myriad of factors, some individual (e.g., motivation, self-confidence), other more technical (e.g., digital infrastructure, data quality, trustworthy information) and other of systemic nature (equity, digital access, health systems organisation). Thus, enhancing (d)HL must be seen from various perspectives: not only at the citizen level, through the development of their own knowledge and skills but also by creating and developing health-literacy-responsive settings, with policies and environments that enable citizen empowerment, participatory democracy, and a collective capacity of citizens to act and

shape their own (healthier) communities. It is also obvious that challenges in this area will come higher for people in vulnerable or social exclusion situations.

The term 'digital divide' is often used to describe the difference between those who are IT proficient and those who are not, and this does influence a person's (d)HL. Older people, racial/ethnic minorities, those with a lower level of education and low socioeconomic status have less access to and understanding of digital media (Din et al., 2019; Chang & Schulz, 2018; De Rosis & Barsanti, 2016). Considering gender and inclusion and ethics and privacy in all aspects of (d)HL is therefore of the utmost importance to ensure that much of the already existing inequities within health care are not continued or exacerbated in these fields too. The present toolkit puts forward reflections and recommendations in this sense.

1.2. IDEAHL AND (D)HL STRATEGY

IDEAHL aims at developing and testing **new models and approaches of (d)HL intervention development and application through the co-creation of a comprehensive and inclusive EU (d)HL Strategy.**

The IDEAHL consortium is composed of 14 multi-disciplinary partners from 10 EU Member States, which are expected to work hand in hand with patients, citizens, and the broad socio-economic sector at local level. The project has first been conducting an extensive mapping of health literacy (HL) and (d)HL research, initiatives, and projects in the EU and beyond. It has been working to define best practices and champions in these fields to foster knowledge exchange and uptake of selected practices.

Building on these foundations, IDEAHL is now preparing the launch of a large co-creation process to design and plan its EU (d)HL Strategy. The project shall involve over 1,300 different stakeholders, from citizens and patients to healthcare and social services, policy makers, non-health sectors, academia, etc.

The collected feedback will allow to develop an inclusive Strategy to improve (d)HL for the benefit of all citizens focusing on health promotion, disease prevention, treatment and (self-)care as well as on monitoring its impact on the wellbeing, productivity, and the economy. The Strategy will pay special attention to social innovation, inclusion, gender, ethics and privacy dimensions.



Finally, a number of actions of the Strategy will be piloted in the 10 project countries. From the testing and evaluation of the pilots, IDEAHL will be able to put forward a common EU monitoring model and indicators for (d)HL levels.

The ultimate purpose of the project will be to empower EU citizens in using digital tools to take a more active role in the management of their own health and well-being, as well as supporting social innovations for person-centred care models, by acting on individual-, group-, organisational- and policy level.

1.3. INCLUSION, GENDER, ETHICS AND PRIVACY IN HEALTH AND CARE

Before introducing the scope and content of the present toolkit, it is important to situate inclusion and gender and ethics and privacy in the context of EU health and care.

Equality and digital accessibility are fundamental for IDEAHL target groups, who are representative samples of all Europeans in the EU, especially those who are at risk of exclusion from the digital world. Digital accessibility is defined as the ability for individuals to easily use information technology products and services regardless of any physical or mental deterioration they may be affected by. These tools and services can be used to improve prevention, diagnosis, treatment, monitoring and management of health and lifestyle. This is known as eHealth.

To help the EU overcome social gradients in each country, health and care approaches need to be defined considering the health needs of the most vulnerable people in terms of access to and understanding of digital health information.



For citizens and patients, digital health means better access to information and care, increased convenience, and more opportunities for greater control of their own health.

For the health system, it means more effective delivery of care, better outcomes, and reduced costs. However, it is essential to have a high degree of digital abilities, which not everyone possesses, not even health systems, in order to benefit from digital health.

Being able of affording Internet access and having the digital skills to use technology are now essential aspects in many EU countries for education, employment, income, social participation and access to information and services. This shows that digital literacy and Internet connectivity constitute “super determinants of health” since they address all other social determinants of health (SDOH) (Gibbons C., 2018; Sieck et al., 2021).

In the wake of COVID-19, there has been an increase in the use of digital technologies, especially in the health and care area. According to the annual *GP Patient Survey 2020*, before the pandemic, 66% of adults had never used apps to manage their health, rising to 79% among those with low digital engagement (Lloyd, 2020). During the pandemic, online consultations doubled from around 900,000 to over 1.8 million in UK (Bibby & Leavey, 2020).

Nevertheless, the pandemic and the changes it brought have raised questions around the links between digital exclusion and health inequalities. A greater reliance on digital tools has the potential to exacerbate existing health inequities by widening the gap between those who have access to and the abilities to use them and those who do not.

To address these issues properly, it is essential to mention the concept of **intersectionality**, which refers to the study of overlapping or intersecting social identities and related systems of oppression, domination, or discrimination (Crenshaw, 2018). This theory asserts that inequality is not created equally because, within each group of people with a common oppressive characteristic, there may be a wide variety who encounter challenges and another who do not recognise them (Davis, 2008). Intersectionality is one of the reasons why it is actually difficult to categorise the vulnerable situations that people can face in (d)HL as these are diverse and experienced in different ways by citizens. However, some of the population groups in vulnerable situations that can face more challenges in (d)HL are people with limited or no access to Internet or limited digital skills; population living in low-income households; older population groups; population with lower socioeconomic level; migrants; population with disabilities or long-term health conditions; population living in rural areas, among others (UNICEF, 2018).



In this context the gender dimension also needs to be considered, mainly in line with key policies as mentioned in the IDEAHL Grant Agreement – the EU Gender Equality Strategy 2020-2025; the SDG5 on gender equality; and the EU Directive on reconciliation of work and family life 2019.

Gender refers to the characteristics of women, men, girls, and boys that are socially constructed (World Health Organization [WHO], 2019). This includes norms, behaviours and roles associated with being a woman, man, girl or boy, as well as relationships with each other. As a social construct, gender varies from society to society and can change over time. It is hierarchical and often carries with it inequalities that intersect with other social and economic disparities such as ethnicity, socioeconomic status, disability, age, geographic location, identity, and sexual orientation, among others (WHO, 2019).

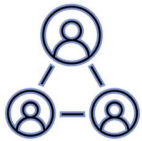
People's experience and access to the health and care services is highly affected by gender. Women usually face greater barriers than men when accessing health information and services (European Institute for Gender Equality [EIGE], 2021). As reported by EIGE, barriers worldwide include restrictions on mobility; lack of access to decision-making power; lower literacy rates; discriminatory attitudes of communities and health and care professionals; and lack of training and awareness amongst health and care professionals and health systems of the specific health needs and challenges of women and girls.

Consequently, women and girls are more prone to face violence rooted in gender inequality and be at greater risk of harmful practices such as obstetric violence. According to WHO (2021), about 1 in 3 women worldwide have experienced either physical and/or sexual intimate partner violence or non-partner sexual violence in their lifetime. Such violence often leads to the abuse of certain drugs, which also constitutes a challenge to women's health. All this results in a greater demand for healthcare by women.

On another note, increasingly health information is being collected, disseminated, and transformed through online platforms, e.g., websites and social media, forums, or blogs. This raises new challenges on the quality and reliability of platforms and information, including the



issue of misleading fake information that represents a potential risk for the population's safety. This is directly related to **ethics**, which **constitutes an integral part of clinical medicine, as health and care professionals have an ethical duty to help patients avoid harm and respect patient values and preferences.**



Ethics in health and care sector, also known as bioethics, constitutes an interdisciplinary field that covers a wide range of topics such as privacy, inclusion, and gender since its main objective is to ensure equal access to health and care and treatment of all citizens, regardless of their ethnicity, origin, religion, age, or gender.

Ethics, applied across health and care settings, builds on four basic and widely accepted principles that are beneficence, nonmaleficence, justice and autonomy (Beauchamp, 2007).

Beneficence. It refers to the physician and all other health professionals and social workers' commitment to act in the best interest of the patient and uphold a set of ethical standards to protect and defend the rights of others, prevent harm, help people with disabilities, and rescue people at risk. This principle requires not only preventing harm, but also benefiting citizens and promoting their well-being.

Nonmaleficence. The duty of health and care professionals to act in the patient's best interest is known as nonmaleficence. This principle underlies a number of moral obligations: do not kill, do not inflict pain or suffering, do not incapacitate, and do not deny others the necessities of existence. Nonmaleficence is particularly relevant when making decisions about end-of-life care, such as those regarding the withholding and withdrawal of life-supporting treatments and the management of pain and other symptoms.

Justice. The justice principle is understood as the fair, equitable and suitable treatment of individuals in medical decisions. Although there are several categories of justice, the most applicable to ethics in health and care is *distributive justice*, which refers to the equitable distribution of health care resources in society.

Autonomy. This principle refers to the control that each person exercises when making individual decisions, especially regarding well-being. In health and care, autonomy is the freedom of the



patient to maintain control of their body and mind, before, during and after treatment. Through the practice of autonomy, medical personnel are prevented from influencing patients to follow a particular course of action that might not be in their best interests. The objective of this principle is to allow the patient to be in full command of their care as much and as often as possible. It fosters self-respect, self-knowledge, and self-worth.

Within this framework, in the EU, the concept of fundamental rights provides a basic value framework to guide bioethics related policy development and implementation – incl. for (d)HL and eHealth – at European policy level, as well as in the Member States. On the same line, research activities and innovation projects funded by the European Union are to be conducted rigorously applying fundamental ethical principles and relevant national, EU and international legislation. A fundamental principle underpinning research activities is the respect for the welfare (health and safety) of the participants who take part in the research work, and this principle overrides all other considerations when the work is executed. Likewise, research in relation to (d)HL of the IDEAHL project will be conducted ensuring respect for the participants and their dignity, protecting their values, rights and interests and fair distribution of research benefits and burden. Major international ethical guidelines that drive research activities and projects in the EU and are considered for IDEAHL co-creation activities and its (d)HL Strategy are the Declaration of Helsinki (sets out the principles for medical researchers to guide the ethical conduct of research involving human participants), the *Universal Declaration on Bioethics and Human Rights* (provides ethical guidelines concerning medicine, life sciences and technologies applied to human beings), the *EU Convention on Human Rights (ECHR)*, signed in Rome in 1950 and came into force in 1953, is an international treaty to protect human rights and fundamental freedoms in Europe), and the *Charter of Fundamental Rights of the EU* (defines the concept of fundamental human rights and provides the framework to guide ethics related policy development and implementation at European policy level, as well as in the Member States).



The framework of fundamental rights and bioethics, and in particular the previously discussed principle of autonomy, are directly related to another of the key aspects to be considered in healthcare and in the IDEAHL project: privacy.

It should also be noted that attention to the right of privacy has particularly increased with the advent of **Information and Communication Technologies (ICT)**, intended as a diverse set of technological tools and resources used to transmit, store, create, share or exchange information such as computers. Nowadays EU Member States must respect the rules included in the EU **General Data Protection Regulation (GDPR)** entered into force in 2018 and have to apply the same core principles for data privacy and protection, even though Member States have a margin of latitude in the implementation of the regulation (European Commission, 2019).

The main justification for respecting **privacy** lies in the principle of respect for autonomy since respecting the privacy of others also means respecting their autonomous wishes to, for instance, release or not personal information about themselves. Privacy refers to the right to keep one's personal matters and relationships secret, and it gives patients the freedom to trust health and care professionals about their most sensitive personal or medical problems. Ethical justifications for protecting patient information also include financial loss (e.g., loss of job, health insurance, or housing) and potential social or psychological harm resulting from failure to disclose required health care information.

Privacy is important in the health and care field due to its utilitarian features: it creates trust between health and care professional and citizen/patient avoiding personal embarrassment or social discrimination; it may also promote better communication between the two parties and enhance patient's autonomy. While the justifications for privacy are based primarily on protecting the rights of the individual, the justifications for more efficient use of health information are based primarily on its collective benefit to society. Better scientific research, more cost-effective services, and more successful public health initiatives would all result from the more effective use of health information. Achieving goals through collective action that people alone could not achieve is one of the objectives of EU governments.

2. IDEAHL TOOLKIT FRAMEWORK AND METHODS

2.1. SCOPE

2.1.1. PURPOSE AND USE OF THE IDEAHL TOOLKIT

Work Package 4 (WP4) of the IDEAHL project foresees the development and update of a toolkit on inclusion, ethics and privacy. Its purpose is to ensure that relevant **inclusion and gender, and ethics and privacy, are considered during the co-creation and pilot of the EU strategy for improving (d)HL**. To do so, the toolkit shall provide health and care professionals and policy makers with recommendations on how to take into account the inclusion, gender and cultural adaptation of (d)HL initiatives in compliance with privacy and ethics and the socioeconomic framework of EU countries.

2.1.2. TOPICS AND AREAS OF THE IDEAHL TOOLKIT

The first version of the toolkit (toolkit v.1) serves to establish an overall framework within the project, providing theoretical background and initial practical recommendations on the tackled domains – gender and inclusion and ethics and privacy – to be considered in the co-creation and subsequent implementation of the project (d)HL Strategy. During the course of the project, the toolkit will be updated with enhanced **recommendations** and new perspectives stemming from activities’ implementation as explained in the table below.

Table 1. Presentation of versions of the toolkit deliverable from the Grant Agreement.

Versions of the toolkit	Due date (month)	Description
<i>IDEAHL inclusion, ethics & privacy toolkit V.1</i>	M8	An overview on the general aspects to be considered in the elaboration and subsequent implementation of the (d)HL Strategy will be elaborated addressing inclusion, gender and ethics & privacy issues. Implications relevant to data quality, patient-professional relationships, and the equity of access to healthcare services, as well as other potential questions arising from the utilisation of digital technologies in the health and care settings, will be explored.

<i>IDEAHL inclusion, ethics & privacy toolkit V.2</i>	M18	Based on the direct experience of WP2 and WP3, the toolkit will be updated at M18 with more in-depth recommendations and to tackle how to include the gender and cultural adaptation of (d)HL initiatives considering ethics compliance and the socio-economic framework in each EU country by policy makers and health and care professionals.
<i>IDEAHL inclusion, ethics & privacy toolkit V.3</i>	M24	The toolkit will be further updated at the end of the project (M24) and previously established guidelines and recommendations for policy makers and health and care professionals on the three main domains (gender, inclusion, ethics & privacy) will be revised and fine-tuned, if applicable, in the light of the whole IDEAHL experience with stakeholders and citizens' groups.

2.2. METHODS

This first version of the IDEAHL toolkit is produced using three different methods: literature review, policy desk research, and stakeholder consultations.

2.2.1. LITERATURE REVIEW



Desk research was carried out to conduct a non-systematic but **comprehensive literature search** on relevant existing studies, including literature searches of relevant databases; grey literature searches; and relevant national eHealth authorities' publications. Relevant databases used were Science Direct, Google Scholar, PubMed, MEDLINE, Embase, CINHAI, PsychInfo, DARE and Web of Science. Searches were performed using as keywords (digital) health literacy and eHealth combined with data, gender, data quality, privacy, ethics, empowerment, equity, access, education, barriers, vulnerable, patients, health care professionals in different combinations. Terms were omitted if the search became too narrow.



Main criteria used for inclusion were peer-reviewed articles in English language addressing a specific topic of concern (gender, inclusion, ethics and privacy in (d)HL) and published between 2000 and 2022 for gender and inclusion thematic cluster and between 2015 and 2022 for ethics and privacy (to further narrow down search); without limiting search to any geographical context in order to compare the reality in Europe with that of other places, thus making it possible to formulate appropriate recommendations. To broaden the search approach as much as possible, empirical works, theoretical works, and conceptual frameworks and models were included. Search excluded publications that were not looking specifically at gender and inclusion and/or ethics and privacy in (d)HL and eHealth literacy; organisational projects; and conference papers.

2.2.2. POLICY DESK RESEARCH



Policy desk research was conducted according to the Grant Agreement to further investigate the framework of the thematic clusters (gender and inclusion, as well as ethics and privacy). The IDEAHL Grant Agreement foresees the review of a number of international and European policies currently in force that were addressed in Chapter 3 of the present deliverable.

2.2.3. STAKEHOLDERS' ENGAGEMENT AND CONSULTATION



Stakeholder consultation is an essential part for the development and progressive update of the toolkit, as it is for the project itself. It is essential to know people's opinions on the aspects to be included in the toolkit, as there are specific needs for different population groups. Engaged stakeholders are not only the experts on the field or partners of the project, but also policy makers, citizens, and care professionals.

- **Stakeholders' workshop**

The first stakeholder engagement action under WP4 was the **workshop 'Health Literacy through the ethics lens', held on November 23, 2022**. In this online event, the most important aspects

related to inclusion, gender, ethics, and privacy to be considered when implementing (d)HL strategies were discussed with experts in all those fields. The workshop has counted with representatives of all partners, advisory board members and expert stakeholders. It was conducted online, via Zoom, with a total duration of 2 hours, from 10:00 to 12:00 (CET), and the agenda was the following:

Table 2. Agenda of the 23rd November stakeholder workshop

Time (CET)	Topic / activity name
10:00	Opening and welcome
10:05	Introduction to IDEAHL
10:15	Framework and objectives of the workshop
10:25	Jamboard tool
10:35	Plenary discussion <ul style="list-style-type: none"> ▪ 10:35 Gender ▪ 11:00 Inclusion ▪ 11:25 Ethics & Privacy
11:50	Conclusions
12:00	Closure

To pool all stakeholder input, and to make the workshop more interactive, a digital co-creation and brainstorming tool - called Jamboard - was used. Jamboard is a digital whiteboard that allows collaboration in real time. This supports having all the answers collected in one place and makes it easier for partners to understand what the most relevant aspects in terms of inclusion, gender and ethics and privacy are, as well as the measures that can be implemented to overcome the challenges encountered.

A second workshop will be held in one-year time to collect additional feedback from experts and partners.

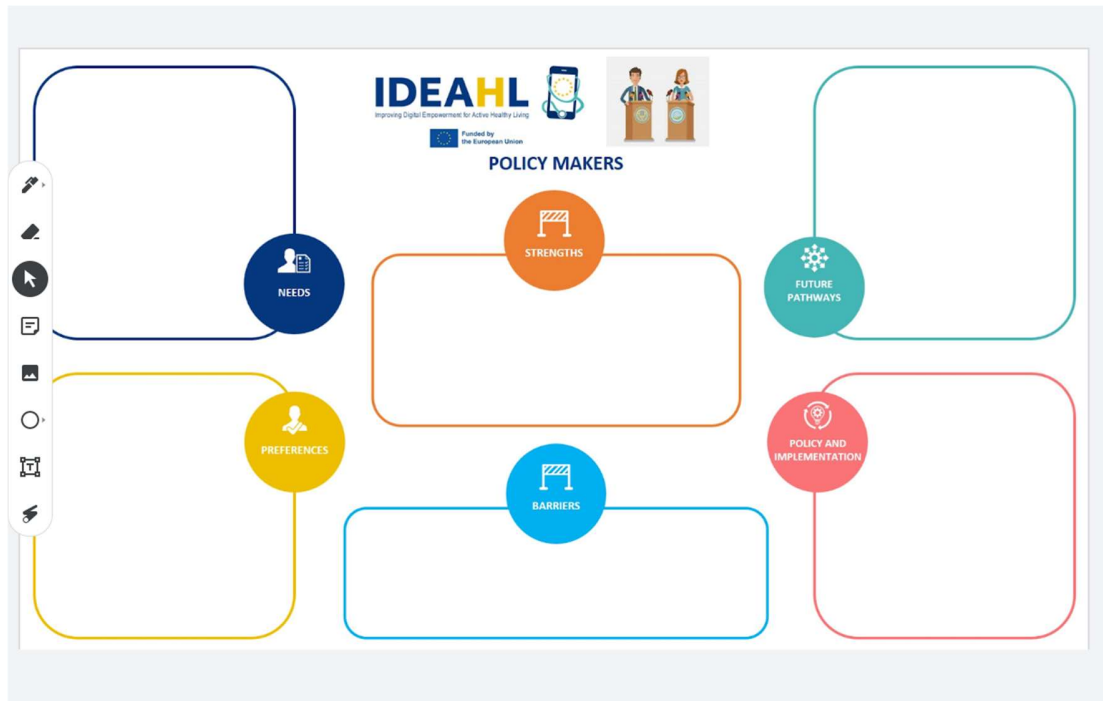


Figure 1. Jamboard template

- **Stakeholders' offline consultation**

Another technique was used to have all the information collected, and it consisted of asking partners for their **written contributions prior/after the workshop**. The coordination team of IDEAHL contacted stakeholders and provided them with a series of key questions (attached to the deliverable) that they could prepare in advance so that they could participate with great ideas for the event. Collecting written feedback turned out to be very effective, not only for the participants but also for the IDEAHL project team. By collecting written feedback in advance, some people that could not attend were able to give their ideas on the topic, and it facilitated participation for those not fluent in English and consequently not comfortable speaking in this language in events. It allowed coordinators to conduct a very fluent debate with a lot of ideas that will certainly be of great relevance to ground the future vision of the (d)HL Strategy. Thematic outcomes were merged with the results of the workshop and presented in Section 3.

- **Stakeholders' follow-up**

Upon the release of the first version of the toolkit, stakeholder consultation will continue throughout the project as an essential factor in the development of the (d)HL Strategy as reported in the table below.

Table 3. Stakeholders' engagement planning and roadmap

STAKEHOLDERS	WHEN WILL THEY BE ENGAGED
Policy makers	Policy makers' event in Brussels (March 2023) Co-creation activities (February-July 2023)
Health and care professionals	WP4 workshops (November 2022; October 2023) Co-creation activities (February-July 2023)
Dedicated experts	WP4 workshops (November 2022; October 2023) Co-creation activities (February-July 2023)
Citizens	Co-creation activities (February-July 2023)



3. THEMATIC OUTCOMES

Using the different search combinations and inclusion/exclusion criteria, and sifting through the results, partners identified relevant publications to be extracted for the clusters of the toolkit (gender and inclusion as well as ethics and privacy). The publications retained for analysis were used to build a picture of what information is important for policy makers and health and care to consider when setting up (d)HL interventions, systems, and projects, to ensure all groups can avail of the service.

3.1. INCLUSION AND GENDER

3.1.1. LITERATURE REVIEW ON INCLUSION AND GENDER

- *Main literature results and discussion on inclusion*

Issues around (d)HL and those who fall into the ‘digital divide’ tend to be centred on persons already marginalised in health and care settings. The **digital divide is often understood as uneven access to the Internet, but it also includes differences in use, skills, and abilities to not only get information but to manage and monitor one’s health** in conjunction with health and care professionals. While Internet use is growing among older adults and racial/ethnic minorities, these groups still have lower levels of Internet use and access (Din et al., 2019). There are in fact some specific barriers which tend to make eHealth access more difficult for some populations. These include **low digital literacy, lack of digital skills, lack of confidence and anxiety relating to digital solutions, lack of trust in privacy and security of digital formats, lack of understanding of the relevance of technology** as a basis for medical improvement, low levels of education, old age, poor or no access to computers/smartphones and broadband, to name but a few (Tohver et al., 2019). Neglecting these groups has the potential to increase already existing health care disparities and contributing to eHealth benefitting only a select group of patients (Clarke et al., 2021).

Virtually all studies relating to (d)HL highlight the difficulties in full participation for disadvantaged populations. Patients’ interest and ability to use patient portals is heavily influenced by demographic factors such as **age, ethnicity, education, health literacy, health**



status, and caregiver roles (Guendelman et al., 2017). **Cultural appropriateness and language** are two other major barriers to (d)HL (Heiney et al., 2020; Hinami et al., 2017; Hyman et al., 2022; Jacob et al., 2022). Barriers also exist for those with physical, visual, neurocognitive, and intellectual disabilities (Antonio et al., 2019). In addition to barriers, **eHealth may also contain biases**. For example, an algorithm working from a dataset that lacks diversity, may not work for the people who are not represented in the dataset. Those responsible for developing the algorithm may make assumptions or decisions based on biased data, which then becomes unintentionally reflected in the design of the technology (Jacquemard et al., 2021).

Race/ethnicity is another major factor in low (d)HL levels, together with low socioeconomic level. Research showed that if these factors are considered, the development of (d)HL interventions and eHealth tools would be more successful. For instance, one (d)HL good practice worth to be mentioned relates with a healthy heart app developed in the USA and specifically targeted at African American older people in the lower socioeconomic scale in rural areas with low literacy levels. The developers included their target group in the app's development through engaging in focus groups. The focus group guided the app to include not only clear, simple layout and easy to read text, but also culturally appropriate content, including spirituality-based tips and quotes. The study found that those using the app demonstrated clinically relevant changes in health-failure self-care maintenance, management, and confidence (Heiney et al., 2020).

An additional variable that also has an impact on (d)HL and eHealth is **language**. For instance, studies from the USA have found that participants of Hispanic ethnicity are less likely than their more affluent, white counterparts to engage in Internet health-seeking behaviours (Guendelman et al., 2017); and that among Hispanic individuals, Spanish is the primary language in which media is consumed and therefore searching, reading and comprehending health material can be very complex, leading to lower use of portals (Din et al., 2019). Limited proficiency in the primary language of the country where patients live, accompanied by inadequate reading health literacy, significantly contribute to lower engagement, even as access to smartphones increased (Hinami et al., 2017). For instance, a sample of Punjabi-speaking South Asian individuals in Canada found that low English coupled with low technology literacy created a major barrier to using digital health tools (Hyman et al., 2020). Another recent study found out that among low-income patients with asthma living in Philadelphia, Spanish speakers experienced more barriers to portal

use than their English-speaking counterparts, including more difficulty navigating the portal, feeling less comfortable using a computer to access the Internet, and having heard of the patient portal less often (Localio et al., 2022).

Apart from race/ethnicity and language, another major barrier often cited in relation to poor (d)HL is **age**. Older people may lack the necessary digital skills to use the technology or are simply less likely to use technology. Barriers to Internet use among older adults include problems with technical knowledge, the sheer amount of information available online leading to confusion, disability in terms of psychomotor function, cognitive disabilities, health literacy, costs, and distrust in internet sources. Also, older adults tend to have a lower incidence of Internet access in their home (De Rosis & Barsanti, 2016). Despite these numerous barriers, some studies have reported that older patients are as interested in adopting technology as their younger counterparts, especially after adjusting for other factors, such as existing technology skills and experience. Age as a barrier to eHealth or poor (d)HL may instead depend on context and other related factors. This in turn suggests that easier use and delivering better training could help remove age as a barrier, and that a better understanding of how (d)HL and technological tools work may help older people improve their condition and it could motivate their decisions to partake in technology (Jacob et al., 2022).

Geographic residence may also affect the (d)HL, with living in a rural area tending to be a barrier to adoption of eHealth, often owing to poor access because of a less developed infrastructure in some rural areas (Jacob et al., 2022).

The issue of health and care **professionals' involvement** is important, and their input and investment into their patients' (d)HL is critical. Research showed that one barrier to using eHealth tools was that patients preferred to meet with their doctor in person (Schrauben et al, 2021). Health and care professionals were not always knowledgeable about the various eHealth infrastructure and did not have the time or the material to help their patients with (d)HL (Busse et al., 2022). One Swedish study on patients with COPD found that acceptance of technology in health and care fields was greater when the eHealth aspect of the care was presented as a complement to, rather than a replacement of, the personal care and contact which the patients had with their doctor (Lundell et al., 2020).



The (d)HL barriers described in the literature all point to the **importance of diversity and of inclusion of large groups of society such as older people or those of lower socioeconomic level, not to risk leaving them behind.**

- *Main literature results and discussion on gender*

Gender intersects the various disadvantages related to (d)HL and as previously mentioned, necessitates an intersectional approach where it is crucial to grasp how these multitudes of social identities intersect with each other. Intersectionality is understood as the interaction between gender, race, and other categories such as sexual orientation, age, disability, and so on, and the outcomes of these interactions in relation to power structures (Tohver et al., 2019).

In terms of the impact of gender on (d)HL and the usage of eHealth, the evidence base is smaller and is more affected by the many intersections of gender with other categories. Literature shows that **women tend to have a higher use of eHealth than men**, mainly because of their higher engagement in health and care related online activities and the fact that generally assume the role of “health care liaison” for their families (Kontos et al., 2014). A systematic review on adoption of eHealth behaviours and (d)HL levels in Europe found that women tend to be more willing to use eHealth related tools, again because of the societal care role assigned to them. However, some studies found men more likely to adopt eHealth behaviours, often as a result of more widespread male phone ownerships among male members of particular societies or cultures.

Evidence has demonstrated that in certain cultural contexts gender issues can present a challenge. Results from other studies included in the systematic review noted that gender does not play a role in adopting eHealth behaviours (Jacob et al., 2022); this variation highlights the need to continuously look at what other intersecting identities and marginalisation are experienced by a specific population.

- *Conclusions from (d)HL literature on inclusion and gender*

From the overall performed literature review it emerges that one relevant solution to remove the multitude of barriers that exist is generally focused on **improving inclusion and making eHealth programmes and portals more adaptable and sensitive to difference in users.**

Problematic issues with accessing portals, or other eHealth infrastructure, frequently come from a “one size fits all” design approach, poorly designed apps or systems and from a lack of involving different types of end-users in the design process. To overcome these challenges, co-creation and patient-tailored approaches need to be promoted in the health and care fields. Portals tend to be designed and tethered to provider-centred systems, much to the detriments of many of the already mentioned groups. Barriers experienced by, for example, an older person, are not of concern only to that individual and their responsibility to solve them, but it is rather a systemic problem. Even if there are already several initiatives in place across Europe, additional efforts need to be done to design and implement effective strategies to end unequitable outcomes for underserved or marginalised groups (Antonio et al., 2019).

Inclusive design is therefore seen as the most effective way to address the needs of marginalised, disadvantaged or vulnerable users, both from a gender perspective and an inclusion perspective. Such design must incorporate **cultural appropriateness, language options, easy-to-understand lay language, ease of use, and offline use options** (Jacob et al., 2022). What one study called the “design it and they will come” approach to personal digital health is not helpful but creates a situation where created infrastructure is not appropriate or meaningful for individuals who are not fully able to access or use the tools (Guendelman et al., 2017).

In addition to the previous considerations, evidence found that while e.g., old age, racial/ethnic minorities, and lower socioeconomic status were groups that faced a multitude of barriers, they often reported more **interested in using eHealth and learning about (d)HL**, regardless of educational level and yearly income (Antonio et al., 2019). Disadvantaged and marginalised groups often showed interest in learning how to use a patient portal if shown how, and reported a generally positive attitude towards digital health, and improved access and adoption of eHealth measures when properly included or given the correct tools and knowledge (Localio et al., 2022; Dhanireddy et al., 2014; Carroll et al., 2019; Clarke et al., 2021). Many studies have concluded that underlying problems, such as systemic racism and existing disparities in health services, all contribute to the need for alternative solutions to accessing digital health for non-white patients (Clarke et al., 2021; Varkey, B., 2020).

Furthermore, while the Internet use is rising across society, lower levels of education have been shown to be associated with increased use of social media for health, whereas higher levels of education are associated with increased use of Internet search engines to engage in health care-related activities and search for information (Ng, D., 2022). These ways of using the Internet for health information may indicate potential inequalities in not only engagement with the healthcare system, but also the quality of the health-related information obtained on social media (Kontos et al., 2014). More research is needed, especially to address the drop-off of users in the transition from health-related Internet searches to digital health-management practices (Guendelman et al., 2017).

To conclude, with all this in mind, the digital divide between those with, and those without, (d)HL and eHealth skills can seem to be an intractable problem, causing further inequities for already marginalised and disadvantaged groups. However, the evidence points to not only an increase in digital skills in the population overall, but also in a strong willingness to learn and improve (d)HL in those from disadvantaged or marginalised groups.

For (d)HL to be useful for all in an equitable and fair manner, gender and inclusion are crucial considerations at all stages of development. Without ensuring that marginalised, disadvantaged, and vulnerable groups are included in all development aspects, (d)HL will become something benefitting only certain groups, which will be to the detriment of all of society. Improved access to health care and a better and healthier life is of benefit both on an individual level and societal level, and it is the responsibility of those guiding the emerging infrastructure of eHealth and (d)HL to ensure that no one is left behind.

3.1.2. POLICY OVERVIEW ON INCLUSION AND GENDER

In addition to literature review reported above, EU and international policy frameworks related to digitalisation and gender and inclusion have been analysed to build upon them for IDEAHL experience and this toolkit's recommendations and future versions.

Main identified and reviewed policies were those considered in the IDEAHL Grant Agreement and those that came out from further desk policy review performed during the writing of the present deliverable.

The **Gender Equality Strategy** (European Commission, 2020) presents policy objectives and actions to make significant progress by 2025 towards a gender-equal Europe. It sets out by the European Commission outlines how all EU policies and strategies should include gender mainstreaming, a gender perspective, and intersectionality (*“the combination of gender with other personal characteristics or identities, and how these intersections contribute to unique experiences of discrimination”* (European Commission, 2020) as standard.

“We can only reach our full potential if we use all of our talent and diversity” (European Commission, 2020). This shines a light on the opportunities brought by the digital era. While aiming to bring everyone to at least a basic level of digital literacy, it is possible to do and achieve more by including people of all backgrounds, ages, genders, and ethnicities in the digital transformation.

The Gender Equality Strategy identifies gender-specific structural barriers in reaching the goal of gender equality, such as only 19% of those in ICT studies and jobs are women, and women account for only about a third of Science, Technology, Engineering or Mathematics (STEM) graduates (European Commission, 2021). Moreover, artificial intelligence (AI) provides another example of how lack of diversity can perpetuate inequalities. AI is a key driver of many digital health programmes and technologies, however, as women are under-represented in STEM subjects and careers, AI algorithms and codes are often written by male programmers. Unconscious bias can infiltrate code through data selection and other means, which can risk exacerbating gender and other inequalities.

The **Women in Digital Scoreboard** (European Commission, 2021), a part of the Digital Economy and Society Index which assesses Member States’ performance in the areas of Internet use, internet user skills, specialist skills and employment based on 12 indicators, can be used to monitor women’s participation in the STEM sphere. This is relevant for (d)HL; if women and minority groups are not included in the design of digital health technologies, these applications and products are less likely to cater to them, leaving them behind in the digital transformation,

or providing them with potentially less accurate information on their health. This is especially important as (d)HL is concerned with accessing, understanding, and appraising health information and could unintentionally create a situation where women may not be on a level playing field with men, if tools used to retrieve health information are not built in a way that suits all users.

The **Sustainable Development Goals (SDGs)** (UN, 2015) were devised in the 2030 Agenda for Sustainable Development (UN, 2015), with the intention of creating a more equal and prosperous world. Target 5b of the SDGs, “Enhance the use of enabling technology, in particular information and communications technology, to promote the empowerment of women” (UN, 2015) identifies how the digital transformation has the potential to increase women’s autonomy and independence but emphasises that there must be a concerted effort to have this potential realised. Improvements in (d)HL levels can mean that women are able to access their health information, understand it and use it to make informed choices on their health. While the United Nation states that “ownership of mobile phones has been shown to be an important tool for empowering women” (UN, 2015), this is only a first step. Women should be empowered to take a leading role in their health which is increasingly becoming digitalised.

The **European Declaration on Digital Rights and Principles for the Digital Decade** (European Commission, 2022), published by the European Commission in 2022, recognises that “digital transformation affects every aspect of people’s lives” (European Commission, 2022). Whilst inclusion is a cornerstone of this declaration, it also lists “equality, sustainability, resilience, security, trust, improving quality of life, respect of people’ rights and aspirations” as crucial in this drive to achieve digital rights. All these elements must work in synergy to ensure gender and inclusion are adequately considered in the co-creation, development, and implementation of the IDEAHL (d)HL Strategy.

In the **Communication from the European Commission on the Digital Rights and Principles for the Digital Decade** (European Commission, 2020), it was discussed how the COVID-19 pandemic became a catalyst for the acceleration of the digital transformation as communities, industries and public and private life went virtual. Within the realms of healthcare, the pace of this transition increased disparities between those in urban areas and those living rurally. While

digital access was one element of this inequality, (d)HL was another important factor. As many health institutions have begun to take advantage of online tools, it is critical that rural and other vulnerable populations, such as older persons and people living with disabilities are not left in the dark with regard to health appointments and other important notifications. It is important to analyse how to bring everyone up to speed and promote access and digital literacy for all.

Another project, the **European Skills Agenda** (European Commission, 2020), a 5-year plan was developed to help individuals up-skill and re-skill. It emphasises the “right to quality and inclusive education, training and lifelong learning” and pledges to improve the digital skills of the existing workforce. Although this is important, it omits those who may be out of work. Whilst this document speaks about inclusion and upskilling, it doesn’t necessarily mention digital literacy or more specifically, (d)HL. It sets out the target of “by 2025, 230 million adults should have at least basic digital skills, which covers 70% of the adult population in the EU”, however, the definition of basic digital skills in this document is not clearly defined (European Commission, 2020).

Other initiatives include the **European Pillar of Social Rights Action Plan** (European Commission, 2021), which sets out key principles and objectives for the labour markets and social welfare systems of the EU. It states that “at least 80% of those aged 16-74 should have basic digital skills”. Again, basic digital skills are not defined, and digital literacy is not mentioned.

The **DigComp framework** (2022) devised by the European Commission, sets out 5 areas of digital competence: information and data literacy; communication and collaboration; digital content creation; safety; and problem solving. It highlights that literacy is only one part of digital competence but that it is fundamental in the Digital Decade.

The **2030 Digital Compass** (European Commission, 2021) mentions the myriad of ways the Digital Decade has revolutionised medicine and healthcare. For example, the use of telemedicine and robotics allows health and care professionals treat patients remotely. Digital health allows and empowers citizens to monitor and improve their own health status and supports independent living. This document highlights that these digital technologies must be “coupled with adequate digital skills” across the population. The opportunity to learn basic digital skills should become a right for all Europeans. Non-discrimination should be evident in access to online services. Access and education are key principles of this plan.

Surprisingly, the **EU Directive on Work-Life Balance for Parents and Carers**, which aims to make it easier for people working in the EU to balance paid work and private life, including caring responsibilities, does not contain any mention of gender and inclusion in relation to (d)HL.

- *Conclusions from (d)HL related policies on inclusion and gender*

To conclude, the performed policy review showed that digital inclusion has clearly become an EU-wide priority. The pandemic accelerated transition to the online world as everyday tasks have become increasingly digitalised; however, certain groups may have been disadvantaged in this transition. The EU recognises the need to put “people at the centre of the digital transformation” (European Commission, 2022), but to achieve this, it is important to understand who is unable to benefit from this virtual shift, and more importantly, who is being disadvantaged by being unable to access online services. The European Commission envisions **“a digital transformation that leaves nobody behind”** and mentions specific groups such as older persons, those with disabilities, vulnerable, etc. This approach **shall be also envisaged when planning and implementing interventions and actions for (d)HL.**

3.1.3. STAKEHOLDERS’ WORKSHOP RESULTS ON INCLUSION AND GENDER

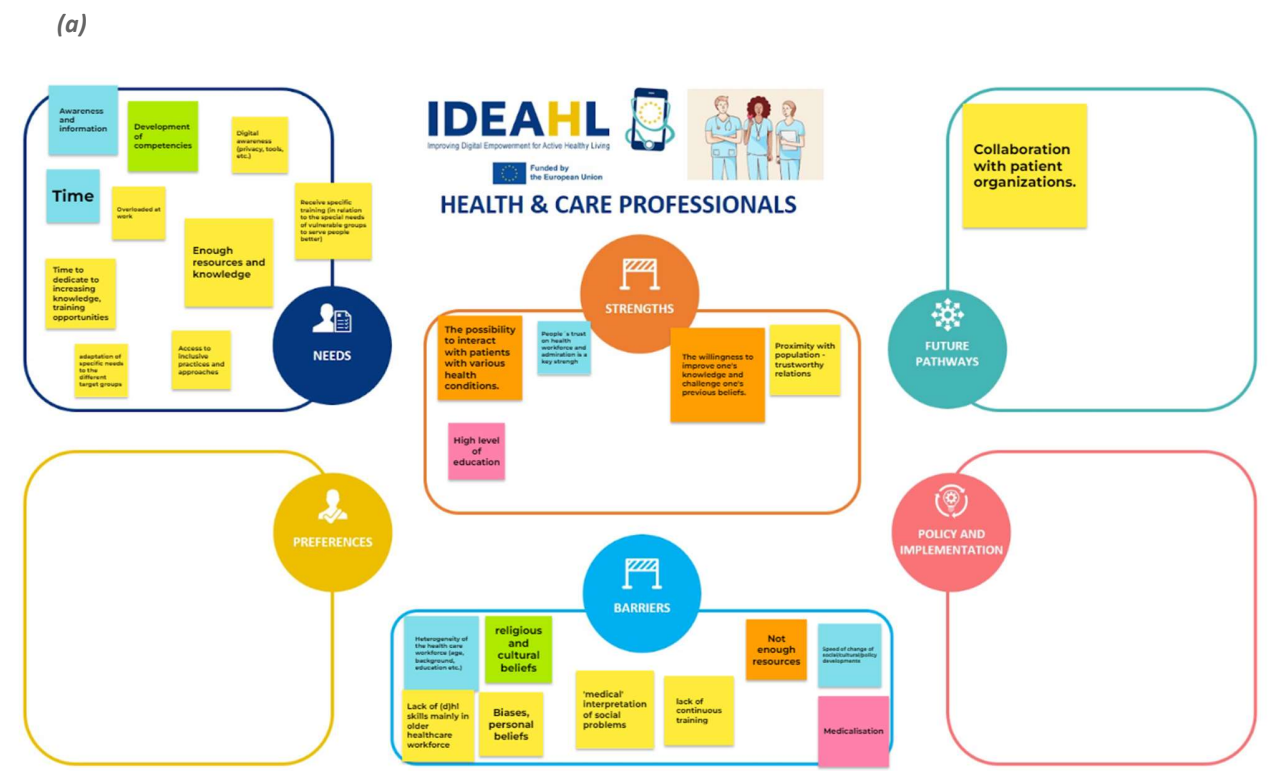
Workshop “Health Literacy through the ethics lens” was attended by 49 participants including experts, members of the Advisory Board and the project partners themselves. In the following, both findings from the stakeholders’ offline consultation and the workshop is presented. It consisted of an introduction to the project and the objectives of the workshop, followed by a plenary discussion in which gender and inclusion and ethics and privacy were discussed.

Figure 2. Screenshot of the online workshop



As introduced in Section 2, the purpose of the workshop was to gather information from partners on the most relevant ethical aspects to consider when developing and implementing a (d)HL Strategy. To do so, a set of questions regarding inclusion, gender, ethics, and privacy were raised and are attached to this delivery (Annex 2). Feedback collected (see Figure 3) from stakeholders related to gender and inclusion has been summarised below, and it has been used to draft key recommendations of the toolkit. These results will also be taken into account for the development of the IDEAHL Strategy.

Figure 3. Jamboard results. Needs, Strengths, Future Pathways, Preferences, and Policy and Implementation regarding (a) health & care professionals, (b) vulnerable people and (c) policy makers

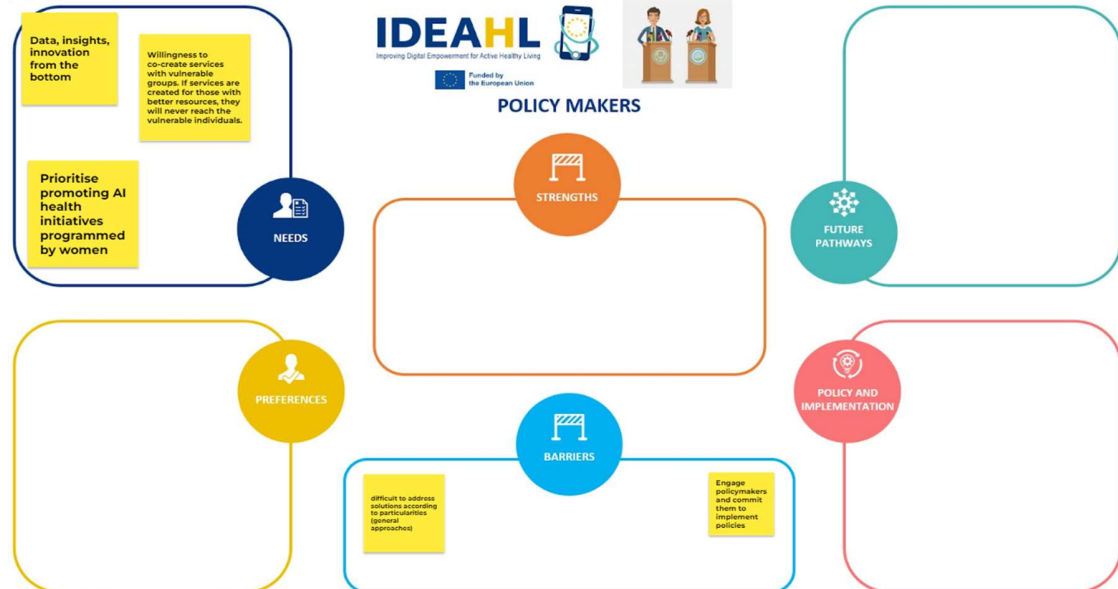




(b)



(c)





The first topic discussed at the workshop was the *gender dimension* in health and care services.

- *Main workshop results and discussion on gender*

Experts concurred that there is **evidence of gender bias in the access to health and care**, as well as during the experience. To address this issue properly, it is essential to talk about the relation between intersectionality and gender. Understanding how gender intersects with various cultural and social concepts is fundamental to grasp the different challenges women face.

Being a woman can frequently involve being underrepresented in positions of power; being less educated; being more exposed to violence; and/or having a greater social vulnerability, among many other things. And this, naturally affects many different areas of their daily lives, including the access to health care services and (d)HL.

Experts agreed that women's greater socioeconomic vulnerability makes them more vulnerable in the field of health, both in contracting diseases and in access to prevention, diagnosis, and treatment. Several also pointed out that most victims of domestic violence and all other forms of gender-based violence (GBV) are women. They commented that there exists a large body of evidence that confirms the often severe and long-lasting impact of GBV on human health, including mental problems.

This inevitably leads to a bigger demand for health and care services. It is ironic how women are the ones who have a greater demand for health and care services, and still there is so little information about how to treat their diseases or concerns. This can be evidenced, for instance, by the fact that the symptoms of myocardial infarction in women are much less well known than those in men, which makes it difficult to identify the first symptoms and, consequently, leads to a lower diagnosis.

On the other hand, experts participating in the IDEAHL WP4 workshop noted that compared to men, women are significantly more affected by diseases that cause pain (arthritis, neck pain or other chronic neck problems, low back pain, and other chronic back problems), which decreases their quality of life and increases health care expenses.



In addition, traditionally women have been responsible for taking care of their families, and this is something that remains in the collective imagination. For this reason, they are often the ones who take family members to the doctor, or who take care of their medication (EIGE, 2021).

Women may also suffer negative experiences when they are pregnant. This is called obstetric violence, which refers to the harm inflicted during or in relation to pregnancy, childbearing, and the post-partum period. As commented in the workshop, such violence can be both interpersonal and structural, arising from the actions of health and care professionals as well as from broader political and economic arrangements that disproportionately harm marginalised populations. All these challenges faced by women in the health and care services make the implementation of new measures in (d)HL a necessity.

Experts from the workshop highlighted the following gender-based considerations in relation to healthcare:

- To keep in mind the equity approach, considering the social determinants of health.
- To raise awareness of women's needs and to educate on how to address them.
- To respond to existing gender bias in the health and care system.
- To educate the workforce with training to teach them how to serve women from the very beginning.
- To adopt gender-inclusive communication and investing in targeted dissemination strategies in order to ensure equal opportunities between men and women regarding accessibility to services and programmes in the different areas of health, including prevention, diagnosis and treatments.

There were also **comments on how health and care professionals can better facilitate (d)HL improvement among women and girls**. Some of the most repeated solutions were the following:

Digital skills should be taught at primary and secondary schools for future generations, but it is also important to consider the older ones and provide them with training. The intersectional approach has to be taken into account, and the information, contents, and access should be adapted and with a user-friendly interface for all.



Training courses on (d)HL focused on different age groups must be ensured, while increasing the role of the city councils and social centres of the different cities in the development of training and information sessions on these aspects and with a gender perspective.

Health and care professionals are on the frontline of the provision of health services; therefore, they are in proximity to the population. It is important they receive proper training and guidance both on gender issues, digital literacy, and (d)HL. They should also be encouraged to participate in the elaboration of health policies and work closely with policy makers when addressing (d)HL.

- *Main workshop results and discussion on inclusion*

Enhancing digital skills and providing help to people lacking digital skills is essential for (d)HL, and to do so, the first thing to do is to categorise the situations that can make people being digitally excluded. However, as it has been seen with the intersectional approach, this is not an easy task.

The experts of the workshop highlighted the following as potentially digitally excluded groups:



Older people. Older people, including those with dementia, whose cognitive skills are diminishing or who suffer from multiple long-term diseases, are in danger of facing challenges. Also, one's life history affects a lot: if an older person has not got used to the digital environment in her/his active years, it is probably challenging to learn to use digital tools in old age.



People with disabilities might also have challenges, especially when they have cognitive or visual impairment disorders. Sign language has to be considered.



Marginalised people in vulnerable conditions e.g., drug and substance abuse, homelessness, low socioeconomic status, or lacking financial resources which cause isolation and



losing the meaning of life. These are problems people face at any age and they can be long-standing or temporary. In these situations, people might not have access to digital services, they might not have skills to use them, or they have no strength to prioritise health issues in their life situation.



LGBT community. LGBT people face several difficulties in accessing adequate and competent health care, as well as in digital health, some of which are generated by the invisibility of diverse sexual identity and orientations by health professionals.



People with lower socioeconomic status and/or with lower education. Living a healthy life is expensive. Healthy food is expensive, and so are the devices needed to access digital health service. Some people do not have the devices to go online, and this is something that has to be considered. Measures must be implemented in order to make technology available to people. Also, citizens with lower education may not have the digital skills to manage technology.



Migrants. Apart from language barriers, migrants face many obstacles such as the difficulties to obtain health insurance and they can also face discrimination in the care system that limits their access to health literacy.



People living in rural areas. Sometimes people living in rural areas have very limited access to the Internet, so they are more likely to use technology much less than people living in cities.

In general, **the main challenge in terms of digital inclusion, largely mentioned by the workshop's experts, is the access to the Internet itself, along with the different levels of (d)HL.** This shows the importance to consider the lack of digital skills when designing (d)HL actions.

- *Workshop conclusions on gender and inclusion*

According to the experts who attended the workshop, it is essential to recognise the challenges for improving (d)HL, and to identify the most important problems. This should be done together with service users and organisations that represent people facing these challenges. **User-involvement** in designing the services is very important. Combining digital expertise with social and health expertise and again with the perspective of service users could be done in designing (d)HL actions.

Concrete actions to be taken to enhance (d)HL in people in vulnerable situations were proposed by experts and partners. These actions were divided into the ones addressed to policy makers, others addressed to health and care professionals, and the ones addressed to citizens.

a) ***Actions addressed to policy makers***

<ul style="list-style-type: none"> • To promote dissemination and education of citizens from a critical vision so that they are aware of the risks/benefits of (d)HL.
<ul style="list-style-type: none"> • To formulate (d)HL policies and strategies in close collaboration with organisations representing and working with these digitally excluded groups.
<ul style="list-style-type: none"> • To facilitate the use of translated contents and translators during health appointments to facilitate the comprehension of the individual's health issues and help them reach more information on these issues.
<ul style="list-style-type: none"> • To reimburse more health consultation time for patients who need more time to understand issues related to their health and thus give health professionals the time to give complete advice in order to enhance (d)HL.
<ul style="list-style-type: none"> • To give resources for development and testing of (d)HL interventions.
<ul style="list-style-type: none"> • To take into account the heterogeneity of the population and different scenarios should be taken into account so that all people have equal access to means to support digital health literacy.



- To attribute funds to be able to hire and pay professional and trained staff, as well as to create (d)HL projects that allow access to digital literacy in the area of health.

b) *Actions addressed to health and care professionals*

- To consider the needs and challenges of vulnerable groups when implementing health and care interventions and to build on the advantages of (d)HL and positive attitude towards it.
- To counsel people on what kind of digital tools are useful for them.
- To be able to respond to different needs, considering the intersectional approach.
- To be informed on migrants' culture and living conditions to adapt health promotion to their particular situation (eating habits for instance or absence of a stable living place) and give achievable objectives for them to take care of their health.
- To cooperate with other clinicians, patients, media, decision-makers and citizens. Integrated approaches are essential for effective (d)HL initiatives to ensure a clear understanding of key societal needs, transparent and successful dissemination of clinical evidence to citizens, and ultimately, sound health decision-making.

c) *Actions addressed to citizens*

- To improve and raise their awareness of (d)HL and their digital skills.
- To ask for support from professionals and voluntary organisations.
- To participate in the training aimed to improve citizens' digital skills and how to use eHealth tools for health management and better quality of life.

To conclude this overview of the key ideas that arose during the workshop, it could be said that although access to reliable health information is considered a fundamental human right, the information disseminated is not enough. It is crucial to empower people to use this information in critical decision moments, as well as to invest in (d)HL initiatives that train and motivate health professionals to better understand the benefits of the correct use of digital tools and to help to decrease the digital social divide. The involvement of health professionals in the creation of trustworthy and user-friendly eHealth solutions can facilitate the interaction between citizens

and health services while ensuring respect for the principles of safeguarding in health. In this sense, citizens would be informed about their health and will also be driven towards better health self-management skills.

3.2. ETHICS AND PRIVACY

Similar to the discussion on gender and inclusion implications for (d)HL, an overview of **ethics and privacy implications for (d)HL** is delivered in the following sections based on literature and policy research (see [3.2.1](#)) and experts' opinions (see [3.2.2](#)).

3.2.1. LITERATURE REVIEW AND POLICY DESK RESEARCH ON ETHICS AND PRIVACY

In order to secure basic rights, transparency and autonomy and to overcome barriers of (d)HL, a broader understanding of ethics and equity is essential (Sørensen et al., 2013). In April 2018, the European Commission in *Communication on enabling the digital transformation of health and care in the Digital Single Market* identified three areas for action: citizens' secure access to and sharing of health data across borders; better data to advance research, disease prevention and personalised health and care; and digital tools for citizen empowerment and person-centred care. Several investments were made at the European and national levels to further promote such aims, but there are still several challenges connected to the implementation of digital solutions for person-centred care at scale in Europe (European Commission, 2018).

Issues such as Intellectual Property Rights, certification and ethics requirements are referred as **hindering factors to the broader use of digital health products and services**, as they are allegedly confusing, bureaucratic and impede agile processes (Thapa & Camtepe, 2021). **Lack of interoperability** is seen as one of the greater barriers for digital innovation in health and care, along with the low digital literacy of professionals and citizens and broad and sustainable business models that include alignment with reimbursement models and fair return on investment.

Moreover, challenges still to overcome on the technical and ethical sides, are physical and technical safeguards, confidentiality, integrity checks, transparency, fairness, availability, minimum and limited use, breach notification, ethics approval, awareness, limiting information

leakage, proper data-sharing management, privacy, security, confidentiality, and trust, among many others (Thapa & Camtepe, 2021).

The Broadband Commission for Sustainable Development, led by International Telecommunication Union and UNESCO, identified a set of good practices to realise the potential of digital technology in health and care, the first of which is to formulate and execute a national digital health strategy (Aerts & Bogdan-Martin, 2021).

However, many of the challenges highlighted above are interlinked with (d)HL and its practical implementation. From the countless aspects that are relevant to the area of ethics and privacy in (d)HL, the current literature review mainly focused on four areas perceived as essential and that are also directly tackled in the IDEAHL Grant Agreement: data quality; patient-professional relationships; equity of access to healthcare services; and utilisation of digital technologies in the healthcare settings.

- *Main literature and policy results and discussion on ethics*

In relation to health data, there are several barriers still hindering its full exploitation, for historical, technical, legal, and political reasons (Auffray et al., 2016). On one side, the autonomy of European countries, including EU Member States, in what concerns health policy and systems (Digital Economy and Society Index, 2022) brings **diversity and fragmentation to health data organisation, format, structure, taxonomy, as well as to the processing**, analysis and transfer methods that makes it very complex to find harmonisation and interoperability procedures.

An analysis performed under the works of the DigitalHealthEurope (DHE) project mentions that Electronic Health Records (HER) and the integration of processes between hospitals and communities are areas where developments were made and funding was provided, but barriers do persist. Even if legal frameworks for data sharing are evolving, there is still the need to improve the quality of health data, e.g., due to lack of harmonisation.

According to the Organisation for Economic Cooperation and Development “...*access to and sharing of health data is needed to improve the quality, safety and patient-centricity of health services...*” (OECD, 2021). The COVID-19 pandemic made the need for data much more visible, as an extraordinary amount of personal and health data became urgent for issues such as pandemic

monitoring, contact tracing, monitoring the impact of restrictive measures, new treatments research, among others. The possibilities highlighted during this period, such as vaccines developed in record time, opened a clearer vision of what could be done, also on the field of personalised medicine, if data was gathered timely and efficiently and the needed investments were in place.

However, and unfortunately, health data in general is still rather unstructured, dispersed across multiple sites, with no pre-defined data model and often difficult to be combined with conventional relational databases (IC PerMed, 2019). For data to have quality, several characteristics are needed: availability and accessibility, accuracy, validation, completeness, currency, consistency, identifiability, provenance, usability, security, and confidentiality (Ehsanelahi, 2021). To be useful, it is thus necessary that data is correct, complete, reliable, and accurate and even if most health and care facilities collect patients' data through digital means, they still need systems and procedures that allow them to maintain the quality of services provided. However, this proves to be a complex situation as each facility is not isolated, because patients navigate through different services.

Even inside each Member State, the lack of integrated care pathways between different providers – public and private, on health, social care, and wellbeing – **implies that harmonised and connected data is still not a reality.** The lack of a common framework and organisational model between these services, initially at the national level but also at the European level, is the first main hindering factor for data quality in health and care.

Another important aspect is **quality of data** in terms of representativeness of the population. This is quite relevant for health research, in order to avoid specific individuals, groups, or populations benefitting from a discovery or innovation because of insufficient representation. This is called **data poverty and originates biases in datasets** (Ibrahim et al., 2021). These biases are unfortunately still existing, e.g., related to gender, race or social vulnerability situations.

As stated by the Ada Lovelace Institute (2020) *“Missing data matters: it can exacerbate inequalities on a societal scale. When that data is operationalised into algorithmic decision-making systems and AI, the social processes that produce racial inequality – mechanisms of power, economics, knowledge, culture, and language – can be written into technologies with*

huge societal impacts.” Data poverty can, and should, be addressed by policy making and by a proper stewardship procedure.

Although the challenges referred are systemic and mostly directed to policy makers, others exist that are related to health and care professionals and researchers, such as mindset and working methods, that also influence the free flow, maintenance, and access to data.

Research shows that big differences in data management are highly influenced by factors such as primary funding agency, subject discipline and work focus. On the side of health and care professionals, it is relevant to highlight that a Health IT Analytics survey reported that one-third of younger professionals in health care feel overwhelmed by digital patient data. The time available for each medical appointment and the need of extra time when having to change praxis, low (d)HL, hygiene challenges, no instructions and implementation strategy for new technologies, the threat of being out of work, the variety of existing data recording systems and the lack of knowledge or skills about how to use patient data and analytics to inform care are potential issues at the root of such concerns and they directly impact on data quality.

These challenges should be seen as an opportunity for the search of new governance frameworks and policy priorities to be taken at the national and local level immediately.

In this regard, and for health and care professionals to be skilled and better motivated towards the collection of quality health data, several types of **education, training and organisational interventions** are useful. In addition to promoting competencies for using different eHealth systems and devices is important, **motivation** is also crucial for competent eHealth and (d)HL performance (Virtanen et al., 2021) with empathy, encouragement, evidence-based techniques and user-centered changes in the work environment at its core.

One specific key role among the class of health and care professionals is the one of **General Practitioners (GP)** / family doctor, who are the first meeting point between patients and health information and usually a figure trusted by patients in the health system (WHO, 2018). Due to their knowledge of each patient’s life story, family and health conditions, but also of their personality and needs, the GP can offer or validate information as trustworthy, but also assist each patient to apply it in place. GPs have **a main role in each stage on individual (d)HL process**

and therefore need to have the necessary “*tools, organisational resources and knowledge (...) to help patients on their way from the information to the empowerment*” (Traver et al., 2016).

Finally, to conclude on considerations on ethics, it is needed to highlight the work of the High-level Expert Group on Artificial Intelligence, namely the Ethics Guidelines for Trustworthy AI. Their work has been extremely relevant to foster highly important aspects such as transparency, ethics and the common good. In the health domain, this area is also benefitting from the work of the Joint Action “Towards the European Health Data Space” (TEHDAS), which is supporting the Member States and the European Commission in developing the future policy, legal and technical framework for the sharing and secondary use of health data in the EU (European Commission, 2019). Some of the conclusions of this Joint Action refer to **data altruism** as a potential concept to frame the sharing and controlling health data specifically for secondary uses by citizens; and also, that citizens shall be allowed to choose the purpose, entity or research topic for which their consent is given. **This central role of citizens in sharing their data implies that building trust is the main prerequisite.** For citizens to decide whether they want to share their data, **they need to be informed and fully acknowledge their data is being used, what for and who is using it.**

Citizen education is a cornerstone, as well as citizen engagement, in a more active form that encourages the involvement of citizens on health research purposes. To enable this, methods and tools for sharing health data must be simple and user-friendly, to avoid that people with lower level of digital literacy are left behind, but at the same time they must be secure and respectful.

- *Main literature and policy results and discussion on privacy*

The above considerations are also valid for the issue of privacy, in line with the EU **GDPR regulatory framework**. GDPR updates and modernises the principles of the EU 1995 Data Protection Directive, and it sets out the rights of the individual and establishes the obligations of those processing and those responsible for the processing of the data. It also outlines the methods to ensure compliance as well as the scope of sanctions for those in breach of the rules.

Core data privacy and protection principles enshrined in GDPR and Member States’ related legislation include:



- Personal data are obtained fairly (e.g., not violating informational self-determination) and lawfully (e.g., consent-based).
- They are used only for the original specified purpose.
- They are adequate, relevant and not excessive to purpose.
- They are accurate and up to date as well as accessible to the subject.
- They are kept secure and destroyed after their purpose is completed.

GDPR and its implementation in Member States have greatly helped the building the foundations for more secure data collection and processing and for enhanced respect of citizens' privacy. Nevertheless, although security and privacy must be respected, literature reviews highlights that **this is often not the most usual scenario in eHealth apps yet**, as they are not always used with altruistic purposes.

A study developed by researchers at Macquarie University (Tangari et al., 2021) identified more than 15,000 free mHealth apps in the Google Play store and found “serious problems with privacy and inconsistent privacy practices” – as 88% could access and potentially share personal data, two thirds could collect advert identifiers or cookies, one third could collect a user's email address, and about a quarter could identify the mobile phone tower to which a user's device is connected, potentially providing information on the user's geolocation. Moreover, 28% did not offer any privacy policy text and at least 25% of user data transmissions violated privacy policy statements.

Another study that reviewed mobile apps retrieved from iTunes and Google Play stores (O'Loughlin et al., 2019), assessed 68% as having “unacceptable” transparency of data handling procedures. In the USA the scenario is identical with a study (Gerke & Rezaeikhonakdar, 2022) concluding that much more work is needed to adequately protect the privacy of consumers using health apps.

If this may have less impact on chronic disease patients, who are often more prone to share their data as they can directly benefit from research results, it directly impacts the trust of citizens in digital health products and services, thus hindering their adoption.



In a research action comparing cancer survivors with healthy adults (Brannon et al., 2022), it was interesting to learn that both groups were not specifically concerned with the information privacy, but instead with ownership related to data sharing: *“Participants felt that their information being out beyond their control could be problematic. Knowing who has access to one’s health information, and the implications for how they might share or use their health information was of great importance for several participants, but the topic was more common for non-patients than cancer survivors. Data sharing was another primary theme and was characterized by a tension between perceived benefits and perceived barriers”*.

According to the EU factsheet (2018) on “The EU Data Protection Reform and Big Data”:

- 81% of Europeans feel that they do not have complete control over their personal data online (Eurobarometer, 2015).
- A large majority of Europeans (69%) would like to give their explicit approval before the collection and processing of their personal data (Eurobarometer, 2015).
- Only 24% of Europeans have trust in online businesses such as search engines, social networking sites and e-mail services.

In the same veins, the results of a comprehensive public consultation on the three health priorities identified by the *Communication on enabling the digital transformation of health and care in the Digital Single Market* (European Commission, 2018), carried out in 2017 in preparation for the referred Communication, confirmed that most of the respondents (93%) either agreed or strongly agreed that “Citizens should be able to manage their own health data.” However, interestingly, the consultation also showed that >80% of respondents have confidence that sharing data could improve treatment, diagnosis and prevention of diseases across the EU (European Commission, 2018).

While respondents highlight in their views a clear preference for always being able to manage their data, certain organisations responding to this survey refer that a full control of health data by the citizen can raise challenges, mainly in two situations:



- when individuals have complete control over editing the information contained in their file and they could then delete information created by the doctor or other health and care professionals;
- in the case of an emergency requiring immediate access to the information, it can be a real problem if the patient is unable to give consent to access his/her health record.

Other stakeholders underline that individual health data management should be optional and go hand in hand with the interoperability of data but also the necessary protections that should be set in place.

On a different perspective, respondents showed concerns that their health data may be accessed by commercial organisations and by government authorities without their consent. They also expressed their preference that only the necessary data for a particular treatment is shared with the health and care professional after explicit consent, and that the patient should be able to revoke it. The possibility to opt out if the person is not able or unwilling to manage their data was also considered of interest. **Individuals and organisations both agreed that appropriate information and education on how to manage data and interpret the contents is essential** (European Commission, 2018).

All in all, and despite disagreements or different perspectives on details, the majority of EU responding citizens think that health data sharing can be beneficial to diseases' prevention and management. To such aim, privacy by design and universal usability seem to be relevant examples of best practice guidelines for designers, health and care professionals, and researchers developing digital health solutions that can support citizens to make better and more informed decisions about data sharing (O'Connor et al., 2017). The WHO has also been calling for the adoption of community data oversight: *"both private and public sectors should seek meaningful social engagement when deploying digital health tools and using personal data for health research"* (Ferretti & Vayena, 2022).

- *Conclusions from (d)HL literature and policies on ethics and privacy*

Based on the outcomes of the above literature and policy reviews, it can be concluded by summarising a number of **key concepts to consider for an ethical and privacy-based (d)HL**, being the first layer the area, the second the challenges and the bottom one the recommendations for improvement. Their interrelations are depicted in the self-made graphic below (Figure 4).

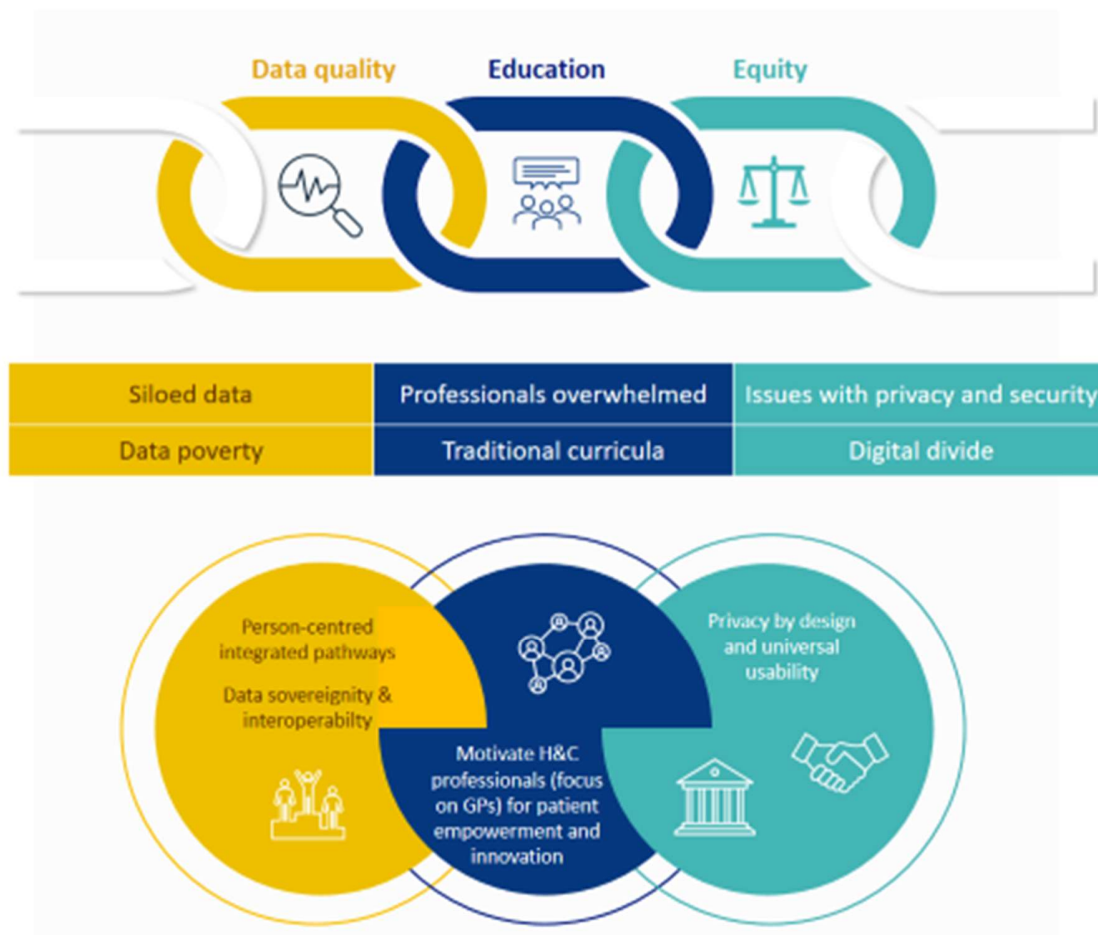


Figure 4. Summary of key ethical challenges for (d)HL

3.2.2. WORKSHOP RESULTS ON ETHICS AND PRIVACY

Like for the thematic cluster of gender and inclusion, the workshop “Health Literacy through the ethics lens” gathered information on ethics and privacy for (d)HL. Feedback has been summarised below, and it, together with literature research, have been used to draft initial key recommendations of the toolkit (section 4). These results will also be taken into account for the development of the IDEAHL Strategy.

- *Main results and discussion on ethics and privacy*

Experts of the WP4 workshop pointed out that there is a very **strict relationship between participants and researchers, having these ones the main responsibility to safeguard participants’ best interests** and provide them with fruitful information so they can give informed consent. It is essential to create trust between researchers and subjects involved in the research.

From a legal perspective, it is a condition that, as far as possible, **only necessary data is collected** (especially sensitive personal data) and that it is collected in line with the purpose of the project. In addition, when the project extends over several years, there should also be a continuous study of the empirical material, including following up on and possibly updating already collected data, if required. This is to ensure data quality.

Sharing data is very important for science, and it has been demonstrated during COVID-19. However, privacy is a fundamental right to the people, and this is something that has to be considered when treating people's personal information. Professionals have to respect people’s right to do whatever they want with their data, because it belongs to them.

According to the workshop’s experts, in terms of balancing privacy and data collection, one should, as far as possible, consider the individual's premise. The ethical and privacy challenge, which often arises from an unequal balance of power, should be addressed in (d)HL projects and interventions like IDEAHL prior to data collection and in line with the Helsinki Declaration and GDPR framework. One possible solution that can help ensure the privacy of the participants could be the possibility of an active opt-in and opt-out for individual parts of the envisaged research

actions. So that it is not an all-or-nothing approach, but where participants can actively and informedly decide to what extent they want to participate. This approach creates transparency, which will lead to more qualified data, according to the workshop's experts. This also contributes to a qualified decision on the extent to which the participants/informants wish to consent to future publication and or use of results in another research context.

This is directly related to (d)HL, as **information and education are the bases of ensuring both (d)HL and the right to privacy**, according to the consulted experts. In the field of (d)HL, new challenges show themselves to allow people to get prescriptions, to have appointments and follow-ups through digital means. It brings new ethical impositions to professionals, carers, and users. Another aspect that relates straight with (d)HL is that more information does not necessarily mean better knowledge; in fact, people have become more susceptible to false information. So, **(d)HL has to somehow strengthen its foundations in critical thinking, with respect for the privacy of people's personal and health data, and with the ethical dimension as a guide.**

Two further barriers to consider, which experts and partners highlighted at the workshop, were:

> *The complexity of guidelines and regulations.* Most of the time this process becomes too bureaucratic and time-consuming – leading to some participants not being involved in research because it seems too difficult to involve them. This leads to research only including some participants' perspectives. Often, those with the strongest voices, not giving a full and nuanced picture of how different groups experience for instance their life, disease, disability, etc.

> *Queer data, queering data.* Current data practices reflect an incomplete account of LGBTQ lives, which creates data biases that are sometimes used to delegitimise the experiences that queer people live. This therefore foregrounds longstanding concerns in the social sciences over the representational limits of data. It is important to reflect the realities of all citizens in order to obtain real data.

- *Conclusions on ethics and privacy*

Regarding the search for solutions to barriers related to ethics and privacy, the experts proposed some actions that could be taken to mitigate them.



a) Actions addressed to policy makers

<ul style="list-style-type: none"> • To start promoting data collection mechanisms and to harmonise them.
<ul style="list-style-type: none"> • To promote guidelines for ethics; to promote trust.
<ul style="list-style-type: none"> • To make resources available so that the citizens involved can be informed and guided in the process. This includes ensuring that the technology is adapted to the user/citizen and not the other way around. This means that it must be possible to make the differences in use and function depending on whether the technology is targeted at a child or an adult.
<ul style="list-style-type: none"> • To have people committed at the governmental level.
<ul style="list-style-type: none"> • To raise funding in order to spread information as much as possible, as well as to invest in research and innovation.
<ul style="list-style-type: none"> • To ensure smooth and easily understandable regulation which does not become too difficult to collect and work with data.
<ul style="list-style-type: none"> • To ensure that the healthcare professionals who have contact with the patients have the right skills to handle the above task. This can be ensured, for example, through education, ongoing evaluations, etc.

b) Actions addressed to health and care professionals

<ul style="list-style-type: none"> • To include health and care professionals in the design of software for healthcare.
<ul style="list-style-type: none"> • To teach them how to address people, and how to proceed with their personal information.
<ul style="list-style-type: none"> • To explain in a concrete way how their data is going to be used and to highlight the importance of going digital.
<ul style="list-style-type: none"> • To promote collection mechanisms and consistency between databases.
<ul style="list-style-type: none"> • To do training in order to teach them how to use these new tools.



c) Actions addressed to citizens (namely the most vulnerable or excluded)

- | |
|---|
| <ul style="list-style-type: none">• To open their minds and trust health and care professionals as well as policy makers. |
| <ul style="list-style-type: none">• To involve them in the process as much as possible. Citizens' active participation is crucial. |
| <ul style="list-style-type: none">• To provide them with ongoing guidance and possible affiliation with a permanent contact person (to maintain the arrangement/commitment to submit data). |

4. A ROADMAP FOR THE IDEAHL TOOLKIT – ACHIEVEMENTS OF VERSION 1

The IDEAHL Toolkit Version 1 supports and underpins the next steps of the IDEAHL project (Strategy co-creation and implementation). The deliverable established the knowledge foundations for the two WP4 thematic clusters – inclusion and gender and ethics and privacy.

The project toolkit is also thought to guide practitioners and policy makers towards establishing and promoting actions and measures for (d)HL, taking into account inclusion and gender as well as ethics and privacy considerations to protect citizens and be more inclusive and gender sensitive.

To this end, based on the results of the literature and policy reviews and the experts' workshop, **initial key recommendations for policy makers and health and care professionals** for (d)HL have been put forward by the authors of the deliverable in cooperation with the IDEAHL project consortium. Recommendations are listed in the following sub-sections:

- Gender and inclusion recommendations for policy makers (see [4.1](#));
- Gender and inclusion recommendations for health and care professionals (see [4.2](#));
- Ethics and privacy recommendations for policy makers (see [4.3](#)), and
- Ethics and privacy recommendations for health and care professionals (see [4.4](#)).

The present toolkit is considered a “living” document to improve throughout the project experience based on lessons learnt while co-creating and implementing the EU Strategy with citizens' groups. According to the established roadmap for WP4, more elements will be integrated in the next two versions of the toolkit, such as a self-assessment adapted to stakeholders, and initial recommendations will be extended and enhanced with the feedback collected throughout the co-creation phase planned in the first half of 2023.



4.1. GENDER AND INCLUSION RECOMMENDATIONS FOR POLICY MAKERS



Focus on identifying groups that already are, or may become, disadvantaged in relation to health care and (d)HL. Health care bias and systemic failures such as racism and discrimination that exist in health care systems risk being copied into eHealth systems. Ensure these groups are considered in policies and action plans.



Build (d)HL and eHealth strategies and interventions with an inclusive approach in mind, which recognises vulnerable or marginalised groups such as older persons, minority ethnicity/race, language abilities, socioeconomic level, migrants, people with low education level, those living in marginal geographic areas, and people with physical and intellectual disabilities.



Inclusive design is key to addressing the issues of access and low (d)HL; all types of users must be involved and considered from the very outset of planning a design. A “one size fits all” or “build it and they will come” approach will lead to exclusion and exacerbate already existing inequities in the health care system.



Consider, within (d)HL & eHealth strategies and interventions’ development, the challenges of lack of Internet access and a low awareness of data protection and rights as patients, which can be common for disadvantaged groups.



Always take into account gender in health and care policies and related (d)HL interventions. Gender mainstreaming shall underpin any action in relation to (d)HL. Gender inequality and women's greater social vulnerability contributes to the risk for women in the health and care area, and these intersect with other factors that shape women's experience e.g., race, religion, socioeconomic class, age, disability, etc.



When planning (d)HL/eHealth strategies and interventions, consider the higher risk of gender-based violence and the great health-related challenges experienced by women. Take into account that women live longer than men but have less healthy life years. The poor health that older women may experience can make their health needs more demanding and their ability and/or willingness to adopt (d)HL smaller.



Address healthcare workforce gender bias. The healthcare workforce is overwhelmingly female, but women tend to be underrepresented in decision-making positions. Also, a healthcare education with integrated sex and gender education is necessary for health and care professionals.



While recognising where extra support is needed for marginalised or disadvantaged groups, it is also important to acknowledge that sometimes a patient simply does not want to get involved with (d)HL / eHealth. While all offers of support and help should be given to such a patient, they should not be put under pressure to participate and a decision to abstain must be respected.



4.2. GENDER AND INCLUSION RECOMMENDATIONS FOR HEALTH AND CARE PROFESSIONALS



Receive proper training and guidance on gender perspective, interculturality and inclusion of health literacy and digital health literacy, as well as be trained to help patients approach and adopt (d)HL and eHealth and how to use the different digital healthcare infrastructures that their patients are expected to use.



Develop and use dedicated user-friendly materials and tools for their patients, especially those in more vulnerable situations and for women.



Identify women experiencing gender-based violence, and that the role of health and care professional in supporting the woman does not get lost in transition to eHealth.



Take part in the development of tools and interventions to encourage (d)HL and eHealth use, and counsel patients in what tools/actions are useful for them specifically. Health and care professionals should also be encouraged to participate in the elaboration of (d)HL related policies and work closely with policymakers.



Promote use of digital tools for health among patients but at the same time recognise when a patient wishes to continue with personal visits/contact, and not pressure a patient into adopting (d)HL measures.



4.3. ETHICS AND PRIVACY RECOMMENDATIONS FOR POLICY MAKERS



Establish leadership at the governmental level in regard to a data structure that encompasses the different services in health and social care, designing the data collection based on the citizen's care pathway.



Promote health literacy friendliness in all digital communications and technologies, having (d)HL contributing to decrease inequalities and social exclusion.



Promote collection mechanisms and consistency between datasets, with a portfolio of non-sensitive health data that can be shared without endangering the confidentiality of the person's most vulnerable data, always in compliance with GDPR rules.



Develop forward-looking health policies that are clear and easily understandable, realistic to implement and encompass sustainability aspects, highlighting the role of (d)HL in laws, strategies, and action plans related to health information innovation and health services delivery.



Include principles of ethical and meaningful communication in policy making to promote trust, namely by providing reliable information to citizens on the importance of certain actions for their own benefit or that of the community.



Create and establish a system for monitoring and assessing (d)HL at national level (accompanying similar efforts in other countries, notably at European level).



Support an empowering approach to the use of digital communications and technology, with the necessary resources available for citizens to be informed and guided in the process.



Promote measures to train the health workforce with the adequate skills for addressing patients and promote their empowerment towards self-management.



Have grassroots organisations, e.g., municipalities report on the health and wellbeing of the population in their area and include (d)HL in the indicators.



4.4. ETHICS AND PRIVACY RECOMMENDATIONS FOR HEALTH AND CARE PROFESSIONALS



Be included in the design of software for health and care.



Acknowledge that the information that is not relevant does not have to be taken. There is a general feeling that more and more irrelevant data is requested, but there is the need to be aware of the importance of data minimisation and anonymity.



Acquire or be given the necessary resources to guide citizens, learning how to address patients and how to teach/train them, enhancing their (d)HL.



Learn how to use new digital tools for data collection as well as for eHealth in general, always in compliance with GDPR rules.



Search for or be provided with easy-to-use tools that are not time-consuming to collect quality data and participate in research.



Update curricula and internships for young professionals, enabling them to be more prone to accept innovation and encourage patient self-management.



Have the GP role reinforced as the pivotal point to support citizens and patients in their (d)HL development.



Evaluate the need to rearrange institutional procedures and workflows to apply and promote (d)HL, giving professionals time and effort to engage people and adapt to new approaches.



Understand and respond to different types of patients' vulnerabilities.



Prepare caregivers to support the (d)HL process and to that aim a deeper understanding of the profile of the carers in society is needed.



5. CONCLUSIONS

The understanding of (d)HL may have a wider or more restricted approach. However, **at its core, health literacy, whether digital or not, needs in the first place to contribute to the realisation of the universal right to health.** Only by consolidating knowledge of their own rights, do people have the minimum conditions to claim them.

When we talk about (d)HL it is impossible to dissociate the notion of inequalities in access, because from the moment that technology becomes an elementary issue, people who do not have/or cannot have access to it are automatically excluded. This aspect adds one complex layer to factors that already contribute to inequalities in access to the EU health and care systems.

Equality in access to health and care is influenced by several factors that can determine the individual patient's course of treatment. Certain groups in vulnerable situations may have worse conditions for access. They may need greater support, so that in connection with the roll-out of the technological solutions in the health and care systems, they are not left behind – and thus disadvantaged because they themselves are not able to meet the demands placed on them in this context. A low (d)HL increases difficulties in navigating the health and care system and seeking and understanding health information digitally available, potentially leading to lower compliance. Low compliance to treatment and care can impact the health status and therefore the quality of life.

In general, health and care professionals often overestimate the level of (d)HL of their patients and clients. Additionally, **some professionals might also have a low (d)HL,** making it difficult to support patients and clients to improve their (d)HL, health, and quality of life. **The guided use of eHealth tools, particularly in primary care, is a powerful vehicle to enhance (d)HL** (Mertens et al., 2022). It strengthens various patient skills, especially “the ability to find good health information” and “understand health information well enough to know what to do”. Moreover, as emerged from literature review, patients with lower levels of (d)HL, e.g., those lower educated and lower digitally skilled, usually display a great learning potential.

The success of digital technologies in health and care fields is also dependent on the selection and adaptability of the people that will use them. Some of the results emerged from the deliverable suggest that the use of digital technologies must be accompanied especially by 1) education on (d)HL and its implementations for inclusion and gender and ethics and privacy; and



2) strategies to determine which citizens/patients are or are not suited for existing platforms (and the other way around), leaving behind the “one size fits all” methods and tools.

The deliverable’s outcomes point out at co-creation and patient-tailored approaches for (d)HL strategies and interventions. (d)HL measures and eHealth tools & systems shall be developed by involving end-users in the design process to consider their own personal barriers, concerns, expectations, and usability needs.

Education also emerges as crucial for enhancing d(HL) and its related implications for inclusion and gender as well as ethics and privacy. On one side, university curricula for health and care professionals should benefit from embracing changes based on real-world needs, such as the ones generated by the digitalisation of health and care services and generate professionals that are more fit to the upcoming societal challenges. On the other side, some of challenges related to citizens’ low (d)HL levels could be even addressed in early education years (Paakkari & George, 2018). Although there are still scarce examples of school-based interventions that work around (d)HL with intermediate elementary students, existing research has shown that promoting (d)HL and healthy lifestyle behaviours in children can lead to positive long-term health outcomes and prevent chronic diseases (e.g., Hyman et al., 2020).

To address its challenges properly, (d)HL has therefore to strengthen its foundations in critical thinking for inclusion, diversity, and privacy of people's personal & health data, with the ethical dimension as a guide. To provide a departure approach, key aspects to enhance for the future (and for the next toolkit’s versions) can be summarised in the words of Nutbeam & Lloyd (2021):

- **improving the quality of health communication** that reaches a diversity of populations, especially by improving frontline professional skills and support;
- **enabling people to develop transferable skills** in accessing, understanding, analysing, and applying health information from digital sources;
- ensuring that priority is proportionate to need by reaching and **engaging the population groups who are disproportionately affected** by low (d)HL.

Communication, training, and engagement are, therefore, the tripod for enhancing (d)HL.

The next versions of the toolkit will work in this direction through the continuous consultations with experts and policy makers, as well as through the EU-wide co-creation phase about to be launched. An updated release of the present deliverable is planned for October 2023.



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7. ANNEXES

ANNEX 1 – DEFINITION LIST

Autonomy. The control that each person exercises when making individual decisions, especially regarding well-being. In health and care, autonomy is the freedom of the patient to maintain control of their body before, during and after treatment.

Beneficence. The dedication to safeguard and defend the rights of others, prevent harm, assist those with disabilities, and save those who are in danger while upholding a set of ethical norms.

Citizen. A person who, by place of birth, nationality of one or both parents, or naturalization is granted full rights and responsibilities as a member of a nation or political community.

Digital health literacy. The ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to address or solve a health problem.

eHealth. Tools and services that use information and communication technologies (ICTs) to improve prevention, diagnosis, treatment, monitoring and management of health and lifestyle.

Gender. The characteristics of women, men, girls and boys that are socially constructed. This includes norms, behaviours and roles associated with being a woman, man, girl or boy, as well as relationships with each other. As a social construct, gender varies from society to society and can change over time.

Health literacy. The personal knowledge and competencies that accumulate through daily activities, social interactions and across generations. Personal knowledge and competencies are mediated by the organizational structures and availability of resources that enable people to access, understand, appraise and use information and services in ways that promote and maintain good health and well-being for themselves and those around them.

Health care professionals. A health professional, healthcare professional, or healthcare worker is a person who provides essential services that promote health, prevent diseases and deliver health care services to individuals, families and communities based on the primary health care approach.

Information and Communication Technologies (ICT). A diverse set of technological tools and resources used to transmit, store, create, share or exchange information. These technological tools and resources include computers, the Internet (websites, blogs and emails), live broadcasting technologies (radio, television and webcasting), recorded broadcasting technologies (podcasting, audio and video players, and storage devices) and telephony (fixed or mobile, satellite, video-conferencing, etc.).

Intersectionality. A concept and theoretical framework that facilitate recognition of the complex ways in which social identities overlap and how they can create compounding experiences of discrimination and concurrent forms of oppression.

Justice. The fair, equitable and suitable treatment of individuals.

Nonmaleficence. The ethical principle of doing no harm. In healthcare, it is the duty of health care professionals to act in the patient's best interest.

Patient. A person who is receiving medical care, esp. in a hospital, or who is cared for by a particular doctor or dentist when necessary.

Privacy. The right to keep one's personal matters and relationships secret.



ANNEX 2 – LIST OF QUESTIONS FOR STAKEHOLDERS’ CONSULTATIONS

Key questions

Gender

- a) How does gender impact the experience of and access to healthcare in your opinion?
- b) Which are the factors that transform gender into a potential health risk for women and girls?
- c) In which ways does gender affect the levels of (d)HL and/or its promotion across EU countries in your opinion?
- d) Which are the key measures that can implemented to guarantee gender equality in health & care sector?
- e) How can the health and care professionals better facilitate (d)HL improvement among women and girls?
- f) Other potential key aspects for (d)HL you wish to point out arising from a gender perspective.

Inclusion

- a) Which population groups in vulnerable situations can face more challenges in (d)HL?
- b) How should the lack of digital skills be taken into account in designing (d)HL actions?
- c) What are the 3 main actions to be taken to enhance (d)HL in people in vulnerable situations?
 - a. By policy makers
 - b. By health and care professionals
 - c. By citizens themselves
- d) What action points do you see as key to prevent inequity and enhance (d)HL?
- e) Other potential key aspects for (d)HL you wish to point out arising from the inclusion perspective.

Ethical and privacy implications

- a) How do we balance privacy when considering the need of data for research (COVID-19 example) and the right to consent or choose what data to share?
- b) How can this be connected to (d)HL?

- c) What are the 3 main actions to be taken to improve data quality?
- a. By policy makers
 - b. By health and care professionals
 - c. By citizens (namely the most vulnerable or excluded)
- d) And what barriers need to be addressed in this area?
- e) How does equity in access to healthcare influences or is influenced by (d)HL?
- f) Other potential key aspects for (d)HL you wish to point out arising from the use of digital technologies in the healthcare settings.