

OUR MEMBERS' REFLECTIONS ON DIGITAL HEALTH



#Digital4Care
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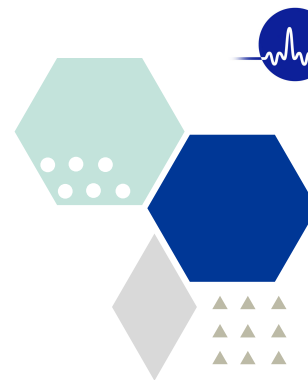
1. Executive summary

The current digital revolution is having a significant impact on our economy and society. In the health care sector, digitalisation has the potential to transform health care systems from a reactive to a proactive system by better preventing and managing conditions, enabling self-management and challenging the relationship between health professionals, patients as well as social care workers.

Health First Europe (HFE) has always been a strong advocate of identifying and using innovative solutions to make patient-centred care a reality; therefore, we welcome all initiatives that pursue this goal. We believe that digital health tools can be instrumental in tackling the rising demand for care while putting patients at the centre of all efforts.

The objective of this paper is to identify digital solutions that concretely demonstrate the above-mentioned potential in practice. **The following document reflects the vision of HFE members on the opportunities existing technologies can offer and the barriers to overcome for their implementation. The paper concludes with some concrete recommendations addressed to national and EU policymakers covering digital literacy, health care financial models, management strategies and patient empowerment.**

2. Background information



Through better management and control, the digital revolution has the potential to meaningfully improve the efficiency and thus sustainability of health care delivery. In this sense, digitalisation can facilitate more personalised treatments leading to better outcomes, improving diagnosis and monitoring, ensuring access to care everywhere via telemedicine, fostering prevention measures as well as improved quality of life through self-management. In addition, digital health can better allocate resources, both in terms of staff and budget investments. Digital health can benefit patient safety, addressing preventable harm, avoiding errors and duplicated tests.

The EU has always been at the forefront of enabling innovation for the benefit of patients. Following the publication of the **Communication on the digital transformation of health care in the Digital Single Market in April 2018**, the European Commission has been working to make digital health a reality to empower citizens and build a healthier society (from the electronic prescription initiative [1] to the common electronic health record exchange format [2]). However, there are still many challenges to face to allow for a broad uptake of digital solutions for better patient care as well as to fully implement the Directive for cross-border health care. [3]

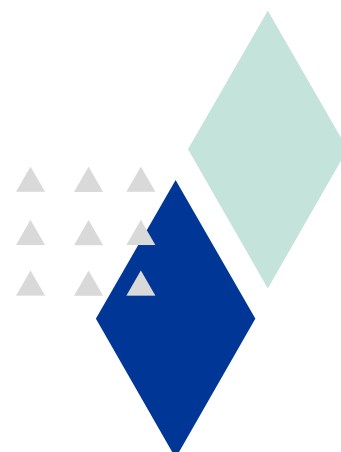
By representing a wide spectrum of health care stakeholders, **Health First Europe (HFE) members** have a unique holistic perspective on identifying the benefits of digital health, remaining challenges for its uptake and recommendations to develop an effective and trustworthy digital ecosystem. To map HFE members' positioning on this topic, the HFE Secretariat has run a survey and conducted interviews amongst its members. The survey and the interviews focused on 3 areas: (1) key priorities with regard to existing digital technologies; (2) opportunities and barriers for their uptake and (3) policy recommendations to overcome these barriers addressed to national and EU policymakers. This paper will explore the results and present the overall position of HFE on this topic.

[1] http://europa.eu/rapid/press-release_IP-18-6808_en.htm

[2] <https://ec.europa.eu/digital-single-market/en/news/recommendation-european-electronic-health-record-exchange-format>

[3] <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32011L0024>

3. Our vision on digital health



3.1 Main priority areas for EU actions on digital health

Digitalisation of care has a wide spectrum of possibilities and domains of action. HFE members give great value to the three areas identified by the European Commission for enabling the digital transformation of care:

- 1  Citizens' secure access to and sharing of health data across borders;
- 2  Better data to advance research, disease prevention and personalised health and care
- 3  Citizen empowerment and person-centred care with digital tools

Amongst those domains, we believe that **citizen empowerment and person-centred care with digital tools** is the one which requires a stronger effort at EU level. Our members stressed patient-centred care as an absolute priority; patients should be involved in decision-making and put in a position that enables them to take responsibility for their care. In order to achieve the best of digitalisation in health, patients need to be empowered to use the available tools. A cooperation among all health stakeholders, from patients to health care professionals (HCPs) and the industry, is crucial to achieve this goal.

Dialogue between doctors and researchers around **personalised medicine through shared European data infrastructure for research** is essential to improve outcomes and care. In spite of their huge potential, health data for research often remain unused and siloed. By encouraging information sharing between providers and research institutes, health care solutions can be developed and improved on, supporting for example the identification of new treatments for rare diseases and the delivery of personalised care.

3.2 5 existing digital solutions & data sharing practices to be implemented

The scope of digitalisation in health care is wide and it touches all the health domains, from administrative workflow to robotic surgery. **Digital solutions support health care delivery across all stages of the patient pathway**, from prevention to after care. HFE members identified some key available digital health solutions and data sharing practices that have the potential to advance health care systems.



2. DIAGNOSIS

Bridging the gap between patients and laboratories: Digital technologies can support early diagnosis by accelerating screening programmes and transfer of lab results. Labs are becoming more and more digital, speeding up advanced and comprehensive patient-centric services and fostering access to reliable diagnostic solutions.



4. MONITORING

Monitoring tools for patients with chronic conditions connected to health care settings: Patients with chronic conditions such as diabetes mellitus, chronic obstructive pulmonary disease, congestive heart failure or hypertension can monitor their data and take action if needed. Through better-connected medical solutions, patients can track their daily activities, take their own blood pressure, blood sugar level and/or pulse, and transmit the readings to a smartphone/tablet or directly into the electronic health record accessible to the caregivers. These monitoring tools can also include devices that detect epileptic seizures or fall monitors which send a call for help, speeding up assistance in case of emergency.



1. PREVENTION

Life coaching via digital tools: Digital apps and mobile kits can promote lifestyle changes, for example by improving daily nutrition, prompting people to exercise, or helping people to control blood pressure as well as foster secondary prevention. This would ultimately support health care systems in tackling the growing demand for care.



3. THERAPY

Development of digital patient records and workflows to keep track of treatments, day-to-day symptoms and important documents: By creating digital dossiers and displaying stored information in dashboards, health care systems can facilitate discussions between patients and their medical specialists. Computers and software can also support HCPs in making clinical decisions and therefore reduce medical errors. In a nutshell, digital health has the potential to make therapy safer and more efficient.



5. AFTER CARE

Remote rehabilitation and post-operative care: One of the biggest advantages of digital health care has been its ability to bring quality care to more people. Technologies allow independent and remote rehabilitation and post-operative care without constant human supervision, increasing accessibility while reducing wait times and saving costs for patients and health care systems. Telemedicine during the post-operative period has been used predominantly for scheduled follow-up, routine monitoring and ad-hoc issue management. Now it is possible to replace traditional follow-up clinic visits with either a telephone call, automated messaging or an online video conference, which can occur from either an affiliated institution or the patient's home.

3.3 5 key benefits of digital health & health data sharing



Digital tools can have broad positive effects on several sectors of care and health management. These solutions can be used by individuals to get insights about their health, improve monitoring of chronic conditions, reducing adverse events and prevent diseases. Digital solutions can be used by physicians to fill health record gaps and conduct informed consultations or to foster patients' involvement and empowerment.

1 Fostering access to care both in remote areas and across borders

Ageing populations are increasing the need for treatment, yet for people living in remote areas, access to health care might be challenging. Digital technologies can improve access to care in remote and rural areas where few HCPs are available and consequently promote equal access to care. Additionally, the exchange of ePrescription, recently promoted by the eHealth Network of the European Commission, is a good example of how pooling patients' data throughout digital platforms can facilitate daily life (e.g. at the moment, most chronic disease patients cannot obtain their medical supplies in another EU country).

2 Improving patients' empowerment & self-management

Digital technologies offer a unique opportunity for people to manage their own health. Good self-management through digital tools and wearable devices can save lives, prevent complications from chronic diseases and ultimately hold down health care costs. Digital solutions can unlock patients' ability to control blood glucose levels, plan nutrition, connect with caregivers, adhere to medication, work out, and keep track of medical visits etc. Patients increasingly expect to have more say in their personal health care, and digital tools can support the shift towards more extensive patient involvement.

3.3 5 key benefits of digital health & health data sharing

3 Tackling the growing demand for care and the shortage of health care professionals

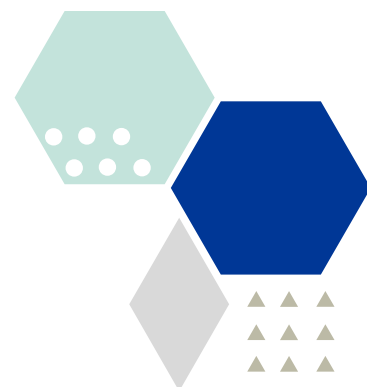
Digital health technologies can support HCPs in overseeing trends through continuous data monitoring, helping them in routine and ordinary tasks (especially in the management of chronic conditions), leaving more time for other responsibilities. Ultimately, digital technologies can help address the shortage of human resources by making the best use of those that are available.

5 Supporting HCPs in their daily work

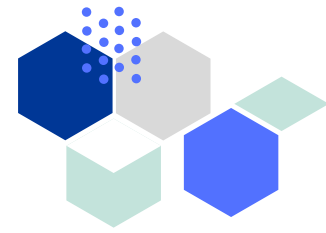
HCPs can better allocate their time for patients in need, through finding out those patients with acute or long-term risks and focus their attention on them. Furthermore, health care professionals can see and assess trends through continuous data (instead of a picture of data on the day of a consultation), ultimately determining better care and better outcomes for patients. Digitally stored data can also help avoid medical errors and duplication of exams (for example, by highlighting that a dosage doesn't correspond to the age of the patient it is being prescribed for or that an underlying disease is a contraindication to the selected medicine).

4 Fostering management of chronic diseases and improving patient outcomes

Digital tools are gradually changing how patients and professionals communicate and interact with each other, greatly benefiting the management of chronic diseases patients and their communication with the health care team. For example, electronic medical records help professionals manage patients' difficulties and communicate across the health care team more efficiently and effectively, also including families and informal caregivers. By providing a comprehensive, digital view of a patient's health history, clinicians can access past results of tests and treatment ultimately leading to a faster diagnosis and improved patient outcomes. By improving clinical management, unplanned hospitalisations can be reduced, together with the associated costs.



3.4 3 Barriers for the uptake of digital solutions



There is certainly a combination of factors preventing the implementation and use of existing digital solutions in health. HFE members identified as major barriers: **(1) lack of infrastructure, heterogeneity of electronic health records, (2) outdated financial models, and (3) lack of acceptance and trust in sharing health data are the major barriers identified by HFE members.**

- 1** The **heterogeneity of electronic health records**, from register parameters to datasets available on one given disease, makes collection and use of data very challenging. Today data are stored in silos, which may include private cloud storage, general practitioners' systems, or hospital patient records. To address heterogeneity and fragmentation, it is crucial to have in place suitable digital infrastructures, standards and a common interoperability framework in order to share relevant health data.
- 2** Stakeholders need the right incentives to invest in digital eco-systems. **Most funding schemes for health care solutions and services are made for an analogue age.** A major obstacle to the development of digital services is the lack of appropriate funding models for remote care, and for patients to purchase apps, wearable devices and other digitally enabled solutions. Caregivers and healthcare settings are paid based on the patients they see and the care they provide, without considering the value of preventing harm and reducing costs in the first place. The funding scheme for preventable solutions and remote monitoring solutions is still weak, although the improved patient outcomes and better use of doctors' time are proven. National and regional policymakers should aim to build healthcare systems which invest in new technologies that prevent harm and reduce costs while also incentivising caregivers and health settings to offer remote care via the internet and mobile tools.
- 3** There are also **cultural barriers** for the uptake of digital health, **namely trust and acceptance** of digital systems and data sharing solutions, among patients and health workforce. HCPs traditionally have always kept data of their patients in their own files and they are concerned that the emergence of digital technologies may challenge their role in the care of the patients. There is not enough awareness about the potential and use related to digital health, which eventually creates hesitancy for its uptake. Furthermore, **certainty over data security and storage as well as anonymisation of personal data is very much needed to foster patients' trust.** Patients might sometimes find it difficult to trust others using their data unless they clearly understand how their information is used and that they remain in control of said data. From the researcher's perspective, looking at GDPR, some of HFE Members see privacy rules to some extent stringent, especially with respect to health data collection and use for research. Overall a culture of sharing, trust and of collaboration with other HCPs and patients still needs to be built across Europe.



4. Our message to national and EU policymakers

The European Commission, the Members of the European Parliament and Member States should join efforts in:

Call addressed to Member States

Call addressed to the EU institutions

1. Investing in HCPs' digital skills and literacy both in medical curricula at universities and at a professional level, helping them to make the best use of digital solutions to deliver better outcomes. It would also be important to define the roles and responsibilities of the professionals participating in telemedicine pathways, identifying the person(s) leading the process. Furthermore, investment is also needed for educational programmes about the benefits of digital health as well as a European study to assess the value of digital solutions in terms of patient safety and health care systems' financial sustainability.

3. Promoting best practices and expertise sharing on diagnosis and treatment throughout common digital platforms: the European Reference Networks on rare diseases is a good example of the benefits of sharing knowledge across borders for the better care of the patients and ultimately to boost collaboration between stakeholders.

2. Reforming the funding / reimbursement model to fit the digital era: European health care systems should jointly address digitalisation challenges and costs. Financing policies should offer incentives for the development of digital solutions and infrastructure while assessing which solutions/technologies will do the most to save lives, reduce costs, improve quality and enhance equal access to care.

4. Fostering investment on digital health under the Digital Services Infrastructures and ensure the health care element becomes a priority in all instruments proposed in the post-2020 Multiannual Financial Framework.

The European Commission, the Members of the European Parliament and Member States should join efforts in:

Call addressed to Member States

Call addressed to the EU institutions

5. Setting the right conditions for building a common digital health ecosystem by promoting interoperability and investing in common infrastructures such as electronic health record systems, patient portals and common platforms for health care research.

7. Fostering patient empowerment and involvement in digital care: digital health has the potential to bring in a new era of patient engagement. To enable it, policymakers should work towards involving and informing patients about digital health benefits and tools, while ensuring data privacy and security in electronic health and telemedicine solutions. Additionally, to fulfil the promises of integrated and patient-centred care, patient data should be securely and safely stored in an electronic health record, controlled by the patient with the possibility to be retrieved, anonymised and used for public health and research. Ultimately, patients should get the chance to engage more actively in the decision-making process around digital health, especially when considering that patients are often the instigators of new digital tools themselves. Consequently, making sure that they have a support framework available at the national level will be very important.

6. Upgrading management strategies and ensuring political leadership to reduce infrastructure fragmentation, foster communication between social and health sector on digitalisation and investing in digital skills. Furthermore, health care management should promote a **multi-stakeholder approach** focused on identifying the different actors' priorities, needs and resources, and skills in order to define realistic implementation roadmaps that could be followed by the actor involved. A multi-stakeholder approach would also help identify which technologies would be beneficial in a specific setting and assess their usability from different points of view (e.g. structural interoperability, resources and pricing, users' skills and innovation preparedness).

8. Political commitment and EU leadership are essential to guide Member States in building effective and trusted digital eco-systems. It is necessary to establish a common policy frameworks and joint strategies but also to allocate the necessary resources to make digital transformation of care possible. We should channel digital governance, infrastructures and practices in a common direction, before they are too widespread across Member States. EU leadership is essential to guide Member States into a common path and address effectively the shared challenges of digital health implementation.

5. Annex

5.1 Learn more about HFE members' initiatives on digital health

A

ACN Active Citizenship Network

Campaign: ACN counts on several imitative at national level, namely in Italy. More information available at: <https://www.cittadinanzattiva.it/>

C

COTEC Council of Occupational Therapists for the European Countries

Project: Some of COTEC members are actively involved in their country to participate in the development of a digital dossiers. E.g. COTEC Belgian member just helped developing a portal for all health professionals.

Publication: Paper on Sensor monitoring to measure and support activities of daily living for independently living older persons. Publication available at: <http://hdl.handle.net/11245.1/866072a0-2b13-4cba-9307-42521b63b01f>

E

EAMBES The European Alliance for Medical & Biological Engineering and Science

Working group: European Parliament Interest Group (EPIG) on Biomedical Engineering

EIWH European Institute of Women's Health

Publication: 2018 EIWH Manifesto for women's health includes references and calls on digital health. Manifesto available at: <https://eurohealth.ie/our-manifesto-for-womens-health-2018-a-background-briefing/>

EFCCA European Federation of Crohn's and Ulcerative Colitis Associations

Project: pilot project on patient data ownership information available at: <http://www.efcca.org/en/active-projects>

EMA European Medical Association

Publication: 'Healthcare Overview', by Roberto Costigliola, available at <https://www.springer.com/us/book/9789400746015>

EHMA European Health Management Association

Projects: EHMA has a long history of projects (especially funded through FP7 or H2020) focused on Digital Health. Recently, EHMA has worked on IC-Health (MOOCs on Digital Health Literacy - H2020) and it will start an Erasmus+ focused on Digital Skills for Health Workforce.

Conference: Digitalisation played a big role in EHMA 2019 annual conference, that took place in Finland in June 2019. Also EHMA Winter School 2019 focusses on Digitalisation and health management. To read more about the EHMA annual conference click here: <https://ehma.org/event/ehma-2019-annual-conference/>

EHTEL European Health Telematics Association

Position paper: Community Position Paper on Digital Health <https://www.ehtel.eu/activities/ehtel-on-eu-affairs/ehtel-community-position-paper-on-digital-health.html>

ESNO European Specialist Nurses Organisation

Publication: ESNO members have been involved in several publications on digital care and specialised nurses as well as in the development of electronic medical records. The records have been used for studies on dialysis, available at: <https://www.sciencedirect.com/science/article/pii/S0085253815303616> <https://www.ncbi.nlm.nih.gov/pubmed/25864164>

Patients' digital app: ESNO members developed a patient App for dialysis patients (data not published yet). Patent Applications based on communications between patients general conditions and dialysis machine. More information available at: <https://patents.justia.com/inventor/maria-teresa-parisotto>

EUROFEDOP European Federation of Public Services Employees Unions

Publication: editorial from Bert Van Caelenberg Secretary General 'Can e-Health improve quality of care in an ageing Europe?': available at: https://healthfirsteurope.eu/wp-content/uploads/2017/10/HFE-EqualityInE-health_BROCH_LayA_V23_spreads-2.pdf

H

Heart Failure Policy Network

Publication: 'The handbook of multidisciplinary and integrated heart failure care' and supplementary materials, also including digital health solutions in heart failure. The handbook and supplementary materials are available at: <http://www.hfpolicynetwork.eu/handbook/>

I

IAPO International Association of Patients Organizations

Position paper: all IAPO positions on innovation, biotechnology and patient literacy are available at: <https://www.iapo.org.uk/policy-positions>

IDF Europe International Diabetes Federation

Position paper: IDF Europe position on mobile applications in diabetes, available at: <https://www.idf.org/component/attachments/?task=download&id=1063>

IPOPI International Patient Organisation for Primary Immunodeficiencies

Campaign: IPOPI has launched a companion app for patients living with primary immunodeficiencies. PID GENIUS is the personal assistant to PID patients in search of an easy and dynamic way of keeping track of their treatments, day-to-day symptoms, vaccinations, contacts, most important documents. More information available at: <https://ipopi.org/pid-genius-personal-assistant-pid-patients/>

M

MedTech Europe

Webpage: relevant publications and news are regularly posted on the Digital Health section of MedTech Europe website, available at: <https://www.medtecheurope.org/digital-health/>

Public consultation: MedTech Europe has also participated in a number of public consultations including the Digital transformation of Healthcare, the Electronic Health Record Exchange Format, and the AI ethics guidelines.

U

UEHP European Union of Private Hospitals

Publication: Opinion piece on Smart Hospital published by the Parliament Magazine", available at: <https://www.theparliamentmagazine.eu/articles/magazines/issue-440-26-september-2016>

Coalition and publication: UEHP is member of the Integrated Care Alliance (<http://www.integratedcarealliance.org/>), which released in 2018 its Digital Health Roadmap, available at: http://www.integratedcarealliance.org/wp-content/uploads/2019/03/04-18035_COC_ICA-roadmap-web.pdf



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