

Executive Digest

Empowerment and capacity building
of digital health stakeholders

In collaboration with

IDEAHL
Improving Digital Empowerment for Active Healthy Living



SIRENE



SHIFT-HUB

Topic: Empowerment and capacity building of digital health stakeholders

Relevance of this topic to Digital Health

Digital technologies are a driving force to help citizens and professionals **address preventable risk factors** associated with diseases. They can **support healthy ageing** and facilitate **early detection and treatment**. Digital solutions empower citizens, with **access to their personal health data**, to be actively engaged in the **management of their own health**. Moreover, they are also central to supporting a shift in care provision. Empowerment and capacity building, particularly in the area of digital health literacy, play a key role in fostering individual engagement, ownership and sustainability. By empowering people to take control of their health and well-being, we cultivate a **sense of ownership** and **commitment** that ensures active participation and use of digital tools. Living Labs and Open Innovation are crucial to empower patients to actively contribute to the development of digital health solutions, fostering collaboration and synergy among stakeholders. Capacity building also ensures that individuals and communities have the skills, knowledge and resources to sustain healthy behaviours, promoting long-term impact.

The overall objective of empowerment is that **all members of the health ecosystem have the knowledge and skills to navigate the digital landscape effectively and that citizens make informed decisions about their health**. The accuracy of health information, user-friendly, user-centred, affordable, inclusive, interoperable digital platforms and solutions, co-created by multidisciplinary stakeholders in responsive environments, contribute greatly to the empowerment mission of the digital health ecosystem.

However, intuitive, open-source, co-created solutions alone are not sufficient for empowerment. This open innovation process should be accompanied by comprehensive **guidelines**, preferably in simple language, using visuals, media components like videos, gamified options. Meticulous assessment of user satisfaction, feed-back and evaluation should also be embraced as part of empowerment. A comprehensive approach to the empowerment of health ecosystem members cannot be built without a solid and quintessential basis of **general education and a minimum level of information technology literacy**.

A **nurturing, responsive environment** around this empowering social innovation process, which equally promotes positive health behaviours, requires a **partnership with key stakeholders**, such as community organisations, policy-makers, local leaders, scientists, innovators and groups of interest. The carefully designed and place-tailored empowerment plans should take into account complex interaction of social, **cultural, economic, and community factors**, the **cultural practices** and specific needs of each community and each member of the community, including vulnerable populations, low-income citizens, older people, people with disabilities so that they can access information and make their own decisions autonomously. Taking a holistic approach to health literacy and promoting gender equality in health can improve health outcomes for all people and promote a fairer and more just societies.

Besides the social implications, the **economic enablers** cannot be neglected either. Empowerment of the health ecosystem stakeholders **nurtures responsible entrepreneurship**, and the other way round, responsible entrepreneurship enables the empowerment process. Social innovation frameworks and supporting tools help to raise entrepreneurs' awareness of potential business, funding and investment opportunities by creating alliances and synergies between different stakeholders within ecosystems and between ecosystems.

Keywords

empowerment, digital health literacy, healthy behaviour, social innovation, inclusive communities, active engagement, partnership

Current focus of policy, legislation, standards, emerging practices in this landscape

In Spring 2024, the European Parliament and the Council reached a political agreement on the Commission proposal for the **European Health Data Space (EHDS)**. The EHDS will empower individuals to take control of their health data and facilitate the exchange of data for the delivery of healthcare across the EU (primary use of data). Furthermore, it will allow health professionals to access data on their patients. Each Member State will establish national health data access services based on the MyHealth@EU platform. EHDS will enter into force in the Member States in 2028 (with some exceptions related to clinical trials' data, human genetic data, etc).

Prior to the EHDS proposal, the European Commission issued a communication in 2018 on **enabling the digital transformation of health and care**. One of its three pillars was dedicated to the empowerment of citizens through digital tools. Digital services enable the individuals to take a greater role in the management of their own health, to lead healthier lifestyles and become more autonomous in managing

chronic conditions whilst providing feedback to healthcare providers. This is a win-win for the citizens and also the healthcare systems which can be discharged from heavy workload and transformed towards integrated and personalised care provisions.

The eHAction, the Member States' Joint Action supporting the eHealth Network, also created an **empowerment policy framework** which the countries implemented and monitored between 2018 and 2021.

Implications for digital health uptake

Developers

- By aligning with international standards, leveraging resources and expertise, prioritising training and skills development, and fostering interdisciplinary collaboration, DH developers can contribute to capacity building and empowerment of DH stakeholders.

Policymakers

- By investing in good education and ensuring that everyone obtains basic literacy skills, further that can critically evaluate information, policymakers greatly contribute to the promotion of health literacy. To ensure full inclusion, policymakers should pay particular attention to different population groups when making decisions, including individuals with mental health issues, intellectual disabilities, older adults, and immigrants.

Payers and procurers

- Payers can promote value-based procurement practices, foster informed decision-making, collaborate with stakeholders and ensure accessibility and equity of digital health solutions, thereby contributing to the advancement of digital health literacy and the uptake of innovative digital health solutions in Europe.

Users

- By empowering end-users, providing access to reliable information, involving them in the co-creation process, and valuing their feedback for continuous improvement, stakeholders can ensure that digital health solutions are user-friendly, effective, and tailored to meet the diverse needs of individuals across Europe.
- Empowering healthcare professionals to confidently use digital health tools can increase the quality of healthcare that patients get, as well as the productivity, efficiency and effectiveness of the health workers.

Remaining gaps and issues

A **digital divide** can still be observed between different parts of Europe, between age groups and different social groups. Health and digital health literacy initiatives are still scattered.

Their **sustainability** and **scalability** are hindered by insufficient political support, financial support and the fact that regional/national ecosystems are not in place or are not yet sufficiently well-structured to undertake the leadership.

Social sciences and humanities are still not sufficiently valued and integrated in the industry efforts of producing solutions.

Person-centred design is still not prevailing. Instead, it is rather market push that orients and guides innovation. Social innovation and bottom-up initiatives that may help developing more inclusive communities should be encouraged and incentivised by policy and other support tools.

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Legislative, regulatory, policy or standardisation instrument, or good practice	
Title	IDEAHL European Digital Health Literacy Strategy
Instrument status	Published
Publisher or source	IDEAHL Consortium
URL or reference	DOI: 10.5281/ZENODO.11395540
Summary of the instrument	<p>The IDEAHL European Digital Health Literacy Strategy is a document aimed at health and care professionals, policymakers and anyone interested in promoting health literacy by digital means. Its main objectives are to empower people to use digital health tools safely and effectively, thereby promoting informed decision-making and self-care, and to monitor its impact on the quality of life, well-being, productivity, and the economy, considering geographic, social and economic determinants of inequities in digital health literacy (dHL).</p> <p>The mission of the IDEAHL Consortium was to build a digital health literacy strategy taking as main sources the exhaustive review of existing literature and projects, incorporating co-creation process with various groups of citizens, stakeholders, health professionals and policymakers, involving health and non-health sectors. The vision of the Strategy is to empower EU citizens in using digital tools to take a more active role in the management of their own health and well-being.</p> <p>Key pillars and dimensions of the IDEAHL European Digital Health Literacy Strategy were identified based on literature reviews and document analysis, co-creation sessions with stakeholders, the gender, inclusion, ethics and privacy principles of IDEAHL, and according to already well-established models for digital health, including those of World Health Organization (WHO) and the International Telecommunication Union (ITU). The Strategy is structured on a dual core framework of digital components (training and skills development, content and curriculum, evaluation and monitoring, policy and strategy) and health information components (access, understanding, critical appraisal and application of the health information) for micro or individual, meso or organisational, and macro or international levels of intervention in each of the self-care, promotion, prevention and treatment health dimensions. In addition, a third level of transversal elements, such as accessibility, collaboration, equity, ethics and privacy, gender, inclusion, participation, social environment and sustainability, give value and help to qualify the recommendations of the core elements. These guidelines are presented as toolkits for each of the domains, giving special emphasis to inclusion and gender, and privacy toolkits. The Strategy also includes a monitoring and evaluation plan with suggestions for the selection of indicators, dHL instruments and a specific toolkit.</p>
Implication for digital health stakeholders	<p>The EU IDEAHL Strategy aims to empower individuals to safely and effectively use digital health tools, promoting informed decision-making, self-care, and active participation in managing their health and well-being. The Strategy emphasizes the importance of digital health literacy in improving health outcomes, enhancing patient engagement, and bridging the digital divide. The Strategy aims to enhance a stronger EU and government investment on dHL education, and promote dHL solutions' process development among stakeholders, making a stronger EU.</p>

Legislative, regulatory, policy or standardisation instrument, or good practice	
Title	Social Innovation framework
Instrument status	Under validation (summary on SIRENE website)
Publisher or source	SIRENE Consortium
URL or reference	https://sireneproject.eu/
Summary of the instrument	

The desired impact of the SIRENE proposal is to improve the wellbeing and housing conditions of the European population by empowering social and private entrepreneurs. To such aim, it is co-creating a Social Innovation (SI) Framework with experts and ecosystems of EU-27 countries and beyond, which is a toolkit composed of five components:

1. a manual for innovation actors on SI methods and concepts,
2. a capacity-building framework for social entrepreneurs,
3. a hands-on toolkit of networking and learning exchange initiatives,
4. a sustainability strategy,
5. a blueprint of good practices.

Implication for digital health stakeholders

The desired impact of SIRENE is to improve the wellbeing and housing conditions of the European population, by empowering social and private entrepreneurs. In particular, we focus on the improvement of lives of people with fewer opportunities due to poor health conditions, frailty or finances, as the main aim is to promote and support a more active and healthier life. By delivering the SI framework and tools for creation and nurturing ecosystems in the area of Smart Healthy Age-Friendly Environments, we are strongly convinced that we will create the first successful steps for a more inclusive society.

Legislative, regulatory, policy or standardisation instrument, or good practice

Title

Transnational Local-sphere Model

Instrument status

Waiting publication in a scientific journal (summary in SIRENE website)

Publisher or source

SIRENE Consortium

URL or reference

<https://sireneproject.eu/sirene-introduces-the-transnational-local-sphere-model/>

Summary of the instrument

Within innovation economics there are several so-called 'helix models', which can be used to define opportunities in innovation. For the SIRENE project it was important to find out which theoretical framework best fits the goal of the SIRENE model and results. For this purpose, a new helix model was created: the Transnational Local-sphere Model. This model puts more focus on stakeholders, organisations, and underrepresented entities, is user-centred by using a bottom-up approach, includes (trans)national collaboration and competition, integrates both global and local ecosystems, and involves civic society, through the media and the public. By using the Transnational Local-sphere model, SIRENE will try to connect existing local ecosystems and create a network of stakeholders in all sectors to ensure an accessible and sustainable result for its users.

Implication for digital health stakeholders

Empowered ecosystems are more prone to uptake digital health in an equitable and accessible manner.

Legislative, regulatory, policy or standardisation instrument, or good practice

Title

The Global Atlas of Literacies for Health (GALH)

Instrument status

Published online

Publisher or source

IDEAHL Consortium

URL or reference

<https://galh/rmit.eu>
<https://ideahl.eu/results/>
<https://www.galh.eu/>

Summary of the instrument

The Global Atlas of Literacies for Health (GALH) is open access and maps European health and digital health literacy, in an important step towards informing health policy and practice across the region. The Atlas is:

- an online data visualisation tool that shows the levels of (digital) health literacy, best practice, policy, interventions and initiatives in Europe and beyond, developed and managed by RMIT University based on the results of the European Union-funded IDEAHL project;
- a comprehensive resource for (digital) Health Literacy policymaking in the EU;
- a tool for enhancing teaching, research, practice and policy in health care;
- a resource for promoting health equity and digital empowerment in the EU and beyond.

The Atlas visually presents the data from different (digital) health literacy scales, best practice, policy, interventions and initiatives on an interactive map. Users can filter data by population: adult, child and adolescence, health workforce, or select to present only country or region level data.

The Atlas includes a list of available variables within the GALH datasets, along with their corresponding definitions and explanations of their meanings, serving as a valuable resource for data analysts to ensure consistency in terminology and facilitate accurate interpretations.

Implication for digital health stakeholders

The Atlas is open access, free of charge and can be accessed via your web browser. The Atlas works best on a computer or tablet. The data dictionary describes the data elements in the Atlas.

We await your contributions. Please, follow this link: <https://www.rmit.edu/galh/galh-submissions>

Legislative, regulatory, policy or standardisation instrument, or good practice

Title

The SHIFT-HUB Catalogue of Educational Resources

Instrument status

Published online

Publisher or source

SHIFT-HUB Consortium

URL or reference

<https://shift-hub.eu/resources/>

Summary of the instrument

The SHIFT-HUB Catalogue of Educational Resources pool of online assets selected to allow community members to become proficient in the exploitation of emerging solutions in the field of Smart Health.

The Catalogue contains:

- Courses around topics like Artificial Intelligence, Big Data, Digital Health, Health Literacy, Entrepreneurship and many more.
- Courses targeted towards citizens and patients, health care professionals, students, researchers, companies, trainers and informal trainers.
- Courses in the format of online learning platforms, books, apps, reports, scientific publications, videos or master programs.
- Courses with and without certification, free and at a cost, open access and restricted access.

Implication for digital health stakeholders

The Catalogue itself is open access and links to resources that are also mostly open access. The courses contained spring from sources like other European funded projects, as well as national and private initiatives.

Legislative, regulatory, policy or standardisation instrument, or good practice

Title

SHIFT-HUB Smart Health App

Instrument status

Published online

Publisher or source

SHIFT-HUB Consortium

URL or reference

[Smart Health App - SHIFT HUB \(shift-hub.eu\)](https://shift-hub.eu)

Summary of the instrument

The SHIFT-HUB e-learning gamified Smart Health app is a customised, low-barrier tool that through the implementation of the gamification methodology, has the following objectives:

- To facilitate the development and promotion of Smart Health technologies and services;
- To enable the transition from reactive to proactive and personalised healthcare, emphasising the maintenance of good health;
- To improve the digital literacy and awareness of patients, citizens and health professionals;
- To promote a patient-centred approach, enabling people to actively participate in their own healthcare.

It contains five different games, which are:

- A card association game for disease prevention;
- A Drag&Drop game for chronic diseases;
- A Basket collection game for cardiovascular diseases;
- A quiz for mental disorders;
- A simulation game for cancer.

Implication for digital health stakeholders

The Smart Health App is available via the project website. Users have the opportunity to try out and experience smart health tools in a gamified way. After playing the games, they are presented with more educational resources from the catalogue described above, as well as other smart health solutions from a catalogue prepared by the SHIFT-HUB consortium. Patients and citizens will be encouraged to use digital solutions to prevent and manage disease and improve their health.