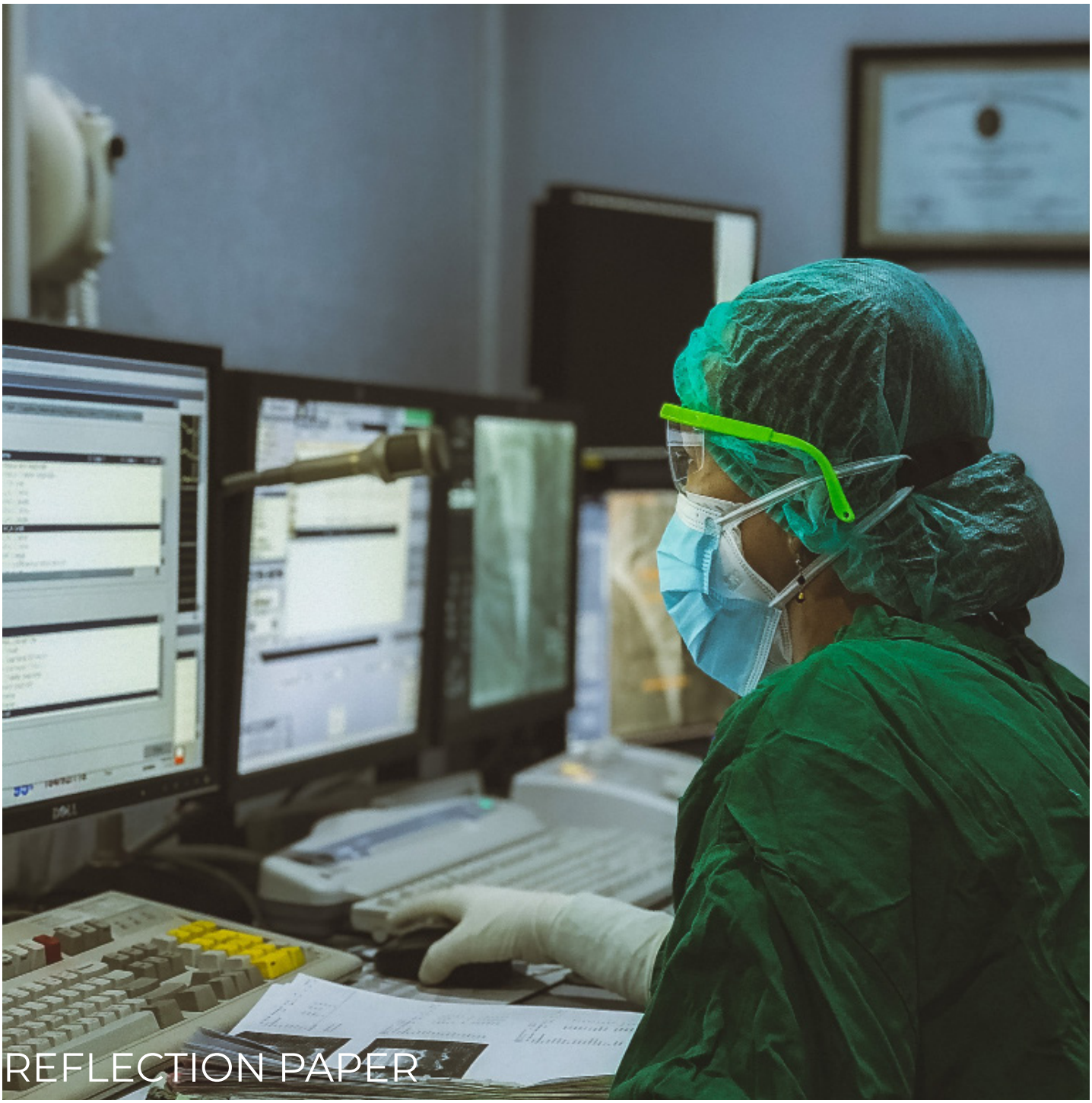


DIGITAL EPIDEMIOLOGY AND OTHER TECHNOLOGIES / INNOVATIONS RELEVANT FOR PUBLIC HEALTH FUNCTIONS

DECEMBER 2021

epha european public health alliance

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.

The Authors:
Sascha Marschang & Filip Karan

Co-funded by the
Health Programme of
the European Union

The European Public Health Alliance has received funding under an operating grant from the European Union's Health Programme (2014-2020). The content of this document represents the views of the authors only and is their sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the European Health and Digital Executive Agency (HaDEA) or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.

Transparency Register Number: 18941013532-08

Introduction

The ongoing COVID-19 pandemic has contributed to a higher recognition of the contribution of digital solutions both in the healthcare and in the public health realms. The introduction of contact tracing apps and Digital Green Certificates in Europe has also demonstrated how closely intertwined personal actions - such as the decision to get vaccinated and share personal health data with health authorities and other end users - and public health functions are under pandemic conditions, thereby also demonstrating how individuals can contribute to protecting population health and solidarity.

However, there are many other digital developments that can contribute to better preparedness and surveillance of communicable diseases and other cross-border health threats, as well as to strengthening key public health functions and, by extension, advancing health system reforms.

In this context, digital epidemiology describes a new field which has undergone rapid growth in the past few years, fuelled by the increased availability of Big Data and technologies powered by Artificial Intelligence (AI) and relying on new data analysis methods. The reliance of digital epidemiology on non-traditional data sources is not without controversy, but it is also contributing to a broader understanding of the different factors that can influence contagious disease outbreaks and other epidemiological events.

It is still too soon to judge whether the impact of digital technologies in public health is predominantly beneficial or whether its effects could also be described as disruptive. While a degree of disruption is a necessary ingredient of any technological transformation process, perhaps the most important measuring stick will be whether the increased deployment of data-driven digital technologies in public health will lead to better health outcomes across population groups, and whether stakeholders' trust in digital health technologies dependent on vast amounts of data will rise to a sufficiently high degree to draw quality inferences.

Digital epidemiology – an emerging field

Digital epidemiology occupies a particular interesting role in the digital transformation of health and care, which is also impacting key public health functions. Although the goal of digital epidemiology is similar to that of classic epidemiology, according to Salathé (who coined the term) the main difference is that the former makes effective use of data not primarily designed for the purpose of epidemiology,[1] thus complementing the epidemic intelligence routinely collected by governments and public health agencies. These additional data are derived from a variety of different sources, inter alia smartphones, social media posts, sensors, call centres and search engines. Other relevant sources can be health and patient registries, city and environmental monitoring data.

Accordingly, methods of digital epidemiology include making use of digital trace data, for example from Internet-based sites such as Google Trends, Twitter and Wikipedia, as well as crowd-sourced information (e.g. from web-based surveys) which can expand established disease surveillance systems by capturing and recording real-time data (e.g. in combination with geo-location) and trends regarding health outcomes. This combination is e.g. leading to a better understanding of public attitudes, perceptions, and behaviours towards health issues.[2] In addition, digital epidemiology data can help capture societal and environmental changes, e.g. pertaining to mobility, climate change and communication. The use of social media networks like Twitter also serves a dual function as it allows governments, public health agencies and civil society groups to inform the public by making available evidence-based information.

COVID-19 underlines the benefits of gaining a rapid understanding of disease spread, risk factors, and intervention impact to mitigate the health and economic consequences of the global pandemic. Better, more comprehensive public health surveillance and early pandemic detection are two areas facilitated by digital epidemiology which, by extension, is also contributing to global health security.[3] However, to really achieve impact on a sufficiently large scale and benefit from dynamic and timely public health information, efforts to coordinate the sharing, combining and analysis of data from disparate sources need to be stepped up as part of strategic approaches at all levels (international, national and regional).

Other digital technologies relevant for public health

There are many other digital technologies and innovations that are advancing healthcare delivery on the one hand, and key public health functions (see below) on the other. Over the years, EPHA has advocated a cautious approach that recognises the added value of such technologies and promotes their full integration into European health systems as vital complementary tools, albeit depending on sufficient evidence proving their effectiveness, quality, safety and meaningfulness. While fully aware that digitalisation is a reality that will progress in the future

1 Salathé M. (2018). Digital epidemiology: what is it, and where is it going?. *Life sciences, society and policy, 14(1), 1.* https://doi.org/10.1186/s40504-017-0065-7

2 Park H. et al., Digital epidemiology: use of digital data collected for non-epidemiological purposes in epidemiological studies. Healthcare Informatics Research 2018;24:253–62. doi: 10.4258/hir.2018.24.4.253.

3 Tarkoma S. et al., Fighting pandemics with digital epidemiology, *EClinicalMedicine 26 (2020), 100512*

irrespective of whether everybody 'agrees' with all of its many dimensions, EPHA's previous papers written in collaboration with our members representing healthcare professionals, diseases-specific communities, patients and vulnerable groups have attempted to highlight the real-life impacts and consequences of digital health solutions on end users. These included discussions about their accessibility, practicability and ease of use, as well as the interlinkages with important ethical questions pertaining to data protection, privacy, health equity and fundamental rights.

Public health being the crossroads where private and public considerations intersect, and where decisions need to be taken for the benefit and well-being of all members of society, the introduction of digital technology is thus particularly important yet sensitive in the sense that it may be harder for individuals to grasp their purpose and relevance. This may be especially true for technologies and innovations that are less tangible than the coronavirus apps and digital certificates introduced during the COVID-19 pandemic, where deployment is now explicitly linked to being granted certain advantages – proof of vaccination, negative test results or full recovery now being prerequisites in many countries to enter restaurants, gyms and entertainment venues, in addition to being able to travel internationally.

Other technologies are less easy to grasp for many individuals as they do not necessarily encroach directly on individuals' day-to-day actions and mobility. Rather, they are features of large and powerful data analysis structures tailored to the specific needs of public health decision-makers and healthcare providers (e.g. hospitals), key components of systems designed for data / privacy protection and preventing cyber-attacks, or they allow for the exchange of data across countries and sectors by enabling improved interoperability, standardisation and data governance. It is a big domain that includes data derived from mobile health applications, wearables, automated sensors, robotics, virtual reality and related solutions on the one hand (which may or may not be used also by individuals in their homes to manage their health conditions), and more abstract technological innovations such as supercomputers, machine learning, blockchain, image processing, nanotechnologies, etc. on the health systems and informatics side.

In 2021, the European Centre for Disease Prevention and Control (ECDC) organised a series of technical consultation meetings[4] with European representatives of learned societies, professional associations and industry representatives to help assess the scope and possible impacts of digital technologies on key public health functions. A non-exhaustive list of the latter – part of a scoping review - contained important activities such as the following:

- communicable disease surveillance, prevention and control;
- signal and outbreak detection and validation;
- identification, collection, appraisal, analysis, reporting and visualisation of surveillance and research data (incl. from grey literature and social media);
- monitoring and assessing the effects and effectiveness of public health measures;
- epidemiological, modelling and forecasting studies / preparedness; and
- provision of evidence-based guidelines and advice

4 https://www.ecdc.europa.eu/en/news-events/consultation-digital-technologies-public-health-functions

The expert consultation meetings, which also included representatives of the European Commission, its agencies (European Medicines Agency - EMA, European Food Safety Authority - EFSA) and WHO, resulted in a technical report published by ECDC in November 2021[5]. The consultation took place at a critical juncture for the digital transformation of health and care overall, given the allocation of vast amounts of funding under the new EU Multiannual Financial Framework (including the Digital Europe and EU4Health programmes) to ensure that Europe will be able to make a giant leap ahead and fulfil the ambition of the future European Health Data Space, in which Big Data analytics and AI deployment play a centre role.

Similar to EPHA's paper on digital solutions introduced during the COVID-19 pandemic crisis[6], the ECDC report also includes a number of case examples collected during the workshop, including the EMA's DARWIN project, the French Health Data Hub, and Public Health Canada's AI strategy.

Previous and ongoing EU-funded data science projects analysing the spread of communicable diseases such as EIPWORK and the MOOD project have also greatly improved forecasting, e.g. by allowing for realistic simulations through the use of non-traditional data sources such as daily airline passenger traffic, hospital admissions and mobile phone data.[7]

Limitations

Given the high dependency on ubiquitous, comparable data of sufficient quality and reliability, there is still a big gap to be closed before the need for working with open, accessible data and improved computing capability can truly be satisfied as part of a pan-European (public) health data space.

For example, Tarkoma et al. note that, while the digital epidemiology toolkit is constantly evolving, much of the useful data are privately generated or held and therefore they necessitate specific levels of data and privacy protection. Privacy-enhancing solutions certainly exist already – ranging from data aggregation and anonymization to differential privacy-based methods, decentralised data processing and federated (machine) learning[8] - but it will be equally important to ensure the establishment of sound methods. Crucially, expanded data sets should reflect the local context of population groups to avoid the much-maligned bias of algorithms and the exacerbation of already existing health disparities.

---

5 https://www.ecdc.europa.eu/en/publications-data/digital-technologies-key-public-health-functions-results-ecdc-expert-consultation

6 https://epha.org/covid-19-speeding-up-digital-health-and-meeting-peoples-needs/

7 https://digital-strategy.ec.europa.eu/news/how-does-data-science-boost-epidemiological-research

8 Tarkoma S. et al., Fighting pandemics with digital epidemiology, *EClinicalMedicine 26 (2020), 100512*

Where to go from here?

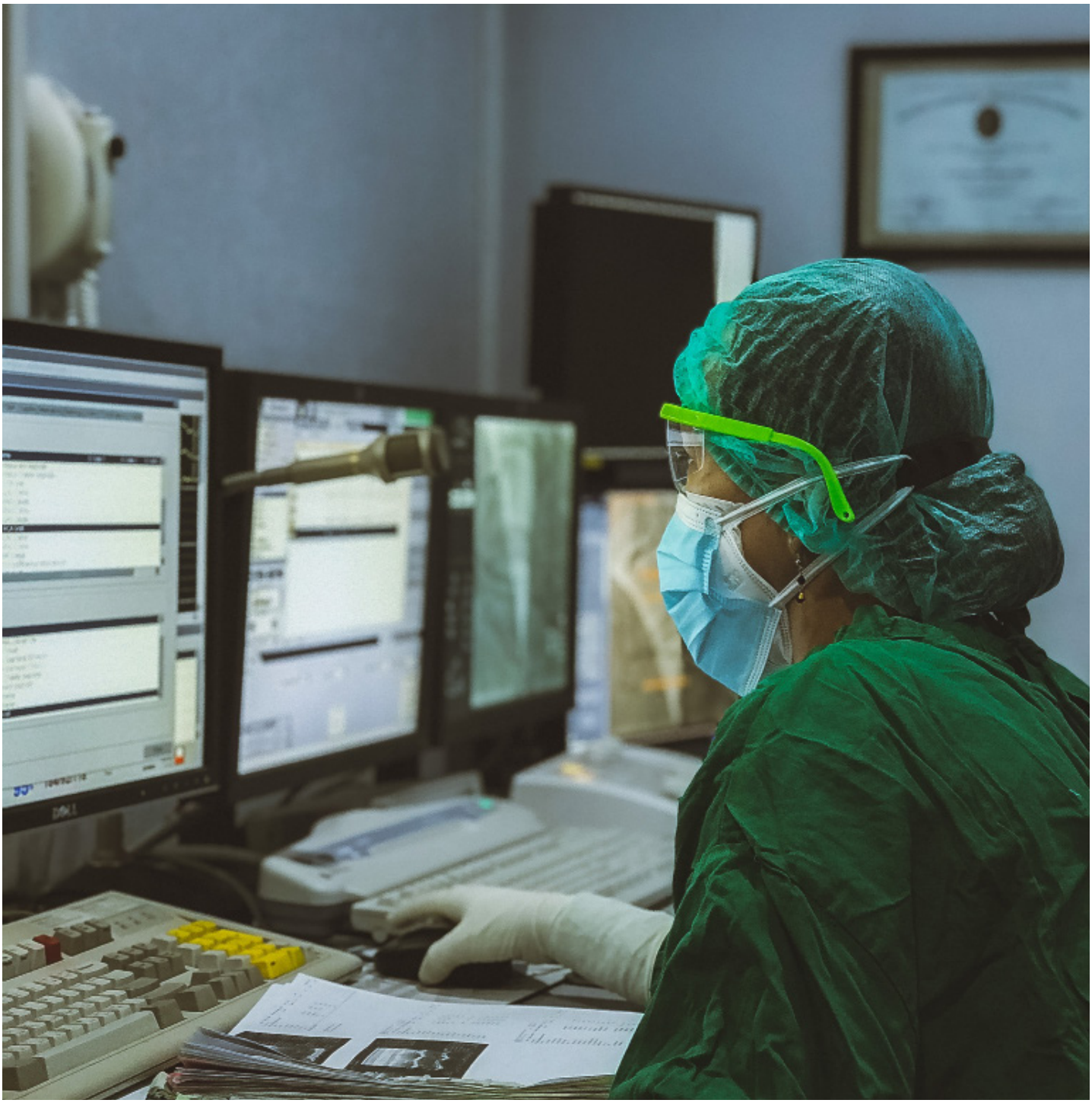
The ECDC consultation confirmed that EPHA, with its specific mission to tackle health inequalities in its many manifestations (including online), does not stand alone when it comes to voicing concerns about the increasing difficulty to evaluate the real added value of data-driven technology in epidemiology and other key public health functions. Many of the other participants, including industry representatives, highlighted the need for digital technologies to demonstrate public health impact in order to justify investments.

Overall, the group argued in favour of taking a holistic approach to applying digital technologies that should consider the various factors that could stimulate or stifle their successful adoption in public health, including the need to work across sectors and disciplines, as well as local context. Hence it is crucial to first identify needs and pinpoint areas where public health practice can actually be improved or complemented by the adoption of digital technologies. Clearly, further improvements to Europe's digital infrastructure must also be made as a crucial prerequisite for ensuring interoperability and being able to create common tandards and terminologies.

Moreover, such an approach should comprise a comprehensive data and analytics strategy given the need to work with many different types of data sources, which in turn are linked to different data sharing licenses and are subject to different analytical needs. Just like in healthcare delivery (where many patients and professionals struggle with using digital health tools), it will be equally important on the public health side to build up the necessary digital literacy and analytical skills to create multidisciplinary teams able to solve pressing public health problems effectively and based on shared values. In the long term, this could be achieved by incorporating digital health into school and university curricula.

Most importantly, there was consensus that digitalisation must not be driven forward simply because technological progress makes it possible to dream big: the introduction of relevant solutions in public health must be guided by end users' real needs, and it must contribute to better health outcomes for all segments of the population. This can only be achieved by increasing opportunities for engaging end users in the co-design, implementation and use of digital public health technologies. Especially in the aftermath of the COVID-19 crisis, Europe cannot afford to leave certain groups behind as many of the existing health inequalities are already far too pronounced and dangerous as they could easily backfire and become threats to public health in their own right.

The ECDC consultation represents a welcome step towards increased multi--stakeholder dialogue about these themes. It is not so much a question anymore of whether different interest groups are 'for' or 'against' digitalisation given that the march of technology is probably inexorable. However, we can and must pull the brakes should it turn out that EU investments do not serve the overall purpose of improving public health functions and population health. Hence, it will be particularly important to ensure that trust in digital public health will rise to a sufficiently high degree to draw quality inferences from the available data.



EUROPEAN PUBLIC HEALTH ALLIANCE (EPHA)
Rue de Trèves 49-51 • 1040 Brussels (BELGIUM) • +32 (0) 2 230 30 56 • https://epha.org/ • epha@epha.org