

Digital Solutions for Health and Disease Management

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Executive Summary

Digital health plays a growing role across Europe despite the fact that there are still many uncertainties regarding its technical, legal, ethical and financial aspects. Mobile Health (mHealth) in particular, enabled through smartphones, tablets and computers, provides patients and carers, but also healthcare professionals and the wider public, with multi-purpose complementary tools that can be useful to support everyday health and disease management and professional practice.

As a consequence, digital tools are gradually changing how patients and professionals communicate and interact with each other, and by enabling patients to compile, monitor and analyse their health data they are also creating a new relationship between Europeans and their health systems. While patients want to be more actively involved as “co-managers” of their health, innovative and cost-effective digital solutions are being embraced by health systems that struggle to cope with growing demand for services due to demographic developments and the rise of chronic diseases and multiple morbidities.

This discussion paper explores some of the key benefits and also highlights some disadvantages of digital health solutions in many of the health and disease areas worked on by EPHA members. Can digital health solutions contribute to achievement of the Sustainable Development Goals – notably the reduction of non-communicable and chronic diseases and the achievement of universal access to good quality healthcare? The paper provides a snapshot of the use of digital health for health stakeholders and focuses in particular on whether and how technology adds value to their daily tasks – does it facilitate or hinder better health and wellbeing?

A key finding of this paper is that some benefits are universal – e.g. more control over routine processes and more active engagement in (co-)managing health – while others are specific, i.e. directly related to particular conditions and the needs of patients.

In the context of this paper, EPHA proposes the following recommendations, aimed at policymakers and regulators working at national and European level, developers of digital health solutions, as well as other stakeholders involved in the development of guidelines, standards and legislation in this area:

1. Meaningful involvement of end users means establishing an effective co-creation process for digital health tools, in order to ensure that the development and implementation of digital health policy is driven by actual health and practical needs of people (patients and their carers, consumers, healthcare professionals) rather than by the demands of the market;



2. Ensure inclusive and ethical integration of digital health into national health systems to improve access to healthcare, as well as across borders;
3. Enhance digital health literacy and expand eSkills among professionals, patients, and the general population;
4. Establish national and European repositories of digital health solutions (e.g. apps) as a form of guidance for patients and healthcare professionals looking for safe and tested solutions;
5. Guarantee that patient safety and quality of care considerations are mainstreamed in all digital health initiatives;
6. Foster research into the use and outcomes of digital health use to ensure continuous improvements in this emerging field.



Digital Solutions for Health and Disease Management

1. Introduction

In most European Union (EU) countries life expectancy now exceeds 80 years. However, this record-high life expectancy is not always matched by healthy life years. Around 50 million people in the EU suffer from multiple chronic diseases, and more than half a million individuals of working age die of them every year, representing an annual cost of some 115 billion EUR for EU economies¹. While there are fewer health professionals available to provide people with the healthcare services they need, the costs of the latter are increasing. Hence, Europe is in need of new solutions to guarantee inclusive and fair access to healthcare for everyone.

Over the last decade, health systems around the world have increasingly recognised the potential of digital health solutions. The idea is that quality healthcare could be delivered better and faster by a set of efficient digital tools to support the administration of healthcare services, the collection of secure health data, help patients monitor their conditions, and promote healthy lifestyles and prevention.

At the same time, consumers and patients have rapidly embraced mobile devices. Smartphones and tablets in particular have become an indispensable tool for many to facilitate the management of various life situations “on the go”. Their built-in or added features – mobile Internet, apps, cameras, GPS, voice recorder, scanners, and many others - support the delivery of mobile health (mHealth) for almost everybody and in almost any location, at least in theory.

EPHA’s Digital Health Campaign is guided by the following strategic objectives, including the following:

- ✓ Ensuring better public health in Europe, due to safe implementation of digital health into health and social care systems, as part of health promotion and disease prevention;
- ✓ Development of inclusive digital health solutions to improve access for all people living in Europe;
- ✓ Guarantee continuity of care in a cross-border Europe.

¹ Health At A Glance: Europe 2016, European Commission/OECD Joint Report, 23 November 2016



Bearing these in mind, this paper discusses a number of digital solutions – the majority of which falling into the realm of mHealth – used in health and disease management, in areas covered by EPHA’s diverse membership including diabetes, cardiovascular diseases, mental health and others. It reviews some of the principal benefits, as well as potential drawbacks, of digital solutions for patients living with specific conditions, while recognising that everybody is a patient at some stage of their life. Moreover, the requirements of healthcare professionals working with digital solutions alongside patients must be taken into account.

While not intending to be comprehensive, the paper aims to provide useful insights into actual uses of digital health technologies by end users. In line with previous EPHA work on eHealth, we underline that it is essential that end users are valued as active contributors to the development, implementation and evaluation of digital health since, without their endorsement, its growth will be stifled. Moreover, digital health only contributes to improving public health if tools are available to – and tailored to the specific needs of – all population groups, including individuals living in vulnerable and isolated situations², in support of universal access to healthcare and achieving the Sustainable Development Goals (SDGs)³.

It is beyond the scope of this paper to discuss the many facets of data protection in the evolving context of Big Data, which will be the subject of a future EPHA report.

Finally, the paper proposes recommendations to inform European policy discussions surrounding the mid-term review of the 2012-2020 eHealth Action Plan (eHAP) and ongoing work in the area of mHealth. EPHA believes it is vital that, as patients and professionals are encouraged to transition into the digital age, an adequate policy framework is created that,

- Empowers confident and informed users of technologies that provide tangible added value;
- Protects individuals from the harms and errors that can occur when things go unfavourably; and
- Enables digital solutions to become part of mainstream healthcare so that the distinction between “health” and “digital health” gradually becomes obsolete.

2. Patients and healthcare professionals

In 2017, Digital Health is nothing new anymore. But while there are many systems and platforms, there is still no common architecture for it. Across Europe, hospitals

² EPHA is a partner in the VulnerABLE pilot project, which seeks to improve health and access for vulnerable individuals. Available at: http://ec.europa.eu/health/social_determinants/projects/ep_funded_projects_en#fragment0

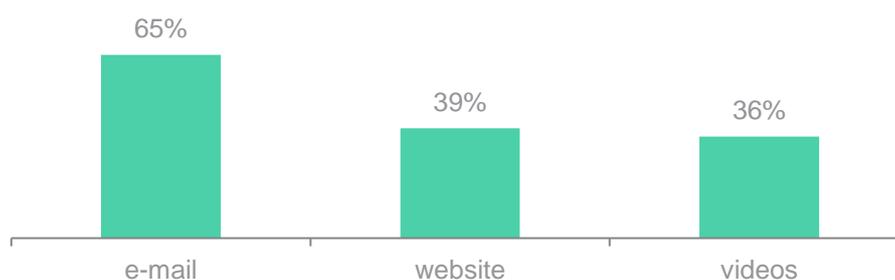
³ The EU committed to implementing the SDGs both in its internal and external policies. Available at: https://ec.europa.eu/europeaid/policies/sustainable-development-goals_en



and national funds are reluctant to change their existing procedures and tools, including costly legacy systems. Moreover, many healthcare professionals including physicians remain wary of digital solutions as they worry, whether rightly or wrongly, that they increase their workload or trigger mistakes in diagnosis, leading to treatment choices that put patient safety and trust at stake.

Patients, on the other hand, appear to be quite enthusiastic about digital innovation. For example, when asked whether cardiac patients would be interested in receiving additional health support via the Internet, 77% responded positively. Within this group, patients indicated e-mail as the most favourable way (65%), followed by website information (39%) and online videos (36%). More than half of the patients surveyed reported their interest in receiving support via mobile phones. This interest decreased with age, confirming young people's relative preference for smartphones over computers⁴.

Table 1 Cardiac patients interest in receiving health support via technology



Source: BioMed Central

The ability to perform simple tasks, such as sending reminders by SMS for ensuring treatment compliance (e.g., patients receiving messages about the correct time and way of taking a medicine) or facilitating medical appointments, are among the key strengths of mHealth, which is particularly relevant in this context (see below).

It is not only patients and consumers who stand to benefit from digital health solutions. All health actors, including healthcare managers and professionals, industry and others should be involved in a co-development process. Once the remaining hurdles (e.g. technical, financial, legal, ethical) have been tackled, digital health holds the promise of generating significant health system savings as it can render processes faster, more efficient, and it will avoid duplication.

Making best use of digital innovation also means supporting health professionals to become competent guides and advisors, thereby helping patients gain more knowledge and control over their conditions in a safe and inclusive way. By being

⁴ Buys R., Jomme Claes, Walsh D. Cardiac patients show high interest in technology enabled cardiovascular rehabilitation. BMC Medical Informatics and Decision Making (2016) 16:95 DOI 10.1186/s12911-016-0329-9



able to view and analyse real-time information partially collected by patients themselves, healthcare professionals can better coordinate health tasks between each other, take decisions more quickly and tailor treatments to patients. To equip health professionals with appropriate digital health literacy level, greater emphasis should be placed on better incentives and improved training during the course of their medical education⁵.

Electronic prescriptions and use of electronic patient records are viewed as a key achievement by the European Association of Hospital Pharmacists (EAHP). It provides an opportunity to improve safety, quality and efficiency in the delivery of patient care, but also assists hospital pharmacists in their role in preventing medication errors, and improving interface management of patient care⁶. Studies also indicate that the use of bedside barcode scanning technology to promote patient safety by giving the right medicine for the right patient and at the right time can reduce medication error by over 40%⁷.

The Pharmaceutical Group in the European Union (PGEU), the European voice of community pharmacists, underlines that electronic health records (EHRs) should be linked with ePrescribing systems and pharmacy-held patient medication records, which would allow pharmacists to securely access and contribute to patient histories, diagnoses, and provide medication information. This would help to promote patient safety and improve quality of care, e.g. by reducing medication errors, avoiding drug interactions and duplication of treatments. PGEU points out that digital health solutions are improving healthcare accessibility for people (the pharmacy sometimes itself being used as an electronic point of access), while specialised “pharmacy apps” feature integrated reminders and alerts which help patients to become more health literate, improve self-care and ensure medication adherence, while allowing pharmacists to share their expertise in multi-professional collaborations with other healthcare professionals (e.g. the *dossier pharmaceutique* in use in Belgium and France). Examples of digital innovation for community pharmacies exist across Europe, as outlined by PGEU in its 2016 Statement on eHealth⁸ and its annex.⁹

The project ENS4Care created a network of 24 partners from all over Europe, with a mix of professional associations in nursing and social care, nursing regulators and unions, informal carers, patients, researchers and research communities, civil society representatives and industry. It has developed guidelines for nurses and social workers on how to use eHealth for promoting healthy lifestyles and

⁵ Policy recommendations on Digital Skills For Health Professionals, European Health Parliament 2016. Available at: http://www.healthparliament.eu/documents/10184/0/EHP_PAPERS_2016_DigitalSkillsForHealthProfessionals_SCHERM.pdf/e07b23d9-e762-4f96-934b-d23e6c5d17af

⁶ EAHP's policy statement on eHealth and mHealth 2016. Available at: <http://www.eahp.eu/practice-and-policy/ehealth-and-mhealth>

⁷ Poon EG, Keohane CA, Yoon CS. Effect of bar-code technology on the safety of medication administration. *N Engl J Med*. 2010 May 6;362(18):1698-707 DOI: 10.1056/NEJMsa090711

⁸ PGEU (Nov 2016), PGEU Statement on eHealth. Available at:

<http://www.pgeu.eu/en/component/attachments/attachments.html?id=4157&task=download>

⁹ PGEU (Nov 2016), PGEU Statement on eHealth – Annex. Available at:

<http://www.pgeu.eu/en/component/attachments/attachments.html?id=4158&task=download>



prevention, clinical practice, skills development for advanced roles, integrated care and nurse ePrescribing. Crucially, they support nurses and social workers in their daily work using eHealth services that may enhance the quality of care and facilitate healthcare delivery remotely¹⁰.

But mainstreaming digital health also implies health technology has to be affordable and accessible for everyone. It must not increase the digital divide by exacerbating health inequalities and excluding vulnerable groups, but rather it should contribute to closing the gap and providing better health for all. People using Digital Health should not be members of an elite “club”. Tailoring it to particular cultures, languages, and ethnic groups may also represent a possibility to provide accessible information and education at minimal cost for patients in under-resourced communities¹¹. The crucial link between eHealth and health inequalities is discussed in a 2014 report of the European Commission’s eHealth Stakeholder Group, led by EPHA¹².

Perhaps the most exciting thing about digital health is that it can provide patients with the intelligence and support for almost any life stage or health condition. Having analysed the pros and cons of digital health along people’s entire “health path” throughout life, French patient group and EPHA members *le Collectif Interassociatif Sur la Santé* (CISS)¹³ has developed a comprehensive position paper with recommendations on how digital health can enable patients to become agents in a changing healthcare environment¹⁴. EPHA agrees with CISS on striking the right balance between enthusiasm and caution: as the ways of rendering sensitive health data become more secure and sophisticated, so do the skills of hackers. Furthermore, commercial actors have much to gain from personal data given the enormous influence they exert on people’s lifestyle choices; data allow them to create detailed profiles that can be (mis-)used for targeted advertising.

In France and elsewhere in Europe, digital health is still an evolving concept: the technology is already there, but the structure of European health systems combined with relatively low awareness and user knowledge means that digital health is far from a regular experience for most. There is still a big gap between health and other online services like Internet Banking, e-Commerce, mobile travel and transport bookings, and it is likely that the affective, private dimension of health is part of the reason why this is so.

¹⁰ ESN4Care, Evidence Based Guidelines for Nursing and Social Care on e-Health Services 2015. Available at: http://www.ens4care.eu/wp-content/uploads/2013/12/ens4care_flyer-rev-Jun.2015.pdf

¹¹ Davis SW, Oakley-Girvan I. mHealth Education Applications Along the Cancer Continuum. *J Cancer Educ.* 2015 Jun;30(2):388-94. doi: 10.1007/s13187-014-0761-4

¹² Marschang, S, eHealth Stakeholder Group (2014), *Health inequalities and eHealth*. Available at: http://ec.europa.eu/information_society/newsroom/cf/dae/document.cfm?doc_id=5170

¹³ Collectif Interassociatif Sur la Santé (Le CISS), now called Union Nationale des Associations Agréées des Usagers du Système de Santé see : <http://www.leciss.org/>

¹⁴ Le CISS (2015), *Pour un patient acteur de la qualité de son parcours de santé. Note de position commune sur le numérique en santé* <http://www.leciss.org/esante-conseilsciss>



That being said, EPHA also agrees with CISS that ignoring digital innovation will only backfire as it appears that our hunger for digitalisation is irreversible and new technology will shape the future. Public health actors must therefore engage with this reality to remain relevant and credible.

3. The special role of mobile devices

mHealth in particular is of important symbolic importance, even if more advanced technologies might soon replace the devices used now. This is because mobile devices (especially smartphones, tablets and other PDAs) unlike preceding eHealth technologies used primarily in clinical settings, have placed everyday digital health tools into the hands of patients and other end users. Thanks to the multi-functionality of smartphones and especially downloadable apps, many people are beginning to consider and monitor health and wellbeing in new ways. They appreciate the vast possibilities mHealth affords them, e.g. the routine tracking of personal health conditions, fitness levels, vital signs, behaviours, etc., as well as direct communication between patients and healthcare professionals.

Although apps could turn out to be a passing “hype” given the unrelenting pace of digital innovation (e.g., artificial intelligence, virtual reality, Internet of Things, Big Data), it is likely that the appetite they have created in individuals for accessing, collecting and analysing health-related information, and for turning to mobile devices into “health companions”, will remain.

Indeed, the number of mHealth apps has grown significantly in only a few years, with over 100,000 mHealth apps available on the market in 2014. Health and Fitness is currently the fastest growing category. In 2015, WHO Europe presented results of the survey where almost three quarters of participants reported using mHealth for appointment reminders, 70% for patient monitoring and 61% for awareness-raising, with a 20-30% increase from 2009 to 2015 for each activity¹⁵. Unsurprisingly, individuals who use smartphones, other mobile devices and the Internet regularly and confidently are also more aware of the ever-growing range of digital health tools available to them.

But what about all those who do not possess smartphones or do not have Internet access? Statistics reveal that, in the EU alone, 14% of adults had never used the Internet in 2016, which amounts to roughly 100 million individuals; this is still a large chunk of the population, albeit with big differences within and between countries. Moreover, only 61% of Europeans knew how to access the Internet through a mobile device¹⁶ and half reported less than medium-level Internet skills.

¹⁵ From Innovation To Implementation, eHealth in the WHO European Region 2016. Available at:

http://www.euro.who.int/_data/assets/pdf_file/0012/302331/From-Innovation-to-Implementation-eHealth-Report-EU.pdf?ua=1

¹⁶ Cyber Security Report, European Union 2015. ISBN 978-92-79-46185-9, DOI 10.2837/411118. Available at:

http://ec.europa.eu/public_opinion/archives/ebs/ebs_423_en.pdf



Table 1. Individuals aged 16 to 74, who had never used Internet, whether at home, at work or from anywhere else and whether for private or work/business related purposes .

Source: ec.europa.eu/Eurostat

Year	EU adults having never used the internet (%)
2011	24
2012	23
2013	20
2014	18
2015	16
2016	14

Despite Europe’s wealth, a significant part of society keeps struggling with various literacy problems, while others remain sceptical of the digital realm. Without a basic understanding and the ability to draw relevant and beneficial conclusions from digital health information, e- and mHealth can also generate adverse effects, e.g. creating misunderstandings and stress, or exacerbating exclusion. Not everybody can afford new technology and the latter also requires regular upgrading and acquisition of new skills.

Most worryingly, self-diagnosis and self-treatment based on online information can be dangerous and harmful, especially when the quality of the information is questionable and patients take decisions without the advice of qualified healthcare professionals.

Furthermore, the communication between users of digital solutions and information systems can be quite complex. While the debate on systems interoperability keeps evolving, a need to focus on social interoperability has arisen. Social interoperability focuses on the effective communication between both users and information systems. Once achieved, it will ensure that patients and health professionals better understand the purpose of digital health solutions¹⁷.

For healthcare professionals, new communication skills are vital. Even highly health-literate patients can be problematic as their interpretation of online information may differ from that of practitioners. While in many cases this can benefit the patient-professional relationship and lead to more democratic decision-making, healthcare professionals have to diplomatically explain on a more frequent basis e.g. why people’s worries are unfounded or based on false assumptions in spite of what they might see and read.

¹⁷ Garlapati R., Biswas R. Blekinge Institute of Technology 2011, Interoperability in Healthcare - A focus on the Social Interoperability see link: <https://www.diva-portal.org/smash/get/diva2:832850/FULLTEXT01.pdf>



The European Patients' Forum (EPF) states that electronic health solutions have the potential to bring better care to patients' lives and ensure better coordination of it through the exchange of information and data between healthcare professionals, but only if trust and user acceptance are met¹⁸.

In the evolving debate around patients' data, the question of who will work with all the data collected and to what purpose must also be asked. While good use can bring multiple opportunities for public health, compiling large amounts of data from diverse sources is not without controversy. Patients' data withdrawn from mobile devices will feed into bigger sets of data called "Big Data". Currently, many health professionals do not know what to do with all the data patients send them. Many users obtain inconsistent data from their mobile devices, which complicates making responsible medical decisions and means that the actual value of digital solutions might not be realised for several years¹⁹.

The WHO found that barriers to Big Data adoption include privacy and security (71%), lack of integration (63%), and information sharing (50%)²⁰. Furthermore, health data analytics is a particular field of expertise and health systems must ensure that all parties involved speak the same language while always keeping in mind the best interests of patients and public health. Also, while medical devices have been calibrated and tested for safety, accuracy and consistency, this is not the case for many apps.

Nonetheless, the potential of digital health is there and it is likely that progress will be made to improve people's trust and confidence.

4. EU Policy Context

Digital health tools are developing very fast, and policy makers and regulators are struggling to keep up with the pace. Moreover, while the organisation of health systems remains a national or regional competence, the deployment of digital health introduces a new layer of complexity in terms of technical (e.g. interoperability), security and safety (e.g. data privacy, protection and reliability), legal (e.g. reimbursement questions and cross-border care) and societal challenges, which may well require European legislation in the future. For example, the process of providing an overview of the national laws on electronic health records in the Member States, and the introduction of legal requirements

¹⁸ EPF Position paper on eHealth, the European Patients Forum 2016. Available at: http://www.eu-patient.eu/globalassets/policy/ehealth/epf-final-position-paper-on-ehealth_19december2016.pdf

¹⁹ Foremski T. Dark side of wearables: Tsunami of useless medical big data, 2017. Available at: <http://www.zdnet.com/article/dark-side-of-wearables-tsunami-of-useless-medical-big-data/>

²⁰ Wyber R., Vaillancourt S., Perry W. Big data in global health: improving health in low- and middle-income countries, Bulletin of the World Health Organization 2015;93:203-208. doi: <http://www.who.int/bulletin/volumes/93/3/14-139022/en/>



concerning patients' data exchanges are among the priorities of DG SANTE's (eHealth Unit) coordination activities for 2017²¹.

To maximise the benefits of technological innovation, the Digital Single Market strategy has become one of the political cornerstones of the European Commission. It covers three pillars: promoting better online access to goods and services across Europe; ensuring an optimal environment for digital networks and innovative services to develop and flourish; and to maximise the growth and employment potential of the digital economy²². The strategy has to also provide a basis for issues such as interoperability and standardisation in the health area, including mHealth and others.

The 2012-2020 eHealth Action Plan (eHAP) outlines the Commission's vision for eHealth in Europe. Among other points, it recognises the added benefit of digital health in the management of chronic diseases and multi-morbidities, as well as for increasing the efficiency of healthcare systems and improving equity of access.

Despite these opportunities and benefits, the eHAP also acknowledges significant barriers, including lack of awareness of and confidence in eHealth solutions among patients and healthcare professionals. The other key obstacles include poor interoperability between Digital Health solutions and lack of legal clarity for health and wellbeing mobile applications, which is also connected with the utilisation of data collected by such applications²³.

In 2014, the Commission published a Green Paper on mHealth and consulted stakeholders on their views about eleven identified barriers to its uptake in the EU. EPHA's response focused on the need for developing inclusive tools that contribute to the entire patient journey (i.e., in primary and secondary care settings, GP practices, pharmacies, and at home) without competing with traditional healthcare delivery, which will continue to require sizeable and continuous investment and upgrading²⁴. The consultation revealed a shared understanding about the health and safety risks of apps and it triggered work on mHealth guidelines and an The Code of Conduct on privacy for mobile health apps on privacy. The industry-led Code has been submitted for comments to the Art 29 Data Protection Working Party. One approved, app developers will be able to voluntarily commit to follow its rules, which are based on EU data protection legislation²⁵.

²¹ Overview of the national laws on electronic health records in the EU Member States, the European Commission. Available at: http://ec.europa.eu/health/ehealth/projects/nationallaws_electronichealthrecords_en.htm

²² A Digital Single Market for Europe: Commission sets out 16 initiatives to make it happen, the European Commission, Press release, Brussels 2015. Available at: http://europa.eu/rapid/press-release_IP-15-4919_en.htm

²³ eHealth Action Plan 2012-2020 - Innovative healthcare for the 21st century, the European Commission. Available at: <http://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:52012DC0736&from=EN>

²⁴ Marschang S., mHealth Green Paper consultation: EPHA's response, the European Public Health Alliance 2014. Available at: <https://epha.org/epha-response-mhealth-green-paper-consultation/>

²⁵ Code of Conduct on privacy for mHealth apps. Available at: <https://ec.europa.eu/digital-single-market/en/news/code-conduct-privacy-mhealth-apps-has-been-finalised>



In 2016, DG CONNECT set out to develop guidelines for a “framework of safety, quality, reliability and effectiveness criteria to improve the use, development, recommendation and evaluation of mHealth apps.” The guidelines cover apps not classified as medical devices (regulated by existing EU legislation) employed in a health and social care context, as well as health and wellbeing apps aimed at prevention. The latter, which process personal data not deemed as “sensitive”, are not required to comply with the stricter rules that apply to medical devices. However, the line is not drawn easily and there is a risk that an increasing number of apps fall into a legal “grey zone” given that the data collected by them could provide insights into physical or mental health status that could be exploited for targeted advertising or to discriminate against individuals. Scheduled for release in 2016, the guidelines are still awaiting finalisation.

The eHealth Network was created under Article 14 of Directive 2011/24 on the application of patients’ rights in cross-border healthcare. It serves as a platform to exchange ideas between the national authorities of member states who decide on common and future orientations of eHealth and to solve the issue of interoperability of electronic and mobile health systems and ensuring safe and continuous cross-border healthcare in the EU. So far the eHealth Network endorsed implementation of the eHealth Digital Service Infrastructure (eHDSI) in the EU, which will enable to exchange personal health data (ePrescriptions and Patients Summaries) between countries, starting from 2017²⁶. In the future they will look into guidelines for assessing the validity and reliability of mHealth apps and implement them at the national level in each MS²⁷.

From a policy perspective, it is also important to take into account the proper implementation of existing and evolving pieces of European and national legislation as well as non-binding guidance documents in areas impacting on e-and mHealth, inter alia the new General Data Protection Regulation, the ePrivacy Directive, the mHealth assessment guidelines and Industry Code of Conduct, and potential future guidelines on Big Data. It is equally important that a distinctly European vision of digital health is not stifled as a result of transatlantic or other international (trade) agreements.

5. Examples of Digital Health solutions

What is clear is that digital solutions are becoming more widespread and relevant in many of the disease-specific areas represented by EPHA members. Patients and healthcare professionals alike are using them in one way or another.

²⁶Minutes from 9th meeting of the eHealth Network (Brussels, 7 June 2016). Available at: https://ec.europa.eu/health/ehealth/events/ev_20160607_en

²⁷ Report on national mHealth strategies, mHealth sub-group, the European Commission 2016. Available at: http://ec.europa.eu/health/sites/health/files/ehealth/docs/ev_20161121_co22_en.pdf



The following overview provides a snapshot of why it is important to keep a close eye on the many aspects of digital health as they evolve and enter the mainstream. Essentially there is still a big gap between digital health's potential to contribute to health and disease management in specific areas vis-à-vis actual uses and policies.

Diabetes

Diabetes is one of the most expensive chronic diseases for health systems, and many early eHealth solutions were designed as support tools for diabetes patients so they could self-manage their condition while at the same time easing the workload on health professionals. The increased use of smartphones, coupled with an ever growing number of mobile applications, but also Internet portals and websites are available to help patients improve their management of daily diabetes care. Different digital solutions can be used for recording and tracking patients' diets, medication, carbohydrates intake and physical activity, and they allow for easy measurement of blood glucose levels, blood pressure and weight. Some gather all of these factors together, while others are designed to only focus on one aspect of care, e.g. coaching and education.

Diabetes patients are particularly dependent on up-to-date data because routine tracking is an inherent part of living with the disease, which is accompanied by stressful trigger points during which health and psychological needs go in parallel. The ability to log and enter relevant data, whether manually or automatically (via smartphones, tablets or computers), and to update or change information in real time, enables diabetes patients to exert greater control over their condition. Many apps allow them to set and track personal goals, thereby providing added motivation to attain health objectives. Furthermore, automatic blood sugar readings and reminders to check blood sugar levels can provide patients with an increased sense of security. Easy-to-use digital tools have proven to be most beneficial for diabetes management.

More advanced innovations include tailored wearables for diabetes patients that integrate smart skin patches, contact lenses, and footwear equipped with sensors and wireless connectivity. Not only do wearables assist users with blood sugar level monitoring, they also connect them directly with healthcare providers in case of emergency; some even release medication into the body (e.g. patches with sensors that measure blood glucose in sweat and correct high levels by releasing a dose of insulin). In the case of a rapidly decreasing blood glucose level, patients receive automatic reminders to take a meal via their mobile phones.

A common complication of diabetes is eyesight deterioration or loss of vision. Many patients are dependent on glasses or contact lenses. Today, special contact lenses exist that can monitor blood glucose levels through tears. Patients suffering from



diabetic neuropathy (a serious complication that affects blood circulation and can result in foot amputation) can benefit from special socks and shoe prototypes containing sensors that point out areas of the feet that do not receive sufficient blood supply. Early detection is vital as it helps to decrease the risk of amputation²⁸.

Younger patients living with diabetes type 1 can receive digital assistance from a “friendly” robot called Charlie (Personal Assistant for Healthy Lifestyle - PAL), introduced in hospitals in the Netherlands and Italy. The robot educates children and their parents about self-management so that severe complications before adolescence can be avoided. Children can talk with their “PAL” both at the hospital and at home, where they can access Charlie’s avatar through mobile devices²⁹.

Many European hospitals have introduced digital health solutions to support health professionals working with diabetes type 2 patients. In Austria, a system gathers patients’ health and lifestyle data and recommends personalised insulin therapy³⁰. It is considered an improvement for blood glucose management workflow between the hospital pharmacy and other departments. As with all system-level solutions involving sensitive health data, they need to be well managed to protect patients’ privacy and security.

International Diabetes Federation (IDF) Europe, an EPHA member, note in their comprehensive position on Mobile Applications in Diabetes that, “the role of healthcare professionals, family and friends is crucial as people with diabetes typically have an easier time with diabetes management when there are other people who are interested in their medical condition”³¹. Furthermore, they stress that healthcare professionals must become familiar with how apps work, and how their patients are using them.

Cardiovascular Diseases

Cardiovascular diseases (CVD) are a leading cause of premature death and disability worldwide. An estimated 17.5 million people are dying from CVD annually, representing about one third of all global deaths. In the EU, it accounts for over 1.9 million deaths annually³², 80% due to heart attacks and strokes. There was a need for CVD patients to take charge of their own condition and mobile technology came as an answer to help them monitor their disease.

According to the European Heart Network (EHN), if implemented efficiently, e/mHealth solutions can improve prevention and treatment of CVD. Mobile solutions

²⁸ Smart Technology for Diabetes Self-Care, Diabetes Self-Management 2016. Available at: <http://www.diabetesselfmanagement.com/diabetes-resources/tools-tech/smart-technology-diabetes-self-care/>

²⁹ Charlie robot new best buddy for children with diabetes, The Daily Star 2016. Available at: <http://www.dailystar.com.lb/Life/Living/2016/Jul-12/361511-charlie-robot-new-best-buddy-for-children-with-diabetes.ashx>

³⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3626139/>

³¹ IDF Europe (2017), *IDF Europe Position on Mobile Applications in Diabetes*. Available at: https://www.idf.org/sites/default/files/MobAppPosPaper2_finalonlineversion_0.pdf

³² Fact sheet on Cardiovascular diseases (CVDs), WHO 2016. Available at: <http://www.who.int/mediacentre/factsheets/fs317/en/>



exist for individuals and population groups of different ages, including for education or public health awareness purposes³³. Smartphone apps can help patients understand their condition after a cardiac event, and they can also improve adherence to rehabilitation programmes.

New technology can also be useful in managing CVD risk factors, including computer-based smoking cessation programmes and telemetrically supervised self-monitoring of blood pressure³⁴. In fact, mobile apps offer a broad range of solutions for treatment support: they help patients monitor their medication for anticoagulant therapy, measure irregular heart rhythm, track blood pressure, remind haemophilia patients about blood infusions, and they provide information about stroke symptoms and techniques of assistance. For emergency events, there are video games that provide instructions for emergency situations, e.g. how to perform cardiopulmonary resuscitation (CPR).

Likewise, digital solutions offer lifestyle support following serious events such as heart attacks. An example is a cardiac rehabilitation programme that includes an Internet-enabled, sensor-based home exercise platform that manages physical activity, diet, stress management, cigarette and alcohol consumption, which enables CVD patients to be more actively involved in understanding and managing their health. Health professionals remain actively involved too: for example, cardiologists can monitor patients with implantable devices remotely (e.g. implantable cardioverter defibrillator – ICD).

However, uncertainty remains. The Food and Drug Administration (FDA) in the US has expressed concern that cardiac devices of this kind can be hacked, with serious risks to patient safety, e.g. by causing injuries or even fatalities³⁵.

The European Society of Cardiology (ESC) argues that closer collaboration between all stakeholders — consumers and patients organisations, health professionals and health organisations, public authorities, mobile applications developers, telecommunication service providers, mobile device manufacturers, and others — will optimise the appropriate development and implementation of new solutions to health and healthcare needs³⁶.

Respiratory Diseases

Patients suffering from respiratory diseases have complex ongoing medical care needs, often involving multiple therapies, as well as self-management responsibility.

³³ The importance of e-Health in daily cardiology practice, Cardiac Rhythm News 2014. Available at: <https://cardiacrhythmnews.com/the-importance-of-e-health-in-daily-cardiology-practice/>

³⁴ European Heart Network (2013), Cardiovascular patients and eHealth – a European Heart Network paper. Available at: <http://www.ehnheart.org/component/downloads/downloads/1438>

³⁵ FDA confirms that St. Jude's cardiac devices can be hacked, CNN Tech 2017. Available at: <http://money.cnn.com/2017/01/09/technology/fda-st-jude-cardiac-hack/>

³⁶ Cowie M., Bax J., Bruining N. e-Health: a position statement of the European Society of Cardiology, European Heart Journal doi:10.1093/eurheartj/ehv416



Importantly, digital solutions enable the optimisation of the quality and timeliness of medical interventions, and they reduce costs induced by prolonged hospitalisation³⁷.

A number of mHealth apps in this category provide support to patients by monitoring asthma and encouraging smoking cessation. The 2014-2016 European Commission initiative, “Ex-Smokers are Unstoppable” helped thousands of Europeans to quit their unhealthy addiction. It involved a free-of-charge digital health “iCoach”, which was readily available, both online and as a mobile app for Apple and Android devices in 23 languages. ICoach guided users through five progressive phases to quit smoking but it also incorporated several personal, phase-specific challenges, thereby encouraging users to take on further challenges to gain control over their habit. First steps included motivating smokers to keep track of the number of cigarettes they consume every day (often smokers underestimate the extent of their addiction); postponing the “nicest” cigarette of the day for gradually longer periods of time; and leaving cigarettes at home when leaving the house³⁸. The campaign had a potential target of 28 million smokers aged 25-34 in 27 Member States. It is regrettably not possible to assess its performance as it is not known how many people took part in it nor how the app contributed to smoking cessation³⁹.

Other types of prevention apps for patients with respiratory conditions offer information about polluted areas. For example, they provide hourly information on urban air pollution, on a scale of 1 to 10. Information can be accessed on current and forthcoming air pollution levels, pollen, ultraviolet levels or temperature. Pollutants included in the daily assessment are nitrogen dioxide, ozone, and particulate matter. Specifically created to warn people about hazardous situations for their airways, the tool allows users to decide on the best time for taking a walk or engaging in physical activity outside. These types of mobile applications collect data from European Space Agency (ESA) satellites, and they combine data on city road traffic levels with conditions reported by local weather-monitoring stations, which make them reliable and useful.

For people living with COPD (Chronic Obstructive Pulmonary Disease), a vest has been developed that measures various physiological signals, including chest sounds, pleural effusion, tachycardia or arrhythmia, and atrial fibrillation. The vest can be equipped with an inhaler device to measure and evaluate patients’ medical adherences. However, the European COPD Coalition states that tele-assistance and remote monitoring of people living with COPD may improve their care and the

³⁷ WELCOME project 2013-2017 (Wearable Sensing and Smart Cloud Computing for Integrated Care to COPD Patients with Comorbidities) see link: www.welcome-project.eu

³⁸ ‘Ex-Smokers are Unstoppable’ initiative, the European Commission 2016. Available at: https://ec.europa.eu/health/tobacco/ex-smokers-are-unstoppable/2014_2016_en

³⁹ Ex post evaluation, ex-smokers campaign, Executive summary, the European Commission, 2016, see link: <https://publications.europa.eu/en/publication-detail/-/publication/b656dd28-cefa-11e5-a4b5-01aa75ed71a1/language-en>



surveillance of their disease but further improvements and research are needed, both for COPD patients and their care givers⁴⁰.

Cancer

Cancer is today one of the world's main causes of death, and affects one in three people in Western countries. It is a highly heterogeneous group of diseases.

The WHO World Cancer Report highlights that global cancer rates could increase by 50% to 15 million by 2020⁴¹.

Given that four in ten cancers are linked to consumption of health harmful products⁴², a growing number of digital solutions allow patients to keep track of cancer treatments and lead healthier lives in general.

Apps for cancer patients were mainly designed to support the continuum of care; they help patients to better cope by facilitating improved organisation of treatments, healthcare visits, and results. Some solutions contribute to improving patients' lives by sending personalised information about when and how to take a prescribed treatment, some provide assistance during the crucial patient-doctor dialogue, and others simplify patients' disease management, e.g. by compiling a calendar that contains all medical visits and check-ups.

Cancer survivors are faced with a significant challenge: to recover from treatment while maintaining health and well-being. The focus of survivorship care lies on managing the after-effects of the treatment and early detection of a recurrence. Digital solutions can provide patients with a comprehensive survivorship care plan (SCP) including a summary of the treatment received and a follow-up plan prepared by a doctor. The active inclusion of patients in the process, e.g. establishing step-by-step treatment plans with them, can make them feel more secure and aware of their condition.

Equally important are the many apps that teach users about healthy life choices and provide advice on how to prevent cancer, whether providing direct information from healthcare professionals or compiling users' data to obtain a better picture of their lifestyle and habits.

As in other areas, cancer apps are not foolproof: EPHA members Cancer Research UK have critically commented on the outcomes of a mobile application designed to recognise skin cancers such as melanoma, the most serious type, based on a photo taken by users - a 'selfie'. British researchers used four apps to analyse 188 images of skin lesions. Three of them incorrectly classified 30% or more melanomas as

⁴⁰ Telemonitoring for COPD patients: more research needed, the European COPD Coalition. Available at: http://www.copdcoalition.eu/what_we_do/advocacy/copd-and-ehealth/telemonitoring-for-copd-patients-more-research-needed

⁴¹ Global cancer rates could increase by 50% to 15 million by 2020, WHO 2003. Available at: <http://www.who.int/mediacentre/news/releases/2003/pr27/en/>

⁴² the Cancer Research UK website: <http://www.cancerresearchuk.org/about-cancer/causes-of-cancer>



“unconcerning”⁴³. This example demonstrates that users must not substitute the advice of competent healthcare professionals with technology: diagnosis by smartphone can generate inaccurate results. As a complementary tool, apps help people be more mindful of their health and manage routine processes, but they are not a replacement for medical consultations, also because external factors (patient histories, drug interactions, work-life balance, etc.) must be considered.

ECCO - the European CanCer Organisation - through its Patient Advisory Committee highlighted the following aspects for primary consideration in the debate on Big Data in Public Health, Telemedicine and Healthcare in response to an EU study⁴⁴ on this topic:

Meaningful and systematic consultation of stakeholders including patient advocacy groups is essential to foster eHealth solutions that are sustainable and respond to the needs of users at large while addressing any individual data security concerns;

Fostering digital health literacy is crucial to achieve maximum benefit and minimalised risk to patients, and it should ideally happen in a coordinated manner involving all stakeholders rather than being a sporadic one process driven only on one side by societal and/or market trends.

Echoing the reflections in the present paper, the ECCO PAC furthermore endorses the recommendations of the EU-funded “Chain of trust”⁴⁵ project.

Mental Health

The development of e-Mental Health solutions is increasingly seen as an opportunity to improve access to care for people experiencing mental health problems and to raise awareness of this. Individuals suffering from mental health problems are particularly prone to being stigmatised (e.g., the negative connotations associated with being classified as “mentally ill” or as a “patient”), which is why many prefer to seek help anonymously online. Depression in particular is becoming a massive challenge.

There are different e-interventions for mental health available. At the most basic level, websites offer information on how to recognise the signs of depression, anxiety, paranoia, and stress (including in the workplace). Many portals offer tests asking users to answer questions about their feelings and wellbeing so they can receive an assessment of their mental health status. The MasterMind project provides guided computerised cognitive behaviour therapy for treatment of depression. Medical doctor and psychiatrist have video consultations discussing

⁴³ Health apps: a note of caution, the Cancer Research UK 2015. Available at:

<http://scienceblog.cancerresearchuk.org/2015/04/24/health-apps-a-note-of-caution/>

⁴⁴ Study on Big Data in Public Health, Telemedicine and Healthcare Final Report, the European Commission 2016. ISBN 978-92-79-63285-3 Doi: 10.2875/734795. Available at: https://ec.europa.eu/health/sites/health/files/ehealth/docs/bigdata_report_en.pdf

⁴⁵ CHAIN OF TRUST Understanding patients’ and health professionals’ perspective on telehealth and building confidence and acceptance., see link: <http://www.eu-patient.eu/globalassets/projects/chainoftrust/epf-report-web.pdf>



each individual patient to ensure knowledge sharing in order to optimise care for patients suffering from depression. It aims to make high quality treatment for depression more widely available across Europe by the use of ICT⁴⁶. Other websites advise patients to contact a specialist (e.g., they list the contact details of psychiatrists offering video consultations) or to join local support groups. Such solutions are principally intended to raise awareness and inform; often they are free and easily accessible. Clearly, it is of utmost importance that they are based on appropriate and validated medical knowledge.

Serious gaming is another growth sector. It offers websites designed for non-leisure purposes, e.g. to reduce children's anxieties and phobias, treat ADHD, depression, etc. Studies show that serious games as interventions for reducing mental health problems may be effective. However, more research is needed in order to attain a deeper knowledge of the efficacy for specific conditions⁴⁷. The general idea is that, by playing special games on their mobile devices, younger patients can improve their mental health without even realising it.

At 2016 eHealth Week in Amsterdam, a dedicated session presented best practices of digital solutions for emotional and mental health already used in the Dutch health system.⁴⁸

However, the quality of advice is often not clear, and there is a distinct risk that anonymous users may not receive "genuine" professional advice or care. For example, many apps offer a chat with a specialist but all too often the person sitting at the other end is not a health professional but rather someone trained in the cognitive behavioural therapy techniques the app is based on. And while psychologists are obligated to report ongoing domestic violence, abuse or neglect of children, the elderly or people with disabilities, it is difficult to do this in anonymous online environments.

Some mental health apps are more basic, e.g. they track users' mood 24/7, and the results can later be shared with a therapist. This can take the form of daily notifications sent to patients prompting them to respond to questions such as "On a scale of 1 to 10, what was your mood today?"⁴⁹ Furthermore, a plethora of apps aim to teach their users how to meditate, improve their concentration, or develop a better sleeping pattern. It has been found that giving people a digital tool for mood management helps make them more aware and encourages them to reach out for help when feeling unhappy or depressed⁵⁰.

⁴⁶ The MasterMind project, see link: <https://mastermind-project.eu/>

⁴⁷ Lau H., Smit J., Fleming T. Serious Games for Mental Health: Are They Accessible, Feasible, and Effective? A Systematic Review and Meta-analysis. *Front Psychiatry*. 2016; 7: 209. Published online 2017 Jan 18. doi: 10.3389/fpsy.2016.00209

⁴⁸ EHEALTH WEEK PROGRAMME 2016, website: <http://www.ehealthweek.org/ehome/128630/overview/>

⁴⁹ Mental-Health Apps Make Inroads With Consumers and Therapists, *The Wall Street Journal* 2015. Available at: <http://www.wsj.com/articles/mental-health-apps-make-inroads-with-consumers-and-therapists-1443407477>

⁵⁰ Joint Action on Mental Health and Well-being, the European Union 2016. Available at: <http://www.mentalhealthandwellbeing.eu/assets/docs/publications/WP4%20Final.pdf>



Our members Mental Health Europe (MHE) argue that e/mHealth solutions play an important and growing role, but should not replace community-based services and should rather be seen as complimentary to existing interventions. MHE underlines that human connections are important for psychosocial and therapeutic interventions and they cannot be replaced by digital tools. Furthermore, MHE argues it is important that eHealth solutions do not reinforce the medicalisation of mental health. Mobile applications and online tools should take account of the psychosocial environment of its users and the impact of psychosocial factors on mental health.

Alcoholism

For people who suffer from alcohol dependency or who feel that they drink too much, there are digital solutions that gather their information on alcohol consumption. For example, users can start a “drinking diary”, which calculates blood alcohol content (BAC) and track the cost of the drinks consumed. The results of alcohol consumption can be seen in the form of plots (BAC level) and charts, also showing the legal limits for driving a car or indicating a return to the state of sobriety. To obtain the approximate level of alcohol intoxication, a user usually has to enter his weight, gender, hours spent drinking, and amount and type of alcohol consumed. What’s most important is that drinking habits can be monitored daily, weekly or monthly.

Our members Eurocare and IOGT-NTO have been calling for labelling of alcoholic beverages for many years now⁵¹. Thanks to labels, the products could be scanned by mobile phones, and consumers could access information on the harmful ingredients that alcohol contains. Recent innovation in biosensor development showed that technology can detect alcohol released through the skin in sweat or vapour. A wearable alcohol biosensor could thus become a valuable resource for the discreet notification for the user that further drinking is dangerous and inadvisable.

Whilst mobile apps are useful, they should not be seen as a panacea. They can help increase alcohol-associated risk awareness among young people but it’s still unclear whether such apps are being used to stop drinking or just to support drinking in a safe way.

Healthy Ageing

AGE Platform Europe is very engaged in e- and mHealth developments. They advocate support for the development of digital solutions that enable older persons, and those living with disability, to lead more independent lives and thus close the gap between care supply and demand. Not only can mobile applications enable

⁵¹ EuroCare website, see link: http://www.eurocare.org/resources/policy_issues/labelling



people with poor eyesight, visual impairment or blindness to identify and count banknotes, but smartphone apps can also recognise currencies and tell them the correct denomination. In like manner, a text-oriented alternative communication tool was produced for people who are literate but have difficulty speaking. Vulnerable people who cannot read can scan with their phones documents, bills, business cards, and their phone will read the text aloud.

Additionally, digital solutions could guide older persons, as well as individuals with a disability, on how to find solutions to a wide range of activities at home that cause them problems. For example, for people with limited mobility who cannot open their front door quickly, there is an app that allows a door to be unlocked with a smartphone application without the need for a key (additional devices on the door are necessary).

AGE Platform Europe is also involved in several projects aiming to support deployment of digital solutions amongst older users. The H2020 i-PROGNOSIS project aims to build early detection test and design innovative interventions for Parkinson's using the potential of new technology such as smart phone and smart watch. MobileAGE, an H2020 project, supports older people's involvement in the development of mobile application to facilitate access to local public services. It includes management of personal health information.

Digital Inclusion

EPHA includes a number of organisations that promote the interests and rights of populations who, for various reasons, are denied full access to healthcare. For example, they include migrants and minorities such as Roma communities, both groups often unable to receive the care they need due to lack of residence documents, exclusion from national health insurance schemes, discrimination or lack of funds. For individuals in vulnerable or isolated situations, digital tools might even represent the only available access to health information and care, and the transnational nature of the Internet and possibility to make use of features including geo-location and translation, online chat fora and anonymous consultation services enables at least a very basic form of care.⁵²

Similarly, homeless people have many unmet health needs and they face a number of barriers in accessing healthcare. Some are financial and administrative, but they are also rooted in fear of being stigmatised and made to feel unwelcome by health professionals. Homelessness is also an example of extreme health inequalities; compared to the general population, homeless people

⁵² Marschang, S, eHealth Stakeholder Group (2014), *Health inequalities and eHealth.*, ibid.



experience higher levels of physical and mental ill health and die on average twenty years earlier than the rest of the population⁵³.

Many homeless people experience mental health problems and substance abuse is common. mHealth can help homeless patients overcome their reluctance to seek help because of stigma or shame. It can be more engaging and interactive and has the potential to renegotiate the strained relationship between healthcare professionals and homeless patients. A pilot study undertaken in the US, which equipped homeless patients with psychiatric problems with mobile phones, showed that it is possible to reach out and improve medication adherence via automated phone calls. Participants reported that they felt cared for, which motivated them to maintain their treatment.⁵⁴ Similarly, Breaking Free Online, a computer-assisted substance abuse therapy project targeting homeless drug users in the UK, reported good results in improving general wellbeing and self-motivation by helping participants attain a wide range of personal, psychological, educational and social goals in addition to reducing drug use.⁵⁵

Other important uses of digital health for better serving homeless patients include the following:

- Better care of homeless patients following discharge from healthcare institutions. Discharge is especially disorienting and stressful for them and often leads to adherence problems, relapses and repeat visits to the emergency department
- Better coordination of various relevant health and social care services and provision of a more holistic picture of homeless patients' histories and needs. Due to fragmentation of services, homeless people are often only treated for the most acute problems only and they are often shunted from service to service.
- Multi-level prevention and health promotion, e.g. the text4baby programme in the US which aims to increase knowledge and awareness related to maternal-infant health via text messages.

Crucially, for mHealth solutions to work, healthcare professionals need to understand better the problem of homelessness and the health needs of homeless people. It is also necessary to gain a deeper understanding of how information

⁵³ Health and Wellbeing for All. Policy paper. FEANTSA (2013), Available at: http://www.feantsa.org/download/feantsa_health_policy_paper-26225495071179409231.pdf?force=true

⁵⁴ Burda, C., Duarte, A.C. (2012), *Medication adherence among homeless patients: A pilot study of cell phone effectiveness*. In: *Journal of Academy of Nurse Practitioners*.

⁵⁵ Neale, J. & Stevenson, C. (2013), *The use of computer-assisted therapy by homeless drug users living in hostels: an explorative qualitative study*. In: *Drugs: education, prevention and policy*.



technologies by some of the most vulnerable members of society can change engagement with services, treatment adherence and health behaviours.⁵⁶

⁵⁶ Brynes, Maureen (2014), *Implementation of mHealth program within a homeless population of young mothers*



6. Findings

At a time when European health systems are slashing their budgets and many qualified health professionals are migrating to regions or countries that offer them better career prospects, technology-supported self-management is becoming commonplace. It appears that increased involvement in one's own health can have a positive impact, particularly regarding the emotional sphere of health.

The examples highlighted above have illustrated that there are a number of important benefits and advantages that apply more or less to the majority of patients using digital health tools, whereas other aspects are more focused on – or tailored to – specific health conditions, and therefore they benefit only the people involved in managing these in their daily lives.

From among the general benefits offered by digital health solutions, we can extract the following functions:

- **Involving patients** by “empowering” them to be actively involved in thinking about, monitoring, tracking and managing their health and conditions;
- **Gaining better control**, e.g. by facilitating disease management and other routine tasks that were previously burdensome (enabled e.g. by smartphone features), allowing (self) collection of condition-specific data, and giving patients ownership of their personal health data;
- **Improving digital health literacy**, e.g. by educating people about their health either independently, as part of a group;
- **Boosting prevention**, by being able to access relevant information and through health promotional messages and public health campaigns;
- **Improving communication**, e.g. by engaging in (real-time) ICT-enabled communication between patients and their carers and healthcare professionals, or between members of both groups;
- **Facilitating inclusion and access**, by reaching patients living in geographically remote areas and catering to the specific needs of patient communities, including people living in vulnerable and isolated situations;
- **Ensuring continuity of care**, between different health and social settings (hospitals, pharmacies, GP practices, care homes, etc.) and in a cross-border healthcare context, provided that patients and authorised healthcare professionals have access to the same information, in the most secure way possible;



- **Facilitating health professionals' daily tasks**, by enabling them to view, analyse information collected by patients themselves, better coordinate tasks between each other;
- **Enabling health professionals to have a better access** to public health data and closer overview of patients' relevant data.

More specific benefits can be discerned when digital tools are used by people living with particular conditions or under particular circumstances that impact their health.

For example, we have seen that, in the area of diabetes, patients are required to be very disciplined, involving rigid monitoring of blood glucose levels but also diets and physical activity on a daily basis. Given the necessity to carry out constant diabetes management tasks, which can be very demanding and stressful for the individual, IDF Europe argues that “the exercise of documenting on its own can prove educational, creating a whole new level of awareness for the individual”⁵⁷, especially given the amount of information patients are collecting, including also intake of other medicines. Moreover, receiving reminders to check blood glucose, to inject insulin or take pills, and, more importantly, the possibility for blood glucose readings to be carried out – and corrected – automatically by tailored wearable digital devices connected to alarm systems and health institutions, helps take the pressure off the patient in case circumstances do not allow them to act in the right way at the right time. At the same time, mobile apps can provide support to diabetes patients by helping to overcome stressful periods during which they are at risk of “drop-out”, thereby preventing hyperglycemia and other complications.

Given the diversity and severity of many cancers, and the long and unpredictable course of the disease, which often recurs after having endured dangerous operations that might involve bodily amputations, survivorship care is particularly important in this area and apps can help patients on the road to recovery and sensitise them to the uncertainties the future might bring.

For mental health patients, high quality digital tools provide a way to receive the care they require in dignity, i.e. without fear of stigma or being pigeonholed as being “ill” or “different”. They offer new ways of interacting with health professionals and other patients, whether anonymously or openly, while advances in virtual reality and serious gaming challenge them to confront phobias and tackle traumatic life episodes.

For older people, digital health tools provide support for leading more independent lives for longer in the comfort of their own home, aided also by developments in the area of domotics (smart home⁵⁸) and robotics. This is particularly important given that many older people are living with multiple morbidities and disabilities, coupled

⁵⁷ IDF Europe (2017), p.7

⁵⁸ Cook D. How Smart Is Your Home? Science. 2012 Mar 30; 335(6076): 1579–1581. doi: 10.1126/science.1217640



with weakened sensory functions. In this way health-specific functions are being combined with general support for leading more fulfilled and active lives even in situations when health is deteriorating.

For the homeless and other marginalised groups such as migrants and discriminated minorities (e.g. Roma and travellers), digital tools might even be the only way they can access the health system that otherwise and for a variety of potential reasons (residence status, stigma, discrimination, etc.) excludes them.

Nevertheless we must not forget that what can be very beneficial for the majority can still represent an obstacle for the few.

There is also another important lesson to be learned for digital health, and this is coming from the largely “consumer” sphere of health and wellbeing apps. While the offer is exploding (over 100,000 have been added since 2016 alone) and competition between developers is fierce, demand for mHealth downloads has decreased between 2014 and 2016 (Figure 1).

Figure 1 mHealth supply and demand growth rates 2014-2016



Source: www.research2guidanc.com

The user experience in the realm of sports and fitness indicates some important insights regarding their practicability and value that can be transferred to the digital health domain and especially core public health functions like prevention and health promotion.

Firstly, usability implies simplicity: where users are asked to provide too much information and enter too much data, this might trigger both “bureaucratic” (in terms of time and effort) and privacy concerns. As a consequence, they quickly lose patience; they delete the app and move on to simpler products. Also, while certain



apps that encourage their users to engage in regular physical activity are very popular, receiving constant push notifications can also be a pest: they are distracting and can make people feel bad about themselves and their lack of motivation, especially individuals with low self-confidence and a negative body image.

Another issue is that, unless the technology is infallible (e.g. by measuring data directly from the body), there is no reason why patients should not “cheat” and over- or understate their efforts or dissimulate their real health status. The increased use of social networks has led to a general embellishment of people’s competences (“report only the positive, and leave out the negative”) and there is a danger that this might also become the norm in healthcare, which could be dangerous given that good health depends on accuracy and sincere judgment.



7. Conclusion

“eHealth has the potential to make European health systems more accessible and sustainable and to empower patients to manage their own health. Let’s make eHealth a reality in Europe”

**Dr. Vytenis Andriukaitis, EU Commissioner for Health and Food Safety,
Conference on the Cross Border Healthcare Directive, Brussels – 24
October 2016** ⁵⁹

Commissioner Andriukaitis also noted that eHealth tools can offer safe and efficient care and should be adapted to the needs of European healthcare systems to support the increasing incidence of chronic diseases, especially costly diabetes.

Burdensome tasks such as routine visits that might entail long waiting times, pain, etc. can be avoided, especially through remote monitoring devices for people suffering from chronic diseases or specific conditions (e.g. heart disease, diabetes, asthma).

Mobile apps have the potential to help patients understand their disease, learn about prevention and healthy lifestyles, and be more aware and responsible of their health status. It appears that a lot of users of e/mHealth get satisfaction from apps and wearables, and they can motivate them to lead healthier lives.

The examples illustrated above provide an idea of how patient empowerment could be achieved. Keeping in mind that digital solutions need to serve distinct practical purposes, otherwise people will not engage in using them.

Digital health solutions provide the opportunity to access health information, arrange medical consultations, and maybe even to receive treatment much faster. The prerequisite is that both patients and healthcare professionals possess a certain level of digital skills to be able to search for, understand, act upon, and thus benefit from e/mHealth.

If mobile technology for health and disease management will continue to be seen primarily as a fashionable consumer trend for the well-to-do and educated, and healthcare systems and professionals are not prepared to incorporate them into their activities, people will eventually stop using them as they will lose their enthusiasm and be unable to trust their safety and value.

⁵⁹ Speech at the Conference on the Cross Border Healthcare Directive – Committee of the Regions, Brussels – 24 October 2016 see link: https://ec.europa.eu/commission/commissioners/2014-2019/andriukaitis/announcements/conference-cross-border-healthcare-directive-committee-regions-brussels-24-october-2016_en



In the context of this paper, EPHA proposes the following recommendations, aimed at policymakers and regulators working at national and European level, developers of digital health solutions, as well as other stakeholders involved in the development of guidelines, standards and legislation in this area:

1. Meaningful involvement of end users means establishing an effective co-creation process for digital health tools, in order to ensure that the development and implementation of digital health policy is driven by actual health and practical needs of people (patients and their carers, consumers, healthcare professionals) rather than by the demands of the market;
2. Ensure inclusive and ethical integration of digital health into national health systems to improve access to healthcare, as well as across borders;
3. Enhance digital health literacy and expand eSkills among professionals, patients, and the general population;
4. Establish national and European repositories of digital health solutions (e.g. apps) as a form of guidance for patients and healthcare professionals looking for safe and tested solutions;
5. Guarantee that patient safety and quality of care considerations are mainstreamed in all digital health initiatives;
6. Foster research into the use and outcomes of digital health use to ensure continuous improvements in this emerging field.

From a policy perspective, it is also important to take into account the proper implementation of existing and evolving pieces of European and national legislation as well as non-binding guidance documents in areas impacting on e-and mHealth, *inter alia* the new General Data Protection Regulation, the ePrivacy Directive, the new mHealth assessment guidelines and Industry Code of Conduct, and potential future guidelines on Big Data. It is equally important that a distinctly European vision of digital health is not stifled as a result of transatlantic or other international (trade) agreements.

Constructive dialogue between authorities, industry, patient and consumer groups, and civil society organisations should be continued to achieve consensus on safe and inclusive use, while improving public health research and innovation. It is time to build trust with one another.

About EPHA

EPHA is a change agent – Europe's leading NGO advocating for better health. We are a dynamic member-led organisation, made up of public health NGOs, patient groups, health professionals, and disease groups working together to improve health and strengthen the voice of public health in Europe. EPHA is a member of, among others, the Social Platform, the Health and Environment Alliance (HEAL), the EU Civil Society Contact Group and the Better Regulation Watchdog.

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For more information visit the official EPHA Digital Health Page

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