

IDEAHL

Improving Digital Empowerment for Active Healthy Living



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Funded by
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INCLUSION, GENDER, ETHICS AND PRIVACY IN HEALTH AND CARE

Equality and digital accessibility are fundamental for IDE AHL target groups, 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.

In this context, the **gender dimension** also needs to be considered, mainly in line with key policies as mentioned in the IDE AHL Grant Agreement.

Ethics in the health and care sector constitutes an interdisciplinary field that covers a wide range of topics such as privacy, inclusion, and equity with a major goal of ensuring equal access to health and care, and treatment of citizens.

The framework of fundamental rights and bioethics, and in particular the principle of autonomy, are directly related to another of the key aspects to be considered in health-care and in IDE AHL: **privacy**.

IDE AHL inclusion, ethics & privacy toolkit V.1

This toolkit provides a 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 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.

Methods



Policy desk search



Stakeholder consultation



Stakeholders' workshop

Results from Stakeholder Consultation

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.

Experts highlighted the following as potentially digitally excluded groups:



Older people



People with disabilities



Marginalised people in vulnerable conditions e.g., drug abuse, homelessness, or lacking financial resources



LGBT people



People with lower socio-economic status and/or with lower education



Migrants



People living in rural areas

Main workshop results and discussion on ethics and privacy

Sharing data is very important for science, and it has been demonstrated during CO-VID-19. However, privacy is a fundamental right for citizens, and this is something that has to be considered when treating personal information — Peoples' right to access, use and share their data should be duly respected.



Recommendations on Gender and Inclusion

POLICY MAKERS



Focus on identifying groups that already are, or may become, disadvantaged in relation to health care and (d)HL. 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



Inclusive design is key to addressing the issues of access and low (d)HL. A “one size fits all” or “build it and they will come” approach will lead to **exclusion**.



Consider the challenges of **lack of Internet access** and a low awareness of data protection and rights as patients,



Always consider **gender** in policies and related (d)HL interventions. Gender inequality contributes to the risk for women in health, and these **intersect** with other factors that shape women’s experience e.g., race, religion, socioeconomic class, age, disability, etc.



Consider the higher risk of **gender-based violence** and other health-related challenges experienced by women e.g., women live longer than men but have less healthy life years.



Address **healthcare workforce gender bias**.



Acknowledge that sometimes a patient simply does not want to get involved with (d)HL. Citizens should not be put under pressure to participate - a decision to abstain must be respected.

HEALTH AND CARE PROFESSIONALS



Receive training and guidance on gender perspective, interculturality and inclusion of (digital)health literacy, as well as be trained to help patients approach and adopt (d)HL.



Develop and use dedicated user-friendly materials and tools for their patients.



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.



Participate in the elaboration of (d)HL related policies and work closely with policymakers.



Promote use of digital tools for health among patients, always recognising and respecting when a patient wishes to continue with personal contact.

Recommendations on Ethics and Privacy

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, realistic and encompass sustainability aspects, highlighting the role of (d)HL in laws, strategies, and action plans.



Include **principles of ethical in policy making** to promote trust, namely by providing reliable information to citizens on the importance of certain actions.



Create and establish a **system for monitoring and assessing (d)HL** at national/European level.



Support an **empowering approach to the use of digital communications** and technology, informing and guiding citizens in this process.



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



Have **grassroot organisations**.

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**.



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.



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.



Understand and respond to different types of **patients' vulnerabilities**.



Prepare caregivers to support the (d)HL process

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