

Position Statement

# Digitalisation and COVID-19: The Perfect Storm

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## What Is It about?

Digital technologies and the digital environment offer new opportunities for identifying needs and delivering healthcare from prevention and health promotion to curative interventions and self-management. This paper sets out the framework for the opportunities both to respond to health emergencies and to deliver the sort of care that can bring personalised healthcare benefits every day. These opportunities, so near yet so far, will remain out of reach until there is real data harmonisation and interoperability, optimisation of data collection, sharing and analytics, and wide acceptance and adoption of innovative digital tools in a COVID-19 and post-COVID-19 world.

## Keywords

Artificial intelligence · Big data · Diagnostics · Digital Health · European Commission · European Health Data Space · Genomics · Innovation · Machine learning · Million European Genome Alliance · Personalised healthcare · Regulatory framework · Technology

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## Abstract

“A ship in the harbour is safe, but that is not what ships are built for,” observed that sage 19th century philosopher William Shedd. In other words, technology of high potential is of little value if the potential is not exploited. As the shape of 2020 is increasingly defined by the coronavirus pandemic, digitalisation is like a ship loaded with technology that has a huge capacity for transforming mankind’s combat against infectious disease. But it is still moored safely in harbour. Instead of sailing bravely into battle, it remains at the dockside, cowering from the storm beyond the breakwaters. Engineers and fitters constantly fine-tune it, and its officers and deckhands perfect their operating procedures, but that promise is unfulfilled, restrained by the hesitancy and indecision of officialdom. Out there, the seas of the pandemic are turbulent and uncharted, and it is impossible to know in advance everything of the other dangers that may lurk beyond those cloudy horizons. However, the more noble course is for orders to be given to complete the preparations, to cast off and set sail, and to join other vessels crewed by valiant healthcare workers and tireless researchers, already deeply engaged in a rescue mission for the whole of the human race. It is the destiny of digitalisation to navigate those oceans alongside other members of that task force, and the hour of destiny has arrived. This article focuses on the potential enablers and recommendation to maximise learnings during the era of COVID-19.

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## Flashes of Lightning Are Not Enough: Data Must Be Enlightening

Against the darkness of the COVID-19 storm, a flickering light gives glimpses of the power of data and digital tools to protect and improve health and wellbeing, and inspires hope of what is to come. Telemedicine has taken on a new significance in care, and recognition has been forced on governments and international agencies of the central role of data in tracking and tracing outbreaks of infection – generating unprecedented activity in the search for and development of suitable technology. But the light is intermittent rather than constant, and the recurrent blackouts expose how much still needs to be done to achieve systematic and reliable healthcare digitalisation. Opportunities are being missed, both to respond to health emergencies, and to deliver the sort of care that can bring personalised healthcare benefits every day. Those opportunities, so near yet so far, will remain out of reach until there is real data harmonisation and interoperability, optimisation of data collection, sharing and analytics, and wide acceptance and adoption of innovative digital tools.

### *Show Me Your Data – and Quickly, Too!*

Data is the essential fuel for digitalisation, and a strong data ecosystem is the infrastructure required to deliver that fuel in a successful response to COVID-19. But at the level of this most basic need, progress is hampered by severe limitations in the ability of many jurisdictions to collect, harmonise, and share high-quality data. These limitations have been more cruelly exposed than ever by the pandemic. The negative consequences for the effectiveness and efficiency of health systems has become all too apparent, as – for instance – in the fragmentation of the US healthcare system’s data pipelines and data reporting, the disconnect between clinical and public health systems, between states, and in the decentralised and haphazard data collection with inconsistent definitions and ontologies. Some countries have proved more effective in building robust data pipelines and interoperability between clinical and public health as well as with partner organisations in immigration, education, and business sectors, notably in Taiwan [1].

The authorities responsible for health systems are being driven to a new recognition of just how critical the availability and sharing of comprehensive health data is to addressing major public health challenges. Acceptance of the principle of FAIRification – of ensuring data meets clear and agreed standards – would expand the concept of quality across the entire cross-border data workflow. The pandemic has shattered widespread assumptions that the type and scope of health information exchange is only a marginal consideration in healthcare, and is highlighting the importance of health information technology and data interoperability. The experience has demonstrated the importance of factors that were known but barely accepted: data have value only if they are used – collection itself serves no purpose without access and use, and aggregations of small collections of data do not necessarily represent value. This is why healthcare institutions and private companies need to adhere to common data standards and give greater importance to the value of federation. It has revealed the risks, inefficiencies, and loss of information by having siloed systems between clinical and public health bodies.

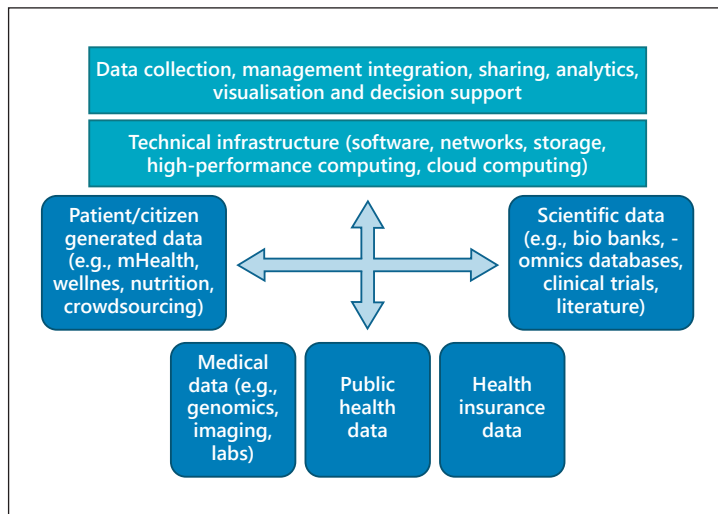
Influential voices from around the world – in academia, governments, and international organisations – are chorusing the need for change. Patients' medical data is not enough to efficiently manage a pandemic like this: collection should also encompass data from a local epidemiologic context [2–4] and individuals' online and offline activity, and the health information exchange should take place “at least nationally, if not internationally,” according to a research fellow at Brookings Institution [5].

The merits of sharing information globally have been repeatedly underlined. “It is a virus that has shown that information sharing, transparency and collective action are necessary,” says an expert in international affairs at the University of Waterloo [6]. Even historians point to “the big advantage” over viruses that humans can deploy by international data sharing: a coronavirus strain in China and another strain in the USA cannot swap tips about how to infect humans, “but China can teach the US many valuable lessons about coronavirus and how to deal with it.” However, there are preconditions, too: “For this to happen, we need a spirit of global co-operation and trust” [7].

Researchers at Oxford also identify gaps that must be filled on knowledge about COVID-19's transmissibility, the risk of geographic spread, routes of transmission, and risk factors for infection, as well as to provide the baseline for epidemiological modelling. “The epidemic is unfolding rapidly and reports are outdated quickly, so it will be necessary to build computational infrastructure that can handle the large expected increase in case reports,” they say: “Data sharing will be vital to evaluate and maintain accurate reporting of cases during this outbreak” [8].

More data, wider, deeper, harmonised and faster data are seen as prerequisites for success: “Rapid data sharing is the basis for public health action,” states a WHO article, highlighting the dependency of decision-makers on information from peer-reviewed journals and online datasets. “The release of full viral genome sequences through a public access platform and the polymerase chain reaction assay protocols that were developed as a result made it possible to accurately diagnose infections early in the current emergency,” it recalls [9]. “It is necessary for all countries including China, to promptly share epidemiological information on this new disease,” adds the Korean Task Force [10] (Fig. 1).

The pandemic has shown the need for creating a cross-border domain for co-operation that must support stakeholders and, in particular, policy makers with responsibilities in the areas of public health and provision of healthcare services with real-time evidence to help them to recognise when to shift the strategies that they are using. Only cross-border, multi-sector, and multi-disciplinary research collaboration based on existing networks and partnerships will create an efficient process of data integration. What is needed is greater political will to align and share data. Greater awareness of the mutual benefit would be a powerful



**Fig. 1.** A data ecosystem.

incentive to share, and to build collection pipelines with interoperability in mind. In this respect, COVID-19 is a rare prompt for new collaboration across industry, academia, and government for the public good – which could permit real insights to be gained from digital data.

### Navigating by More than the Stars

#### *Learning from Experience*

It is now time to learn, and to optimise systems to facilitate the provision of effective patient care, overcoming the traditional difficulties in the translation of biomedical research into clinical practice. A new and effective path is needed to address the organisational, operational, and legal barriers, responding to the urgency that a second wave of COVID-19 or new pandemic will impose.

The greatest successes have been secured in combating COVID-19 by jurisdictions that have leveraged previous efforts in building the principal components of a health data ecosystem, as Taiwan, Germany, and South Korea – and even nations with lower GDP and social infrastructure, such as Uruguay and Vietnam – have demonstrated [11–13].

Taiwan rapidly mobilised and instituted specific approaches for case identification, containment, and resource allocation. It integrated its national health insurance, immigration, and customs databases to exploit big data for analytics. Using data on travel history and clinical symptoms, it generated real-time alerts during clinical visits to aid case identification. It also combined QR code scanning and online reporting of travel history and health symptoms to classify travellers’ infectious risks based on their recent travel history [1]. The process was facilitated by the country’s single-payer health program which contains digital medical records for every citizen [14], with the socio-cultural context another possible factor. To precisely track coronavirus exposure, South Korea used additional digital records – medical and pharmacy visits, history of credit card transactions, and CCTV videos – in determining where potentially exposed people had been and followed up infected people and also their acquaintances [15].

Germany’s implementation of digital solutions for patients and doctors now bring benefits in support from apps and telemedicine services for medical professionals and caregivers and provide patients with information about COVID-19, according to Prof. Jörg Debatin,

head of the Health Innovation Hub think tank, set up by the Federal Ministry of Health. The hub has released a list of trusted telemedicine services (including costs, reimbursement policies, functionality, and pricing) that can be easily integrated into medical practice without technical expertise or hardware investments. Thousands of doctors have started to take advantage of these, says Debatin. Secure digital platforms that enable doctor-patient interactions are also particularly helpful at this time when citizens are concerned about their health and cut off from health services [16].

## Charting New Waters

### *Mind the Gap!*

COVID-19 has exposed the negative impacts of the disconnect between clinical and public health and weak data ecosystems on health system efficiency and public health responsiveness. The delivery of accurate and comprehensive data with the necessary rapidity is a widespread challenge – often because of inadequate processes, aggravated by differing models, methodologies, and technologies across countries and regions that impede compilation, aggregation, and comparison. A lack of centralisation characterised by bespoke systems precludes common expectations or requirements, a lack of adequate agreed data models militates against data quality, granularity, and completeness, and insufficient investment in technology and electronic pipelines impedes reporting and collection. The problems are political, methodological, scientific, technical, and economic. Even the WHO and ECDC are not immune.

Researchers at Duke University point to the lack of a cohesive data model for patients in most electronic health records, which prevents clinicians from tracing back to a patient's signs, symptoms, and diagnostic tests, and there has been resistance in some quarters to interoperability across proprietary systems. Existing capabilities are inadequate for scaling up the tracking of patients in an electronic health record system from the current dozens to hundreds or thousands, they say [17].

Delays in getting results for the thousands of coronavirus tests commissioned daily could hinder efforts to track the number of coronavirus tests performed nationwide and the spread of the disease, warned HHS Secretary Alex Azar, in the face of criticisms of the medical system's antiquated tracking systems, which is expected to reduce some healthcare providers to faxes or phone calls to report data. Brian Dixon of the Regenstrief Institute health research organisation complains that "there is no infrastructure in the USA for tracking the number of tests ordered for just about anything," and even if communications are sorted out between labs and doctors, gaps will remain with public health agencies [18], which have completely different pipelines, governance and reporting rules.

The Swiss government has struggled to maintain an accurate record of novel COVID-19 infections, partly as a result of an outdated methodology and suboptimal data infrastructure, but also because of the decentralised approach. The absence of electronic patient records obliges cantons to flag new cases on forms faxed to the central government, and federal authorities wait for confirmation by the reference lab in Geneva before manually aggregating data [19].

Our World in Data, an online publication based at the University of Oxford, has stopped relying on WHO data for its models, citing errors and inconsistencies, and the lack of good data is frustrating for economists, statisticians, scientists, and public policy professionals. Prof. John Ioannidis of Stanford University fears the pandemic could end up being "a once-in-a-century evidence fiasco" [20].

### *Racing to Remedy the Failings*

Many jurisdictions are bringing in changes in a desperate bid to fill the gaps that have been exposed in healthcare digitalisation – changes that are reimagining relationships with and approaches to managing health data. Governments are investing in enhanced integration of healthcare data and speeding up access, so as to improve clinical and public health decision making and healthcare system efficiency.

In the UK, NHS Digital has been empowered to deliver new services and to use data more efficiently, through collecting and analysing data to help doctors, nurses and other health professionals to understand the illness better, to identify patients or those at risk, to understand NHS responses to the threat, and to provide advice and information for NHS and social care staff [21]. The NHS is also working with Cerner on an electronic health records platform for the temporary Nightingale hospital in London, and on expanding EHR functionality in other UK hospitals to grant clinicians access to real-time information about COVID-19 patients [22]. Integration between public health and clinical practice will also have to be implemented for the full effect.

The Ontario government is developing a secure health data platform that will provide researchers with access to de-identified, integrated data on publicly funded administrative health services records, including physician and medical drug claims, hospital visit and discharge summaries, and claims for home care and long-term care. It will also contain clinical data from special registry collections, extracted from public health, hospital, laboratory, and diagnostic imaging information systems [23]. Moves towards harmonisation in the hospital systems in the neighbouring province of Quebec also have the potential to increase health digitalisation beyond COVID-19 [24].

The US CDC is receiving USD 500 million for modernising its analytics infrastructure for public health data surveillance, and for a new system to gather data on how the virus is spreading [25]. Ireland's Health Service Executive has commissioned a system providing remote monitoring of otherwise healthy patients with mild to moderate symptoms who are in self-isolation [26]. Singapore launched a contact-tracing app [27]. The question remains open, however, as to how far it might prove possible to federate the data from these initiatives.

### *Widening Access to Digital Data*

The challenges are not merely technical. There has also been resistance to change among established systems. But the pressing needs of the moment are starting to erode some of those constraints and to promote a pragmatic flexibility – in terms of accepting new methodologies and even modifying payment systems to permit their deployment.

Jurisdictions are authorising new access to digital health tools such as remote patient monitoring and virtual clinician-patient engagement. In the USA, Medicare telehealth coverage has been widened to reduce patients' need to travel to a healthcare facility, with new payment systems for clinicians for telehealth services [28]. The FDA has also enabled greater use of remote patient monitoring technologies to cut back on hospital visits, and is easing the rules on clinical decision support software in order to promote the development of products that can provide advice on diagnosis and treatment [29, 30]. Also, the Department of Health and Human Services has broadened the acceptable technologies for telehealth to include Apple FaceTime, Facebook Messenger video chat, Google Hangouts video, and Skype [31].

In Canada, British Columbia has lifted a requirement that personal data must be stored in the country, so as to allow the use of digital communication tools such as WhatsApp or Slack [32]. Alberta is now compensating doctors for providing virtual care during the pandemic [33]. France too has authorised unconditional teleconsultation procedures for people potentially infected [34].

## From Astrolabes to GPS

### *Digital Innovation to the Rescue*

The digital tools developed by innovators in response to the pandemic – in some cases in partnership with governments – have reinforced the importance and possibility of digital health innovation more broadly. New approaches are helping ease the strain on overstretched healthcare facilities, or enabling patients to conduct an initial self-diagnosis, or generating macro data on the spread of disease by aggregating individual patient or physician data.

Innovation is leading to rapidly evolving possibilities for dealing with COVID-19 patients. Automated digital tools for triaging patients and healthcare decision making such as Blue Shield of California's COVID-19 Screener and Emergency Response Assistant help hospitals ease the flow of patients seeking advice through initial triage before directing patients to the appropriate sites of care [35].

The potential application of AI to the management of COVID-19 faces several barriers. AI needs large amounts of correctly structured information to be trained and, while information is becoming ever easier to obtain, the infrastructure to mine, integrate, and share the data in compliance with all relevant ethical, legal, and regulatory requirements remains lacking. Epidemiological data are geographically dispersed and siloed in different medical institutions, hindering the building of representative reference population datasets, and the development of unbiased AI-powered tools.

The speed of health system evolution in these new circumstances can also present challenges for many established practices. Because outpatient services may find it difficult to keep up with novel demands, automated logic flows (bots) are being developed that can refer moderate-to-high-risk patients to nurse triage lines and schedule video visits with established or on-demand providers [36]. Hospitals in Baltimore are using a digital telehealth tool that monitors healthcare workers for 14 days after potential exposure to COVID-19, and triages cases [37]. In Chicago, COVID-19 clinical pathways are embedded into electronic health records to maximise efficient workflows [38]. Content from the CDC and the Mayo Clinic is incorporated in devices for front-line health responders to improve screening and support for patients [39].

An AI chatbot helps patients self-assess for the risk of COVID-19 and gives guidance to nearby lab centres, as well as feeding the data into different healthcare ecosystems [40]. In Korea, an automated risk assessment application checks symptoms and epidemiological factors for both health workers and patients [41].

London hospitals are using an app to help track the spread of COVID-19 and identify individuals most at risk [42], and an AI-powered COVID-19 self-evaluation technology combines information inputted by users with professional medical guidance to help determine a potential infection [43]. Real-time COVID-19 dashboards inform healthcare decisions over patient prioritisation and testing availability and production, including data on the number of tests ordered by clinicians and the number of people with risk factors [44].

### *Using Your Intelligence*

The wealth of new data that is being generated presents a problem in itself, since its sheer scale exceeds the capacity of established systems for analysing and exploiting it. Here, the rapidly emerging techniques of AI and machine learning are coming into their own. AI has transformed the scope of many of these data-collection innovations, and is using it for powering tools that convert raw data into valuable inputs to urgently needed developments in outbreak mapping, real-time surveillance, and drug discovery.

A Canadian firm specialised in automated infectious disease surveillance uses machine learning and natural language processing techniques to sift through news reports in 65

languages, and through forum and blog posts, airline ticketing data, and animal disease networks to pick up indications and news of unusual, unfolding events and possible disease outbreaks. The firm employs trained epidemiologists to further analyse outbreak results obtained by automated means before releasing them to its clients [45, 46].

Alphabet's Google, Facebook, and Apple have separately announced launches of COVID-19 mapping tools, which have been built on location tracking data from users' devices. Google's Community Mobility Reports web tool demonstrated that in New York time spent at workplaces was down 46%, and its coverage is being expanded to hundreds of countries and regions. Facebook has launched a "co-location map" evaluating the probability that different Facebook users will come into contact with each other in person, a "Movement Range Map" revealing if people are staying near their homes on a county-by-county level, and a "Social Connectedness Map," using "friends" across geographic lines to understanding where the disease could spread [47, 48]. Alphabet's Google Cloud is collaborating with a Tennessee-based health system on a COVID-19 National Response Portal that promotes safe sharing across the USA of de-identified, aggregated patient-level data (such as ICU bed and equipment supply, diagnostic results, discharge numbers) from hospitals into a single platform to show a complete and real-time view of the pandemic [49]. Other AI applications report on the effectiveness against COVID-19 of a drug approved for rheumatoid arthritis, or assist in the design of new molecules that could halt viral replication [46].

#### *Recruiting Leading-Edge Technology to the Combat*

The battle against COVID-19 has provided new impetus for genome-sequencing tools that are increasingly finding their place in the front line. One free-of-charge web-based bioinformatics pipeline, the Genome Detective Coronavirus Typing Tool, can identify and classify coronavirus genomes at 2,000 sequences per submission, with analysis of a new whole-genome sequence taking just a minute. It also identifies changes to nucleotides, coding regions, and proteins using a novel dynamic aligner to allow tracking of new viral mutations, as an aid to developing diagnostics, drugs, and vaccines [50].

With the advent of rapid bedside-to-bench investigation, new tools such as next-generation sequencing, and open access information, information on the clinical features of COVID-19-infected patients, and the host immune responses are accumulating [51]. Also, a consumer genomics partner of GSK has launched a longitudinal study to investigate genetic influencers of severity in COVID-19 among hundreds of thousands of infected and non-infected individuals [52].

#### *Digital Tools Providing Virtual Care*

The virulence and transmissibility of the virus have conferred new value on safer and easier contact between doctors and patients. Technologies to allow this are becoming the new normal in the face of the pandemic, reducing the number of visits to general practitioners and hospitals and reducing risk, with many using an initial risk assessment questionnaire, and increasingly linked to anonymised population health data so as to display trends and variations.

A free web-based platform to connect healthcare professionals with patients via video consultations during the COVID-19 pandemic is able to facilitate appointments within minutes, and allows safe GP consultations for patients who are self-isolating or with chronic illnesses. Clinicians vulnerable to infection can also offer medical support without risking their own health [53]. Philips has also launched a telehealth solution for remote screening and monitoring of COVID-19 patients [54]. Furthermore, healthcare organisations are promoting personal health and wellness, particularly during increasing levels of stress and anxiety, through providing access to digital mental health apps [55].



### *Time to Check the Spread*

Smart watches and other wearables are being used to collect data and for remote monitoring solutions. Wearables are gaining a new relevance both to assist researchers to understand the pandemic, and also to help people understand their health and react to signals. There are tens of millions of smartwatches being worn that could help in health protection against infectious diseases, in data provision, and in contact tracing. But the key is developing effective apps that can link wearables to data collection under an appropriate ethical governance – and in due course, perhaps for uses such as identifying individuals who have developed immunity.

A Scripps Research Translational Institute program would allow users with a Fitbit, Apple Watch, and other wearable devices to share data to be able to quickly detect the emergence of fast-spreading viral illnesses. Since studies suggest that sleep and resting heart rate data correlated with the reports of influenza-like illness, the program can allow sharing data on heart rates, sleep, and activity levels to help detect viral illness outbreaks [56]. A Boston-based start-up is using its wearable and artificial intelligence technology to remotely monitor coronavirus-infected and suspected patients and to apply personalised predictive analytics to provide more effective interventions. In Hong Kong, volunteers quarantined in their homes or hospitals will wear a device with built-in sensors on their upper arm 24 hours a day, transmitting data on body temperatures, respiratory rates, blood oxygen levels, and heart rates to a digital platform. Real-time monitoring and analysis signals are fed through AI and machine learning techniques to flag key physiological changes that could indicate disease progression, and a linked smartphone app asks patients about symptoms [57]. Germany's Robert Koch Institute and a start-up partner have launched a smartwatch app to monitor the spread of COVID-19 by reporting pulse, temperature, and sleep patterns. Results will be published in an online map detailing down to postcode level [58].

### **Forging New Teams to Crew the Voyage**

#### *Researchers Investigate Innovative Partnerships Too*

This coronavirus outbreak has been unprecedented; so too is the way that the scientific community has responded to it. Researchers have openly and rapidly shared genomic and clinical data, allowing research results to be released almost instantaneously and helping understanding of the transmission dynamics and the development of rapid diagnostics, and informing the public health response [50].

The research community has responded to the COVID-19 crisis by accelerating collaborative efforts and data sharing, affirming integration and connectivity as key success factors in responding to health challenges and driving innovation.

Novel partnership models among researchers and innovative organisations from across sectors are demonstrating unprecedented transparency and sharing of data and resources. As pharmaceutical companies collaborate to speed the creation of therapies and vaccines to treat COVID-19, R&D heads from leading companies meet almost daily to produce an industry-wide response unparalleled since World War II. Regulatory and manufacturing heads have also been meeting frequently to minimise duplication of effort, streamline work, and advance efficient testing of compounds and vaccines. “This is not a time to think about proprietary information or IP or margins. We need to break down the barriers and solve the problem,” said one participant involved in the consortium [59].

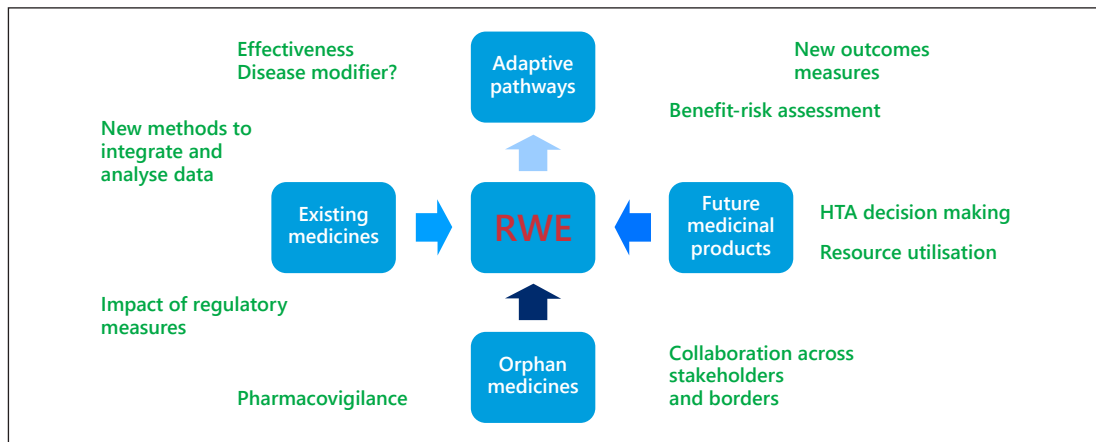
As examples, the Innovative Medicines Initiative project EHDEN (European Health Data Evidence Network) has sponsored a “study-a-thon” to encourage its massive research network to be used for COVID-19-related research queries, which are starting to generate fast

big data results. The recently formed Multiple Sclerosis Data Alliance has developed a COVID-19 research core dataset and started to collect this data from many collaborating multiple sclerosis registries and is diverting some of its funds to support the analysis of this data.

Pfizer, Johnson & Johnson, Merck, Sanofi, and Novartis have joined forces with another dozen pharmaceutical companies to share proprietary compound libraries in an effort to accelerate the development of therapeutics for COVID-19. The Bill and Melinda Gates Foundation, working through the COVID-19 Therapeutics Accelerator it set up with the Wellcome Trust and Mastercard, is screening the libraries for potential candidates [60]. Microsoft, Amazon, Epic, and Mayo Clinic are among the founders of the COVID-19 Healthcare Coalition, which provides real-time learning to preserve healthcare delivery and protect US populations. Partners share assets, resources, and plans to support front-line responders to COVID-19 and a resource library will inform decisions on people at risk, healthy populations, social distancing efforts, and the healthcare delivery system [61]. The White House Office of Science and Technology Policy is developing the COVID-19 High Performance Computing Consortium with partners including IBM, Alphabet's Google Cloud, Amazon Web Services, Microsoft, and many universities, to give researchers access to supercomputers to help speed the discovery of vaccines and drugs [62].

Under WHO's co-ordination, 100 scientists, physicians, funders, and manufacturers are working on the development of vaccines against COVID-19 [63]. The National Research Council of Canada's COVID-19 Pandemic Response Challenge Program has engaged government, academic, and private sector partners to address specific COVID-19 gaps and challenges in detection and diagnosis, therapeutics and vaccine development, and digital health [64]. Italian ministries and agencies have launched the "Innova per l'Italia" call to business and research to identify digital solutions and technologies for telemedicine, home care applications, and active monitoring of the risk of contagion [65].

Mapping population-wide adaptive immune responses to diseases at scale is being stepped up by Microsoft and Adaptive Biotechnologies, who are making the data available to researchers, public health officials, or organisations around the world via an open data access portal [66]. The COVID-19 Genomic UK Consortium, bringing together the NHS, the Wellcome Sanger Institute, and public health agencies and academic institutions, has obtained GBP 20 million for sequencing-based studies of COVID-19 transmission, and will deliver large-scale rapid sequencing of the cause of the disease with hospitals, NHS centers, and the UK government [67]. The Global Initiative on Sharing All Influenza Data is assisting rapid sharing of information about the COVID-19 virus with scientists from other regions around the world – leading to scientists from the Virus Identification Laboratory based at Doherty Institute, Australia, to grow a similar virus after accessing the data shared by Chinese scientists [68]. A non-profit collaboration among a score of major biopharmaceutical companies will share control arm data from ongoing and planned COVID-19 clinical studies and data from past studies in related diseases or patient populations [69]. GSK, AstraZeneca, and the University of Cambridge are collaborating in support of the UK's effort to boost COVID-19 testing, with a new laboratory for high-throughput testing and development of test alternatives to overcome supply shortages, and with automation and robotics expertise for scaling up the production of testing kits [70]. Furthermore, a draft European Parliament report on medicine shortages in the face of the pandemic, to be debated in mid-2020, stresses "the key contribution that can be made by new technologies and artificial intelligence in enabling European laboratory researchers to form networks and share their objectives and findings" [71].



**Fig. 2.** RWE (real-world evidence) throughout medicines decision making.

*Look What I've Found!*

The pandemic has accelerated the shift toward open-access research publication standards, helping to improve timely access to data in the COVID-19 emergency. Given the many unanswered questions on the reservoir, transmission, consequences, and manifestations of COVID-19 infection and associated disease, the goal is to encourage all researchers to share their data as quickly and widely as possible.

The Bulletin of the WHO will implement a “COVID-19 Open” data sharing and reporting protocol, which will assign digital object identifiers to all relevant research manuscripts, and post them online within 24 h, while they undergo peer review, making the data available for unrestricted use, distribution, and reproduction in any medium [9]. Shifts towards rapid peer review and publication online could make valuable contributions on condition that the essential scientific rigour is maintained. This could help to meet the urgent need to refine the risk assessment with real-time guidance for epidemiologists in containing the outbreak, clinicians managing patients, and modellers helping to understand potential future directions and the possible effectiveness of various interventions, say leading academics [72]. A registry of COVID-19 patients in the USA from collated de-identified health records is being compiled, free for government and academic access, to help research into disease spread, vulnerable population groups, and treatment effectiveness. Data from medical insurance claims are also to be added [73].

The US White House is inviting AI experts and research organisations to make use of the COVID-19 Open Research Dataset of 29,000 peer-reviewed research papers on the coronavirus group to elucidate scientific questions about COVID-19 [74, 75]. Hundreds of stakeholders from across government, academia, industry, and the general public are backing a call for action spearheaded by New York University to develop the potential of data collaboration in addressing the pandemic [76] (Fig. 2).

**What's That on the Horizon?**

*A Perspective on Personalised Medicine!*

The COVID-19 lessons and changes could accelerate progress towards the still-distant prospect of personalised medicine. The platforms and ICT solutions that enable privacy-

protective and secure data sharing are pre-conditions, as acknowledged by the International Consortium of Personalised Medicine (IC-PerMed), and as is implicit in the signature by 21 EU member states of the “1+ Million Genomes” Initiative (1+MG), which aims to deliver cross-border access to existing and future genomic databases, making at least 1 million genomes accessible in the EU by 2022 [77].

The dependence of rare diseases on data sharing makes them uniquely positioned to drive the technical implementation of an ethically and legally compliant federated network of data resources enabling cross-border data access. To incorporate some of the mantras heard during the COVID-19 crisis – screening, early detection, testing – into health practices for cancer, dementias, or autism is one of the challenges of the new period.

### All Hands on Deck

#### *Use My Data, but Carefully!*

The public are increasingly aware of the power of individual and population-level data to understand the pandemic, and are demonstrating a willingness to share personal data, while maintaining data privacy standards. Some 320,000 Israelis have responded to a smartphone-based questionnaire designed to identify and predict virus hot zones [78]. Hundreds of thousands of Canadians rapidly contributed to a data pool of symptoms (or lack thereof) that anonymously generates a heatmap [79]. A culture-related readiness to permit use of personal data has been observed in China and across Asia [45]. The pilot of an online tool coupled with physical mobile testing sites has won rapid acceptance among high-risk people in the San Francisco Bay Area [80]. A platform to gather data from people at home and report it to public health organisations has been created by Silicon Valley engineers to foster participatory surveillance and combat the lack of testing [81].

#### *Feeding New Public Hunger for Information*

The power of personal health data and the growing public engagement with personal choices has created new appetites for information about individuals’ data and how they can benefit from its exploitation. For this to work to universal benefit, all stakeholders need the digital literacy and capacity to contribute, use and benefit from health data responsibly, ethically, and sustainably. At the same time, effective information provision to the public – about the pandemic and about the uses their data can be put to – can also benefit frontline health professionals and policy makers, reduce public panic, and help in promptly communicating crucial findings to the international scientific community.

The crisis represents an opportunity to stimulate societal participation through citizens’ involvement and broad stakeholder engagement by engaging society in a co-management strategy where citizens play a proactive role. This effort will also contribute to building a scientifically literate patient community and support their involvement in science and technological development.

The demand for rapid access to information among both expert and general audiences is triggering the use of rapid approaches to knowledge sharing, and the elimination of typical barriers/delays, such as paywalls, and reassessment of peer review processes. In recognition of this demand, and of the importance of reaching the largest possible audience with public health guidance, numerous news agencies – such as *New York Times*, *Washington Post*, and *Globe and Mail* – have removed paywalls that would prevent access to reports on the COVID-19 pandemic.

An analysis in Google Trends demonstrates that the volume of Google searches for “CoV” during the past 5 years has increased by many orders of magnitude since the beginning of the

2019-nCoV outbreak, especially in China [82]. A diverse global community of academic, industry, government, and not-for-profit stakeholders have called for rapid sharing of research data relevant to the COVID-19 outbreak [83], which is driving a surge in (unrefereed) preprints. To help pinpoint the most important research, the Wellcome Trust has supported the launch of an open-source platform for rapid review of preprints related to emerging outbreaks [84]. To allow real-time sharing of scientific information, many international academic journals have speeded up their review and publication of articles on COVID-19, and specific coronavirus websites have been created by publishers such as *NEJM* and *The Lancet*. Many articles have also been translated between Chinese and English [85].

Social media has given real-time public access to data analysis and commentary from experts, including influential exchanges inciting or announcing disclosure and flagging significant omissions or misattributions [86]. Analysis of internet usage in the USA shows shifts in online behaviour, as citizens searching for information on the public health crisis and its economic consequences has increased traffic to local news sites and more established media brands [87]. Coronavirus dashboard applications have experienced increased demand – in the hundreds of millions – demonstrating public eagerness to track health threats [45].

#### *Fighting Fake News*

The importance of accuracy and the danger of misinformation are driving new standards and policies in health information provision. Although the improvement of internet communication largely enhances the availability and dissemination of knowledge, the internet also has the potential for the development and spread of misinformation or fake news, and there is growing pressure on governments and technology companies to take responsibility for providing accurate knowledge and clarifying misinformation to help the public in this unprecedented situation [88].

Leading social media and tech organisations say they are “working closely together on COVID-19 response efforts [...] helping millions of people stay connected while also jointly combating fraud and misinformation about the virus, elevating authoritative content on our platforms, and sharing critical updates in co-ordination with government healthcare agencies” [89]. The Canadian government is contemplating introducing legislation to make it an offence to knowingly spread misinformation that could harm people, including misinformation online about the COVID-19 pandemic [90].

#### **Action Stations!**

- It is now more urgent than ever that health systems across Europe invest substantially in improving the quality of the data captured in routine healthcare.
- Minimum quality standards must be set and adopted for the capability of EHR systems to capture and represent high-quality detailed health information and genomic information in a well-structured and coded form, adhering to interoperability standards.
- eHealth services must now scale up the use of telemedicine and telemonitoring, as these are known to deliver good health outcomes and to be cost effective, supported by trustworthy AI to monitor high-volume data streams for potential health issues needing health professional intervention.
- Individuals must be encouraged to utilise quality labelled and interoperable apps and devices to provide their own health and activity data to health systems and public health agencies.
- Plans, policies, and legislation must now be put in place in all countries to rapidly enable future citizen data to be collected securely to track and trace infections and infectious

contacts, and for this data to be reused anonymously for monitoring and rapid response planning.

- The infrastructure to exchange detailed clinical information security (not just patient summaries and lab data) must now be scaled up within and between countries.
- Research infrastructures must be funded and supported to comply with the GDPR but still enable big data analysis to be conducted rapidly and accurately.
- Countries must put in place organisational structures and policy instruments to continuously undertake effective and prompt international sharing of accurate and complete public health intelligence, co-operating openly on challenges as well as progress.
- Countries and public health agencies must gear themselves to be the primary trustworthy provider of information to the public about the status, predictions, and measures being taken in response to a future pandemic, as a source of facts that is clearly separated from political decision making; this includes rapidly responding to counter fake news.
- Policy instruments are needed to facilitate greater and just-in-time public, private, and inter-company collaboration, including in areas such as data sharing, risk sharing, liability, IP, and costs, in response to future public health emergencies.
- The European Commission, whilst understandably prioritising Europe and its citizens, must play a proactive global role in these actions in recognition that European citizens are impacted by global health issues.

## Land ho!

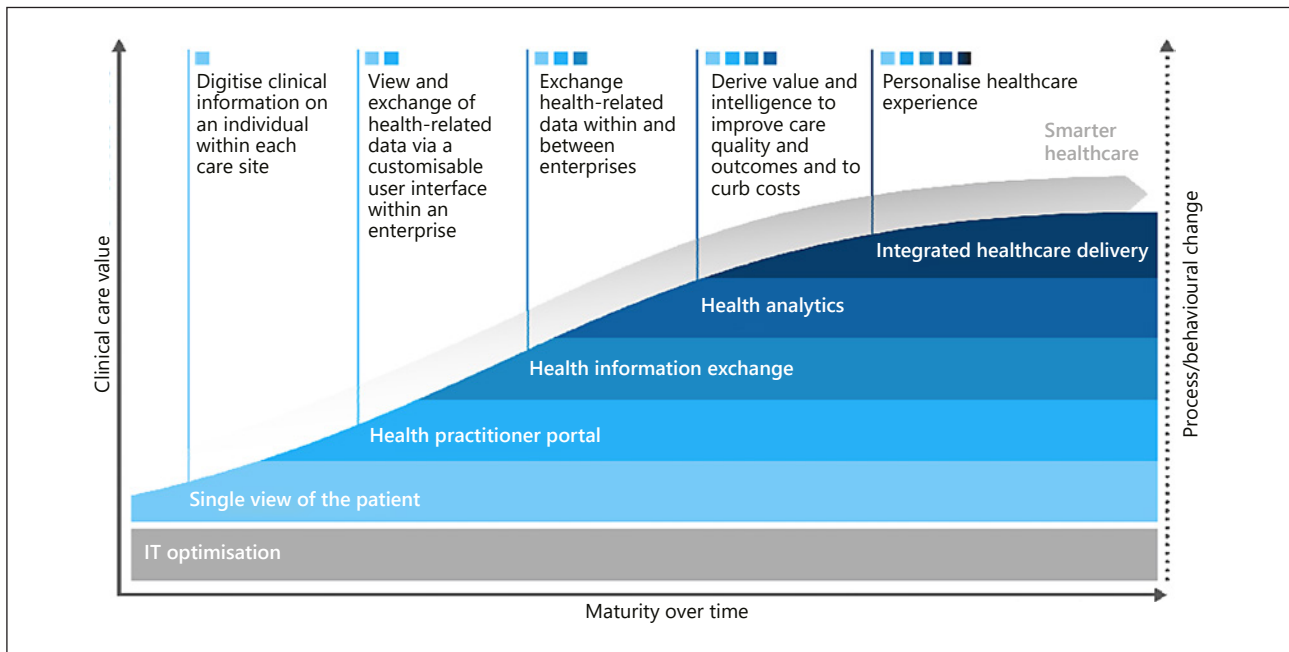
### *Health Data Is Becoming More Widely Accepted*

Data and digital literacy are emerging as an asset among political leaders and the general public, increasingly accepted as assisting sound decision making and knowledge transfer and connectivity during times of physical distancing. However, the merits are dependent in large measure on the skills of the population – which are not evenly distributed across social groups or the demographic.

In Taiwan, the medical expertise of many political leaders influenced the rapid action to counter COVID-19, including the immediate development and deployment of a centralised mobile application to disseminate information to citizens, informing them of transmissions, areas to avoid, and best health practices. The app was able to effectively track the virus, creating a constant and reliable stream of information from the relevant authorities directly to the public. As cases appeared, Taiwan had a system for effectively and consistently alerting citizens [91]. The focus that the pandemic has put on the benefits of remote care has also highlighted the disparate skill levels within populations, leaving some – and particularly the elderly – less able to seek or access remote care [92]. It has also exposed the lack of access to high-speed internet, and the related problem of a growing digital divide [93–95] (Fig. 3).

### *The Future Must Be Digital*

COVID-19 has highlighted the unarguable reality that population health and economic health are intertwined and underlined the need for new ways to measure and share related data. The world is confronted with a compelling demonstration of the need to accelerate digitalisation of healthcare systems around the world. This is ultimately a political issue, and although some jurisdictions have made progress, new policies to enable data collection, sharing, and analytics, and support the acceptance and adoption of innovative digital technologies must be enacted at a faster pace to protect patients, ensure health system sustainability, and achieve better health outcomes.



**Fig. 3.** Realising sustainable healthcare means orientating people, processes, and technologies around the patient for better outcomes.

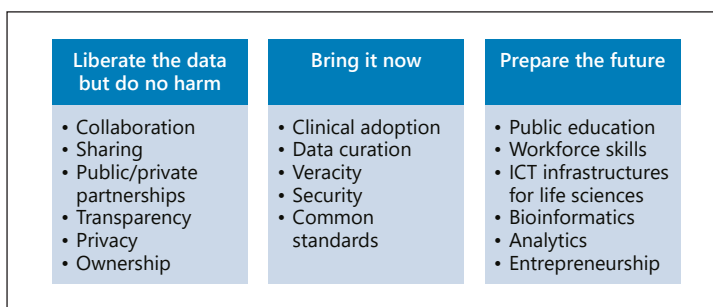
*And It Will Be*

The pandemic has crystallised a vision for – and focus on – the digital data and digital data exchange tools that will improve healthcare systems. The need for rapid data exchange and effective interoperability as vital public health issues has been repeatedly emphasised by senior academics and researchers [17]. It is seen by some as a test-case for the future [17], and it has given new currency to calls for the development of AI [46].

Advancing data and analytics capabilities is seen as crucial to meeting the challenges of current and future health threats. Disease surveillance and response activities are hampered by 20th century technology, with critical health data still managed on paper records, non-searchable EHRs, or in spreadsheets that require extensive manual data entry and analysis. [96].

Progress in digitalisation of healthcare that has improved the capacity to respond to COVID-19 will be a platform to transform healthcare delivery and specialty care, as numerous senior health experts testify. The pandemic will shift the paradigm of where healthcare delivery takes place, rescuing telemedicine from the sidelines and repositioning it as a cost-controlling, high-convenience system as traditional care settings are overwhelmed by the pandemic. The containment-related benefits are also given new value: staying home for a video call keeps you out of the transit system, out of the waiting room, and away from patients who need critical care [97]. The successful application of digital technology to tackle the pandemic will increase public and governmental acceptance of such technologies for other areas of healthcare, including chronic disease [98]. Artificial barriers to moving many aspects of care online will be weakened or eliminated, in everything from allowing billing for telemedicine to permitting the use of a wider range of communication tools – including social media and email [97].

**Fig. 4.** Concerted action is required across three foundational sets of policy actions.



The role of video consultations will be indispensable afterwards, and all healthcare will need to be reassessed in light of COVID-19 [99]. Telemedicine will be seen as just another component of the care model, in a new post-COVID normal [100].

Digitalisation of health is not just one shipload of advanced technology. It is a flotilla of many vessels, armed with many specialisations, techniques, and procedures that can play a part in the battle against coronavirus. As this account suggests, some of them have already entered the fray, and others are on the point of doing so. Some are still held back, by delays in provisioning or the delivery of vital equipment – or, less forgivably, by undue caution and even resistance among still-influential stakeholders who do not perceive the merits of digitalisation. But as the long campaign against coronavirus evolves, the benefits of digitalised healthcare will become steadily clearer, and the eventual victory over COVID-19 will also mark a new phase in healthcare systems, in which digitalisation will have securely established its place (Fig. 4).

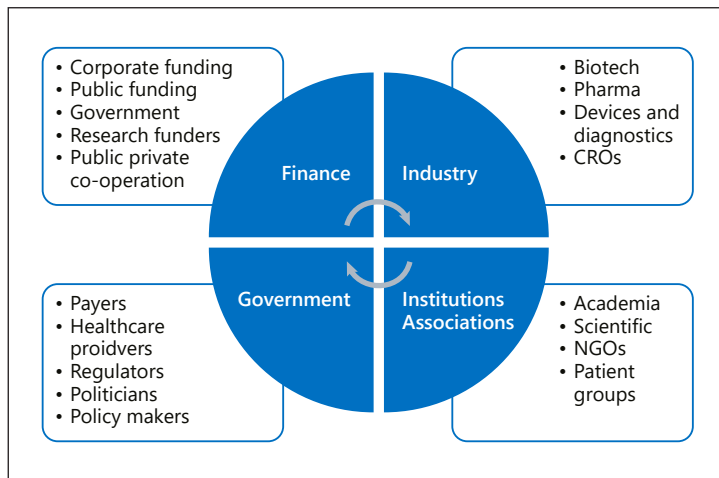
### Conclusion: Digitalisation and Public Health

Digital technologies and the digital environment offer new opportunities for identifying needs and delivering healthcare from prevention and health promotion to curative interventions and self-management [101]. As such, they have the potential to transform healthcare services in ways that may contribute to health system goals of quality, accessibility, efficiency, and equity of healthcare. In this sense, digitalisation should be considered as a means, a set of tools, not an aim for public health [102]. A key challenge is to ensure that all people enjoy the benefits of digital technologies for everyone. We must make sure as public health professionals that innovation and technology help to reduce the inequities in our world, instead of becoming another reason people are left behind.

When it comes to the COVID-9 pandemic, we have learnt that mobile apps have the potential to bolster contact tracing strategies to contain and reverse the spread of COVID-19. In a number of countries worldwide, the use of apps has supported health authorities in monitoring and mitigating the ongoing COVID-19 pandemic, facilitated the organisation of medical follow-up of patients, and provided direct guidance to citizens on playing their part in the control of the disease [103]. The added value of these apps is that they can record contacts that a person may not notice or remember.

The aim of contact tracing and warning is for public health authorities to rapidly identify as many contacts as possible with a confirmed case of COVID-19, ask them to self-quarantine if possible, and rapidly test and isolate them if they develop symptoms. Contact tracing is normally carried out manually by public health authorities. This is a time-consuming process where cases are interviewed in order to determine who they remember being in contact with from 48 h before symptom onset and up to the point of self-isolation and diagnosis.





**Fig. 5.** Key participants in the healthcare open innovation ecosystem.

Digital tools such as mobile apps with tracing functionalities can be of substantial support in this process, identifying both known and unknown contacts of a confirmed case and possibly help in their follow up, in particular in settings with large numbers of cases where public health authorities can become overwhelmed.

Several member states in the EU and EEA have launched or intend to launch initiatives that involve contact tracing apps in the fight against COVID-19. The use of these technologies has raised policy questions about privacy and data management, determining different approaches in different countries, especially between Asia and Europe. The adoption of the digital tools (encouraged or mandatory), a digital infrastructure enabled and activated by the national government, and the possibility to share data represent the main conditions and the most dilemmas related to the improvement of digital contact tracing strategies. In this sense, EU member states should urgently converge towards effective app solutions that minimise the processing of personal data, and recognise that interoperability between these apps can support public health authorities, especially after the reopening of the EU’s internal borders (Fig. 5).

Outside of Europe, China, South Korea, Taiwan, and Singapore have developed several technologies to collect data in order to contain the dissemination of the virus. China adopted a government-mandated QR code that shows the level of risk of the citizen in order to recognise positive cases. Singapore encouraged people to install an app called “TraceTogether,” which uses Bluetooth signals between nearby devices. Similarly, Hong Kong requires all new arrivals to download the “StayhomeSafe” app, while in South Korea the “Corona 100 m” app registers all personal data and movements by GPS that can be used by the government. Taiwan used a similar approach, where the contact tracing system allows the government to contact citizens to ensure they do not evade tracking by leaving their devices at home.

Apps developed in Europe, instead, are based on voluntary use, without a government obligation. For example, from June 2020, Italy developed the app “Immuni” that is recommended, but not mandatory. This app uses a Bluetooth signal that allows recognising possible exposition to positive cases. The French app “StopCovid” works similarly and it is based on voluntary use, as is the German app “Corona-Warn-App.”

There is evidently a different approach in digital contact tracing between Europe and Asia. This could be related to differences at political level but also to the characteristics of the population, where the collectivist spirit of Asian Countries may encourage a common action and effort to face the virus spread. We should keep in mind, however, that such programmes

can only help control the UK COVID-19 epidemic if they are effectively implemented and form part of a wider package of interventions that include social distancing, infection control, and hygiene measures [104].

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### Statement of Ethics

This work was prepared and approved by a multi-stakeholder group of authors which included, amongst others, representatives from patients' organisations and scientific societies.

### Conflict of Interest Statement

The authors declare that they have no competing interests.

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### Author Contributions

D.H. conceived, built, and drafted the article with critical input from his co-authors, expert interviews, and the Million European Genome Alliance (MEGA+) partners.

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