DIGITAL HEALTH

THE FUTURE IS NOW:
DIGITALISATION AND PUBLIC HEALTH

SYNERGY PAPER
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About EPHA

EPHA is a change agent – Europe’s leading NGO alliance advocating for better health. We are a dynamic member-led organisation, made up of public health civil society, patient groups, health professionals, and disease groups working together to improve health and strengthen the voice of public health in Europe.

About EPHA’s Universal Access and Affordable Medicines advocacy

A holistic and socially-inclusive approach to the use of technology in public health is possible. EPHA works to ensure that digital tools are inclusive and integrated into current health systems, rather than being used to replace them. We advocate for a continuity of care in a cross-border Europe and for the strengthening of digital health literacy skills, in order to ensure better access to healthcare for all.

See more at https://epha.org/digital-health/

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Digital health, including its latest data-driven manifestations, is already a steadfast feature of European healthcare systems even if this may not be obvious, and it is heralding major changes in other public health-related areas.
Executive summary

This paper aims to provide a revealing yet non-exhaustive overview of how digitalisation manifests itself in areas covered by EPHA’s membership, which comprises over 80 organisations representing different parts of the public health community. Based partly on a members’ survey conducted in 2019, it complements our previous publications on digital health, and also offers a broader perspective by exploring the impact of digitalisation in other EPHA priority areas: agriculture and NCD prevention, antimicrobial resistance, access to medicines, trade, air pollution, and fundamental rights / tackling inequities, which in turn influence population health. The picture which emerges resembles that of an unsolved puzzle: the pieces are available, yet they do not always fit neatly together. It will still take a good number of years for a coherent image to emerge before a reliable assessment of the value of digitalisation in public health can be made.
1. Introduction

The importance of digital solutions looks set to grow exponentially during the mandate of the new European Commission (EC, 2019-2024), with significant investments announced in many policy areas. Interconnected, data-driven solutions are becoming a feature of all areas of life as the “digital revolution” continues to unfold. Many Europeans feel both excited yet overwhelmed by the digitalisation of society: a vast array of technologies are simultaneously being placed on the market and disrupting familiar ways of operating and communicating. The digital transformation of health and care, as outlined in a 2018 EC Communication, is but a small element of a much larger transformation that is becoming more tangible as Big Data, Artificial Intelligence (AI), medical ‘omics, supercomputing and other innovations are pushing the boundaries of new technology.

Healthcare and public health is often described as a laggard when compared to other economic sectors like online banking, travel, or shopping. As the European Public Health Alliance (EPHA) has previously pointed out, the reasons for this are manifold and they have as much to do with the intensely personal and emotional aspect of health as with the fact that the marriage of digital and non-digital elements has thus far been relatively dysfunctional in the sense that end users – healthcare professionals and patients, health system managers, payers and the general public – have unanswered questions regarding the real costs and benefits of digital health. It is also unclear to what extent individuals will themselves be able to get involved in the process of transformation, which might entail shifting responsibilities, relationships and expectations which not everybody is well-positioned to meet. At the same time, digital health, including its latest data-driven manifestations, is already a steadfast feature of European healthcare systems even if this may not be obvious, and it is heralding major changes in other public health-related areas.

A key recommendation to EU and national policymakers emerging from this paper is the need to pay more attention to how the digitalisation of society, including in healthcare, is communicated. While EPHA has long advocated an end user-centric approach, i.e. involving them in all stages from design to implementation and evaluation, it is of critical importance to avoid silo thinking. Digital health and “traditional” healthcare represent two sides of the same coin, and it is likely

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that developments in other sectors will inevitably also lead to attitudinal shifts in healthcare, e.g. related to data and privacy protection.

In order for health systems to evolve equitably and sustainably, it is important to exploit the potential of digital solutions in the most realistic and inclusive way possible. This entails being honest about their limitations and ensuring that they address the actual problems and needs faced by people and European health systems. For example, by making certain functions faster, safer, more efficient, more accurate, and more accessible or equitable, time can be freed up for patient consultations, duplication of work can be minimised and cost savings should in theory be achievable. The danger is that digitalisation could lead to more exclusion, catering to the few and creating further rifts among socio-economic groups.

Finally, the lure of smart innovation espoused by their developers must be counter-balanced with the constraints faced by public health actors regarding financial, human and technological resources. The integration of digital solutions needs to occur in a gradual and manageable way, which will help build up trust and confidence amongst end users.

2. Digitalisation in healthcare settings

Apart from smartphone health and wellbeing apps, most Europeans will have come into contact with digital health technologies in healthcare environments, first and foremost in hospitals which rely heavily on the constant introduction and upgrading of new technologies to diagnose and treat patients, conduct research and collaborate with other institutions. At the same time, vast amounts of data are being collected by a growing number of technologies and devices, including by healthcare professionals (e.g. tablets) and patients themselves (e.g. smartphones and patient care devices).

To deal with the growing quantities of data efficiently, state-of-the-art hospitals already began going “paperless” a number of years ago while communication and learning across different sites is enabled via instant messaging and specifically designed professional platforms. Moreover, clinical decision support (CDS) systems, fuelled by Big Data, can provide evidence-based information that enables point-of-care decisions, e.g. supporting physicians and radiologists.

In disease-specific areas like cancer, the clinical integration of digital solutions (e.g.

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3 For example, University Hospital Hamburg-Eppendorf (UKE)
connected devices, telehealth, digital assistants, etc.) is taking place throughout the spectrum of care and includes screening, on-treatment patient management, follow-up and survivorship. This has been reported to make an important impact on patients’ and professionals’ knowledge, communication and quality of life.4

The introduction of Electronic Health Records (EHRs) clearly represents an important step for ensuring that those who should have/require access to an agreed set of quality patient data, including healthcare professionals operating in different departments or settings (e.g. hospitals, laboratories, pharmacies, GP practices) can view them and make entries without difficulty – anywhere and 24/7 – based on their assigned roles and responsibilities, not least also patients themselves who have the right to data access and ownership. Apart from providing a useful overview for everybody involved, EHRs offer many other advantages as they help avoid duplication of screening questions and testing, can reduce errors, provide more flexibility through improved workflows, and provide potential opportunities for research in line with applicable General Data Protection Regulation (GDPR) rules. In other words, EHRs are a tool for permitting better continuity of care and they could even make patients feel more secure as they know what has been recorded about them – as long as this information does not get shared with unauthorised third parties.

Another tangible entry point for recording and viewing patient data, coupled with the provision of online services and health information are the comprehensive patient portals which are being operated by a growing number of national health systems, including Estonia, Sweden, Denmark and Malta. In the case of Estonia, log-in for the online patient portal – the development of which was partly supported by EU funds5 - occurs either via an individual’s national ID card or by mobile ID.6 The portal (offered in Estonian and Russian) comprises personal health data which healthcare providers have collected, as well as features such as scheduling appointments, ordering ePrescriptions, accessing lab results, vaccination information and medical imaging reports, etc., depending on the level of access. However, this is merely one part of a much broader, integrated digital health system which offers a healthcare coordination tool to connect providers across different levels of care and disciplines to streamline services, pool data and improve care coordination and efficiency.7

It is not only doctors, nurses or pharmacists who are using digital tools. For example, a couple of Horizon 2020 projects – Back-Up and selfBACK – include multi-

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6 https://www.digilugu.ee/login?locale=en
disciplinary teams of healthcare professionals, in this case chiropractors and physiotherapists, other healthcare operators and researchers from a number of EU countries as part of digital platforms for effective and efficient management of neck and low back pain.\(^8\)

Regardless of its many uses, it is essential to ensure that the adoption of technology in healthcare occurs as part of a collaborative process based on health service gaps, and especially on end user needs. Goals for improving health services or health system performance will not be attained if the technologies procured do not function well in the eyes of their users. Everybody who forms part of a healthcare team, regardless of the setting, is conducting their work based on a set of established routines which need to be followed in order to operate effectively. While certain routines can easily be changed through digitalisation to become more productive and effective, health workers must be the judge of the merits: if digital technologies can be integrated easily or help create new routines deemed to be advantageous, they are more likely to embrace them. If, however, they are imposed top-down and without prior consultation, they are more likely to fail at the implementation stage. Hence, paying attention to service design and work routines is crucial. As noted by Shaw et al., \(^9\)

“Viewing technology adoption as an iterative process, involving complex interactions between a tool, a team, and newly established routines, stands to help teams envision new services arising from the adoption of technologies beyond the added work of new forms of data entry and communication.”

In addition, current trends in public health, such as moving towards integrated and community care models, in which health and social care are closely intertwined and delivered in various settings, will need to be taken into account. They could be boosted by digital tools as they could make a whole out of fragmented silos and contribute to generating valuable data that reflects the growing diversity of life contexts in which people are situated.

### 2.1. Mobile solutions at home & on the go

EPHA’s paper, “Digital solutions for health and disease management,”\(^10\) which was presented at the 2017 eHealth Week in Malta, provides a snapshot of how patients and healthcare professionals are using digital solutions in a number of disease-specific and professional areas covered by EPHA’s membership including diabetes and cancer care, HIV/AIDS, mental health, and hospital pharmacy. It

\(^8\) Khanchandani, B. (2018), Low Back Pain goes Digital: a problem with solutions within a cause

\(^9\) Shaw, J. et al. (2018), Beyond “implementation”: digital health innovation and service design, www.nature.com/npjdigitalmed

also addressed tackling societal challenges including the ageing of the population and migration, mainly focusing on mobile health (mHealth) solutions. The paper demonstrated that patients’ interests in becoming more involved in monitoring and improving their health appears to be positively impacted by digital solutions — in particular, health and wellbeing apps — that stimulate them to become more mindful of their daily routines and potentially make beneficial adaptations to levels of physical activity, nutrition intake, consumption of medicines or to their mood state. It also showed the positive impact on everyday lives: for example, type 1 (insulin-dependent) diabetes patients are literally “left to their own devices” as commonly, they only get to see a doctor very rarely, yet they need to routinely monitor and adjust their dosage based on a number of complex factors such as food intake, physical exercise, etc.  

In the wellbeing sphere, although the offer is continually expanding and improving (although usually involving for-pay subscriptions), much depends on patients’ longer-term commitment and interest: following the initial excitement about the latest app or wearable gadget to facilitate fitness or nutrition regimes, many users abandon them as quickly as they download them. Often, they turn out to be too cumbersome to integrate them into daily routines. While such “trial and error” corresponds to normal consumer behaviour elsewhere, poor attrition could nonetheless also be an indicator for the lack of formal connection between such devices and the healthcare system. In the majority of cases, apps and wearables are selected by health-conscious laypersons without prior discussion with healthcare professionals about their usefulness and their benefits or risks.  

From the perspective of healthcare professionals, an array of clinical and training apps and web-based eLearning materials is available to students and to qualified professionals wishing to engage in continuous professional development to keep their skills up-to-date. In many settings, discussions take place to identify the most user-friendly new apps responding to identified needs, whether related to the provision of time-saving information, enabling collaboration between physicians, or allowing nurses to communicate with patients in a more engaging way. Another benefit of digitalisation in the professional sphere is the ability to create and work in multidisciplinary teams collecting and exchanging data, information and advice in real-time.  

The mHealth market remains vibrant and a great number of apps are introduced every year, which can be hard to follow and creates confusion about their value. In response there is an increasing number of online repositories that are effec-

11 Rose, K.J. (2018), Digital health and diabetes – when the policies become personal  
tively recommending solutions which have been assessed against certain health system standards, the NHS app library\(^{13}\) providing a good example with categories ranging from disease management apps (cancer, diabetes, respiratory) to those dealing with certain body areas, while others cover mental health, pregnancy, child health, dental and sleeping issues, learning disabilities, etc. In addition, the NHS’ own app provides a symptom checker, a system to book and manage GP appointments, register as an organ donor, set preferences for the use of data for research purposes, etc.\(^{14}\) Arguably the endorsement by the national health system can provide doubtful individuals with an added layer of reassurance that they are using a quality product.

Remote monitoring, enabled by sensors and connected devices (the “Internet of Things”) is another growth area. This includes solutions in many disease areas and offers the possibility for patients living in remote areas or unable to see a healthcare professional to feel safer in their own homes knowing that help is available at the push of a button.

Telemedicine enables clinical services (e.g., diagnosis, counselling) at a distance which can contribute to reducing health system costs if professionals are properly trained and relevant guidelines and quality standards are created and applied. It is used in many different settings and contexts, including in specific areas such as chronic wound management to accelerate the healing process and support patients, caregivers and nurses.\(^{15}\) Closely related, telehealth is a broader term that also comprises the remote provision of non-clinical services such as eLearning.

One important challenge identified by EPHA members is how digital health is being communicated in the current fragmented landscape, which differs not only from country to country, but also often between regions. There is a lot of confusion and misinformation, which is growing with the entry of Big Data and AI in healthcare, which has prompted much unhelpful hyperbole from commentators, some viewing them as a future nirvana while others advance a dystopian vision.

### 2.2. Supporting population health... and health systems

Public health as a sub-category of health has been described as an art and a science, constantly reshaping and expanding in response to new societal and population health challenges. In public health, digitalisation contributes to more transparency, the rational use of resources and can help enable the design of better services for

\(^{13}\) [https://www.nhs.uk/apps-library/](https://www.nhs.uk/apps-library/)

\(^{14}\) [https://digital.nhs.uk/services/nhs-app](https://digital.nhs.uk/services/nhs-app)

patients and better support for healthcare professionals.

While the public health approach espoused by EPHA is broad and in line with newer conceptions of public health focusing on tackling health inequities, it is equally important to develop and support key public health functions including epidemiology, prevention and health promotion.

Clearly, digital solutions play a vital role for epidemiologists involved in the development and implementation of surveillance systems for infectious diseases and environmental hazards and in assessing the most appropriate interventions for dealing with disease outbreaks and pandemics. They rely on data and research evidence from a wide range of sources to make recommendations and inform decision-making, and data-driven tools help them to analyse and evaluate vast quantities of data.

Should mass disease outbreaks or other emergencies occur, digital tools can be equally powerful as support tools for crucial tasks such as triage in order to establish the most appropriate order in which individuals should be cared for and treated. Moreover, features such as geolocation (via GPS) and social media entries (Twitter, Instagram, people finder, mapping tools, etc.) allow for better monitoring and tracking of disasters in real-time and enable faster responses in the right location.

EPHA’s reflection paper on Big Data and Artificial Intelligence provides further examples of how data-driven solutions can help tackle public health challenges such as antimicrobial resistance (AMR) by having more ubiquitous, better quality data at the disposal of decision-makers and health system planners. To this must be added the value of video-based solutions such as directly observed therapy (DOT) which have shown in the United States to increase adherence and treatment completion rates for tuberculosis patients prone to the development of antibiotic resistance.16

Making use of digital interventions is recommended by the World Health Organization (WHO) to strengthen health systems, e.g. they can support solving existing challenges while enhancing the coverage and quality of healthcare services. 17

Therefore, the WHO has produced an evidence-based guideline for policymakers and other stakeholders to help make decisions for investing in digital interventions18 which can be delivered primarily via mobile devices, from birth/death notifications

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18 The guideline describes a digital health intervention as a “discrete functionality of digital technology that is applied to achieve health objectives and is implemented within digital health applications and ICT systems, including communication channels such as text messaging” (p.3).
to educational and training support for health workers. Similarly, the European Commission (EC) views digital health as a key enabler for creating more resilient health systems.\textsuperscript{19}

However, as pertinently noted in the report by the EC’s Expert Panel on Effective Ways of Investing in Health, “Decisions to adopt, use or reimburse new digital health services, at different levels of the health care system, are ideally based on evidence regarding their performance in the light of health system goals.”\textsuperscript{20} Importantly, the latter are broader aims which remain independent of the process of digitalisation; apart from quality and safety, they might include considerations related to access, equity and efficiency. The WHO also recognises the limitations of digital interventions, noting that they “(…) will not replace the fundamental components needed by health systems such as the health workforce, financing, leadership and governance, and access to essential medicines.”\textsuperscript{21} In other words, in order to assess the value of digital solutions, a broader view should be taken which evaluates their contribution as complementary tools for health workers to improve their performance (which, ideally, would lead to freeing up time to spend with patients), improve service quality for health service recipients, and allow administrative processes and healthcare operations to function more efficiently, in combination with meeting defined health system goals. This involves thorough prior assessment of what can realistically be achieved and a truthful view at the existing national/regional health system context and entire ecosystem to determine if it can absorb the technology and its disruptive effects. The capacity will differ widely from country to country, both in Europe and globally.

While initiatives such as the 1 million genome challenge currently undertaken by the EU are interesting, they also present challenges for under-resourced health systems in countries struggling with more urgent public health issues such as frequent measles outbreaks due to low vaccination coverage.

3. Digitalisation in areas shaping public health

A clear advantage of the shift towards data-driven technology is that AI and related innovations are revealing connections between different policy areas which were hitherto difficult to establish. Since the notion of public health is continually ex-

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\textsuperscript{20} Expert Panel on effective ways of investing in Health (EXPH, 20 Nov 2019), Opinion on assessing the impact of Digital Transformation of Health Services’; p.4
\textsuperscript{21} WHO (2019), op. cit., p.3
A clear advantage of the shift towards data-driven technology is that AI and related innovations are revealing connections between different policy areas which were hitherto difficult to establish.
Digitalisation influences the public sphere, as reflected in current debates about the limits of freedom of speech and about how to safeguard respectful behaviour online, in a world in which uncomfortable perspectives can easily be “filtered out” and in which fake news, hate speech and cybercrime are increasingly common. This brings consequences not only for health but also for how we campaign and advocate.

3.1. Air pollution and ecological transition

In 2019, the WHO has identified air pollution as the number one global health challenge. In total, 71,000 studies are currently available in the medical literature on the health effects of air pollutants, and the societal impacts range from short-term health effects such as hospital admissions, to ultimately death. It is a relentless “invisible killer;” according to the WHO, the economic and human costs to Europe’s cities and society are huge, at over €1tn per year, and outdoor air pollution leads to significant reductions of life expectancy and productivity.

Compared the combustion engine and fossil fuel-based mobility, electricity is far the most beneficial technology from a public health point of view. Digitalisation can facilitate the electrification of transport. The effects of air pollution on health caused by diesel car emissions are particularly disturbing. Digital innovation could play an important role in enabling cleaner, safer and more sustainable modes of transport which will create less of a burden on the planet, from electric cars to new ways of moving planes, trains, freight and passenger shipping vessels around the globe. Although the notion of autonomous vehicles is greatly disputed, they could potentially improve traffic flows, improve fuel efficiency and allow for better joint

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22 https://www.who.int/emergencies/ten-threats-to-global-health-in-2019
circulation of groups of vehicles ("platooning") on automated highways. Moreover, a number of smartphone apps are now available to measure air pollution levels, helping drivers to consider greener modes of transport.

Digitalisation is also boosting the green energy sector with many developments which should help transform industries and boost the development of a circular European economy. In order to deliver on Commission President Ursula von der Leyen’s European Green Deal, which strives for Europe to become the first climate-neutral continent, digitalisation can become a vector to reshape the economy and enable better decisions to be taken to ensure cleaner industrial production and consumption models in the future.

The healthcare sector, it should be noted, is a significant contributor to greenhouse gas emissions in Europe. Digital solutions can contribute to alleviating climate and environmental damage by reducing reliance on polluting transportation, paperwork, unnecessary prescribing, products containing plastic or chemicals - as part of a broader strategy for health sector mitigation and adaptation.26

The pivotal role ascribed to digitalisation is clearly underlined in the European Commission Communication on the European Green Deal.27 It stresses the opportunities afforded by digital technology for distance monitoring of air and water pollution, as well as for monitoring and optimising the use of energy and natural resources. Taking a much broader view, however, the Commission aims to “unlock the full benefits of the digital transformation to support the ecological transition. An immediate priority will be to boost the EU’s ability to predict and manage environmental disasters. To do this, the Commission will bring together European scientific and industrial excellence to develop a very high precision digital model of the Earth.”28

Regarding the digital sector itself, measures to improve its energy efficiency and circular economy performance will be considered, from broadband networks to data centres and ICT devices.

### 3.2. Food systems

Food systems encompass “everything and everybody involved in producing, stor-
Current food systems drive diet-related diseases, the spread of antimicrobial resistance (AMR), air and chemicals pollution and climate change, amongst others. Considering these challenges, there is immense pressure to ensure a transition towards sustainable production and consumption models. Digital solutions have been proposed to enable such a transition.

### 3.2.1. Precision farming

Digital or precision farming has been described as a promising way to move towards more resource-efficient production as it can support the tracking and management of many factors such as soil fertility, erosion, water and land use, animal behaviour and fertiliser levels in crops to minimise environmental impact. In addition to smartphone apps, farmers can deploy tools such as satellites, remote sensors and drones to collect a wealth of data to monitor plant health, soil conditions, temperature, nitrogen utilisation etc. in real-time, allowing for timely adjustments.

Moreover, digitalisation could support compliance with the applicable rules under the revised Common Agricultural Policy (CAP). AI techniques can also be used to optimise food production, such as by monitoring the movement, temperature and feed consumption of animals, which can contribute to better animal husbandry practices in the fight against AMR.

However, caution is required as precision farming remains contested and costly. It entails, for instance, the risk of a further consolidation of power in the food supply chain away from farmers towards companies which will be controlling data and driving off farm decision-making. This may serve to enhance uniformity in pro-

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duction processes and farm holdings, as not all farmers will be able to afford such technologies, and shape perceptions of what types of farm models are deemed ‘sustainable’, with potential repercussions regarding eligibility for farm support. Such a development could undermine diversity and resilience in production systems, while potentially opening the door for conflicts of interest in the elaboration of algorithms, embedding existing production paradigms and limiting the scope for advances towards more innovative production methods.

Furthermore, efforts to enhance the efficiency of any individual part of the food chain will have to be assessed in light of the system as a whole to ensure that gains lead to absolute improvements in resources use, not relative improvements. For instance, if efficiency gains in food production result in overall increases in demand and supply of certain food products they may lead to greater, rather than lower, aggregate resource use.  

3.2.2. Personalised nutrition

Digital solutions are also being proposed on the consumption-side of the food system, especially to tackle unhealthy diet, which is a leading risk factor for the entire burden of mortality and diseases in the EU. These proposed solutions converge under the term ‘personalised nutrition’, which can be generally defined “as an approach that uses information on individual characteristics to develop targeted nutritional advice, products, or services.”

The starting point for the idea behind personalised nutrition is the well-documented finding that people can respond differently to dietary components. In recent years, technological developments have allowed advances to be made in new areas of science, including epigenomics, metabolomics and the study of the microbiome. As mentioned above, the continuous monitoring, measurement and collection of individual health-related data through fitness trackers, mobile apps and other devices is already becoming commonplace. Taken together, this has opened a ‘brave new world’ vision in which individuals are supported in maintaining and improving their health through diets tailored to fit each person’s genetic profile.

This approach has raised expectations; especially the idea that genetic information might be used to define personalised dietary recommendations has led to much excitement. However, in reality, large knowledge gaps remain, requiring signifi-
cant research before the potential benefits can materialise in ways which are real and meaningful for individuals. Concerns have also been raised about how this approach may affect health equity.41

3.2.3. Consumer information

Another area in which digital solutions appear to be gaining ground is in the field of consumer information. Recent policy developments aimed at ensuring consumer access to nutrition and ingredient information for alcoholic beverages has seen the European Commission agree to proposals for displaying essential information not on the product label, but online through the use of QR codes.42 While online data can always serve as an additional source of information, any development that involves a shift of basic consumer data from the product label towards providing online information only is a worrying trend.43

As the EU moves towards defining a vision and set of actions for a “Farm to Fork” strategy for sustainable food, it should take care to take a systemic approach towards change, moving forward. While it is clear that digital technologies have a role to play in the transition towards sustainability, it is important to take a realistic look at their potential to promote food system transformation, and also at the risks that the ‘great promise’ offered by technological solutions may contain a real paradigm shift, for instance by crowding out social innovation and society-wide policies.44

There is also a danger that policies aiming to augment digitalisation in this area could exert a negative impact on public health through the backdoor, e.g. by invalidating previous important achievements gained through developing society-wide policies in public health. For example, it will be important to ensure that the Digital Services Act proposed by EC President Ursula von der Leyen,45 which is meant to advance liability and safety rules for digital platforms, services and products does not inadvertently dismantle the marketing provisions, such as the ban on marketing unhealthy foods to children contained in the Audiovisual Media Services Directive.

3.3. Access to medicines

In the area of access to medicines, digitalisation can be seen as a double-edged sword: on one hand there is the promise of more tailored treatments based on

41 Ordovas et al. (2018) Personalised nutrition and health. BMJ https://www.bmj.com/content/361/bmj.k2173
42 European Commission, Alcohol labelling. See https://ec.europa.eu/food/safety/labelling_nutrition/labelling_legislation/alcohol_en
43 https://www.beuc.eu/blog/alcohol-information-label-vs-screen/
44 See EPHA, Policies for healthy living environments – Food environments https://epha.org/living-environments-mapping-food-environments/
45 Von der Leyen (2019), op. cit.
the genetic cell make-up of certain groups of individuals; on the other hand, this would come at a very high cost and it is unlikely that such personalised medicines would become available to the poor.

In the same vein, while the increased use of harmonised real-world data derived from many possible sources (including apps, patient registries, biobanks, health records, health insurance data, etc.) is being lauded as an important step to improve healthcare quality for patients living with life-threatening diseases such as heart disease, Alzheimer’s or blood cancers, the real value of having such data available will depend on public health-friendly policy decisions to make innovative solutions available to everyone regardless of their socio-economic background. While there is promise that real-world data can fill a gap by providing information that cannot be collected during clinical trials, which could potentially lead to improved access based on the effectiveness of medicines for patient outcomes, there are many potential purposes (HTA, regulatory decision-making, etc.) while many concerns remain related to the size and quality of data, the applicable standards, etc. and the ability to abuse such data.

3.4. Fundamental rights and tackling inequities

As noted by the EU Fundamental Rights Agency, the current shift towards data-driven technologies and decision-making can create negative fundamental rights implications and it could undermine the principle of non-discrimination enshrined in the EU Charter of Fundamental Rights:

“The use of new technologies and algorithms, including machine learning and AI, affects several fundamental rights. These include, but are not limited to, the right to a fair trial, prohibition of discrimination, privacy, freedom of expression, and the right to an effective remedy (...).”

Although personal data related to attributes which could lead to discrimination (gender, race, ethnic origin, disability, age, sexual orientation, residence status, etc.) are protected under the EU General Data Protection Regulation, the increased use of potentially biased algorithms working with Big Data to inform decisions, and the targeting of individuals based on such characteristics, poses a particular threat for excluded groups. A 2017 European Parliament Resolution recognised this and highlighted the need for action to create an ethical framework.48

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47 FRA Focus (2018) #Big Data: Discrimination in data-supported decision making
From the outset, EPHA has sensitised policymakers to the fact that, if not guided by a holistic, end user-centric perspective, digital solutions can simultaneously decrease and exacerbate existing inequities and forms of exclusion. Like all innovation, it can empower certain disadvantaged or marginalised individuals and sub-groups to enter a process of social mobility, e.g. by exploring the adaptive and creative side of new technology and revealing new skills that may no longer rely on formal notions of education or literacy. At the same time, it is likely that only a small segment of people falling into this category will have sufficient access and exposure to ICT-enabled technology to harness its full potential.

The health and social care domain can be complex to navigate and for marginalised groups it is crucial that information is reliable and correct. Moreover, they may require additional support in order to identify, interpret, analyse and act upon such information as part of a complex cognitive process. Nonetheless there is increasing evidence that members of disadvantaged groups view digital tools, especially smartphones, as a “window to the world”; for example, many refugees in Europe commonly use smartphones to organise their journey, remain in contact with friends and family, or to search for information and support. Individuals belonging to some of the most excluded groups, including undocumented migrants, Roma, the homeless, sex workers and drug users could in theory benefit the most from digitalisation. The prerequisite however is that digital solutions are tailored to their needs in a meaningful and inclusive way, taking into account different educational, cognitive, language and learning capacities. Examples from the homelessness sector are encouraging (e.g., apps providing information about basic needs and connecting homeless people with individuals wishing to engage with them). However, vulnerable individuals’ access to technology is often intermittent and digital literacy is likely to pose challenges. More research is required to understand how various groups use smartphones and other new technologies, and whether they reduce or (re-)produce health and social inequities.

Older people are increasingly using e/mHealth tools, including apps, wearables, websites and video consultation, as part of health promotion programmes and as individuals in the “silver economy”, to monitor, discuss and improve their health (e.g. specific conditions or diseases, weight control, risk factors like tobacco/alcohol consumption), although this remains an under-researched area. Given

50 See EPHA’s 2019 article on this topic: https://epha.org/digital-solutions-for-tackling-homelessness/
52 Kampmeijer, R. et al. (2016), The use of e-health and m-health tools in health promotion and primary prevention among older adults: a systematic literature review. BMC Health Services Research,
that older people are rarely digital natives, they might require extra support and feedback to stay motivated and integrate such tools into their lives. On the other hand, e/mHealth solutions allowing e.g. direct online or virtual communication with healthcare professionals, remote monitoring and automated messaging can help them to feel safer and connected, especially where loneliness or geographical isolation are an issue. The action groups and reference sites of the European Innovation Partnership on Active and Healthy Ageing are scaling up the use of digital solutions and creating cross-border networks.\textsuperscript{53} EPHA member Age Platform Europe is involved in a number of projects that are testing the potential value new technology could bring to older people by supporting healthy and active ageing and independent living.\textsuperscript{54} Given that many older people have multiple morbidities and in the absence of sufficient numbers of available trained healthcare professionals and carers, technology can fill an important gap if it supports actual needs, is accessible and user-friendly, and does not infringe on older people’s rights to manage their health according to their own abilities and preferences.

Crucially, Europe’s digital revolution must not occur at two speeds, with people already receiving good quality healthcare travelling at breakneck speed on the “information highway”, with those who struggle obtaining even basic access as a result of socioeconomic and other inequities relegated to the backroads. Overall, there is still very little evidence about how specific sub-populations are using digital tools, and even less of an understanding of whether they are using them to access health information, health services or prevention and health promotion offers.

\textbf{3.5. International trade}

Paying appropriate attention to digitalisation in international trade is vital to ensure policy coherence between trade and public health and to guarantee policy and regulatory space for governments and the EU to protect the public interest against the challenges of the digital revolution. Digitalisation is a vital component of the new economy, making it possible for businesses and people to trade and consume a great array of products and services across the globe and in real-time via eCommerce platforms. It enables new opportunities for entrepreneurs with the right skills to make their mark, and arguably the Internet has “democratised” a lot of business sectors (e.g. public transport, accommodation, travel) by offering possibilities for ordinary people to earn money as more goods and services have become digitally tradable. At the same time, this is creating new imbalances as only the digitally literate can benefit from these prospects.

\textsuperscript{53} https://ec.europa.eu/eip/ageing/home_en
\textsuperscript{54} https://www.age-platform.eu/project-topic/new-technologies-ict
However, the shift towards digital trade also holds a lot of new challenges, which can be aggravated if insufficient attention is being paid to the consequences of promoting borderless, global trade online. This is especially dangerous in the healthcare sector given a widespread opposition to make health and social care services tradable to begin with in light of the concerns over protecting personal health data and privacy, the selling of personal data for marketing purposes (FT article) and cybersecurity threats posed by hackers. As noted by the Organisation for Economic Cooperation and Development (OECD) in a trade brief, government approaches to regulating cross-border data flows can differ greatly across the world and hence “(...) it will be increasingly important that the international and trade dimensions of data regulations are also considered, to ensure that privacy, security, protection of intellectual property and the benefits of digital trade, are all comprehensively understood, considered, and balanced. Whereas a too lax data regime could mean that personal data can be exploited and used in discriminatory ways against individuals or groups, supported by the biased automated decision-making, a too restrictive regime can hamper innovation and brings trade consequences, e.g. for small and medium-sized enterprises (SMEs).

Most of the international trade agreements in place today, despite the relevant provisions of the General Agreement on Trade in Services (GATS) and the Information Technology Agreement (ITA), were not drafted with digital trade in mind given the recent surge of this business sector. The drafting of new, comprehensive bilateral international trade agreements between the EU and other countries such as CETA (Canada) or TTIP (United States) is therefore of great relevance in this context as they define what does and what does not “count” as a tradable digital service or good. In doing so, they can create pressure on national policymakers to forego established quality standards and inclusion criteria, based on the flawed assumption that trade is always necessarily good for innovation, the economy and for people. This has already led to a slow-down in public health friendly policy take-up.

EPHA’s risk register, developed in the context of the EU trade agreements with Latin American countries, highlights that tools such as lowered tariffs and increased foreign direct investment could pose a significant risk to health by making unhealthy food, drink and tobacco products more widely accessible, while weak wording on procurement rules and labelling requirements could present an obstacle to public health measures. Trade rules that allow for fast-tracking meat imports could trigger potential food safety crises and accelerate the global spread of AMR. By favouring the interests of private investors and multinationals, maintaining unfavourable intellectual property rights rules could threaten access to medicines for patients and keep prices high.\textsuperscript{55} This has been highlighted in the EPHA guide to protect

\textsuperscript{55} EPHA (2018), Unhealthy Trades: The side-effects of the EU’s Latin American trade agreements,
Moreover, digital infrastructures are global by nature and the lack of clearly defined trade borders is creating a lot of question marks. For example, the OECD refers to the confusion about the applicable trade directions for 3D printing trade transactions, which trigger questions about whether rules related to services (a design service crossing borders) or goods (at point of consumption) should be applied, as well as about the origin of the “product” if the server is located in country A but the intellectual property belongs to a company in country B. Also, many companies flexibly operate from multiple locations and increasingly digital products are characterised by a mix of goods and service elements. In addition, the relationship between digital and traditional trade transactions may not always be clear. Apart from Big Data and AI, future international trade agreements will also need to take into account other new technologies such as supercomputing and blockchain, increasingly complex telematics infrastructures and the impact of digitalisation on global health and the distribution of wealth within and between countries.

Finally, even if the healthcare sector benefits from certain trade exemptions such as those which have been carved out in prominent international trade agreements, over time the widespread uptake of digital technology in other economic sectors is shaping behaviours, expectations and attitudes which could transform healthcare without doing so deliberately. For example, the relentless drive to innovate might make it practically impossible to stick to certain practices and technologies in healthcare given that advances elsewhere could render established platforms obsolete or impose Big Data and AI enabled technologies as the new norm, gradually making it impossible to introduce other alternatives which could better reflect the ethics and values of the healthcare sector.

Conclusion

This paper has provided a brief overview of the status quo of digitalisation in public health-related areas across Europe. It demonstrates that they are already part and parcel of European health systems, whether in formal healthcare settings, in the private sphere or as supporting tools for end users in many areas exerting an

57 OECD (2019), op. cit., p.4
influence on population health. Even more so, digitalisation is viewed by the European Commission as a top-line priority essential for solving some of the greatest challenges Europe is facing today, spanning many policy areas.

However, often the introduction and integration of digital tools occurs in a fragmented way, with major differences between countries and regions. In the healthcare sector, the barriers to widespread eHealth deployment have been widely discussed elsewhere and they remain in place. However, the introduction of cross-border ePrescription and electronic patient files is likely to contribute to raising awareness and demonstrating the utility of digital solutions in a practical way: potentially everybody can benefit from them, regardless of their location or condition. Regarding apps and more individualised solutions such as wearables, many studies appear to generate positive results in disease-specific areas such as diabetes, cancer, cardiovascular and respiratory diseases, but ultimately much bigger samples with bigger granularity of data would be required from different countries and patient communities to allow the making of pan-European recommendations. The use of apps is also complicated by the difference between those which are classified as medical devices and others that fall into the health and wellbeing category; apps which have been tested and recommended by trusted authorities like the NHS; and those which are placed on the market primarily as consumer tools.

The evidence about the cost-effectiveness of the digitalisation of healthcare and related public health areas is likely to become clearer once a wider range of solutions are commonly used by professional and individual end users as an integral part of broader strategies. In healthcare, this must involve investments in prevention, health promotion, social and digital inclusion.

The Council Conclusions of the Finnish Presidency adopted on 24 October 2019 envisage a European economy of wellbeing described as “a policy orientation and governance approach that aims to put people and their wellbeing at the centre of decision-making”. Such an orientation requires intersectoral, “Health in All Policies” thinking and practice, which is not easy to translate into policy planning and decision-making structures. In this context, digital tools could help establish new connections between policies, e.g. to determine the health impact on populations of transport, environmental or agriculture policies, by collecting more ubiquitous data from various sources that machines might be able to process and analyse more quickly.

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58 For example, see EC COM(2012) 736 final
Most importantly, the widespread introduction of digital technology is unlikely to result in major changes if it remains disjointed from strategic public health objectives and investments in population health. While the current Big Data/AI discussion places a lot of emphasis on the individual and his/her genetic information, the reality is that millions of people in Europe are not part of any “digital revolution” and they do not even have access to basic healthcare. But even if mobile tools become more ubiquitous and reach the most underserved communities, the latter will require a lot of additional support beyond what technology and data alone can deliver.

Communicating the purpose, objectives and direction of digitalisation in public health related areas, including healthcare itself, will become more important as data-driven solutions become commonplace, presenting new ethical challenges. The end user-centric approach espoused by EPHA is vital to ensure a critical mass of trust and acceptance. An inclusive public dialogue involving civil society must take place to ensure that European health systems are able to evolve equitably and sustainably rather than falling prey to commercial forces flexing their muscles in the Digital Single Market. We need to be honest and realistic about the pros and cons of digital innovation in all economic sectors, and address the constraints faced by public health systems in a more strategic way: we can embrace digital tools, but they must be part of broader actions and plans that promote public health measures, from investing in prevention to health promotion to taxation on health-harmful food and drink to ensuring “farm to fork” methods, in line with available financial, human and technological resources. At the same time, we must be mindful that technological progress in non-health areas can and will have an impact on health itself if the public health community fails to engage in the evolving policy dialogue.
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