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# Governing digital health for infectious disease outbreaks

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## ABSTRACT

How can governing digital health for infectious disease outbreaks be enhanced? In many ways, the COVID-19 pandemic has simultaneously represented both the potential and marked limitations of digital health practices for infectious disease outbreaks. During the pandemic's initial stages, states along with Big Data and Big Tech actors unleashed a scope of both established and experimental digital technologies for tracking infections, hospitalisations, and deaths from COVID-19 – and sometimes exposure to the virus SARS-CoV-2. Despite the proliferation of these technologies at the global level, transnational and cross-border integration, and cooperation within digital health responses to COVID-19 often faltered, while digital health regulations were fragmented, contested, and uncoordinated. This article presents a critiquing reflection of approaches to conceptualising, understanding, and implementing digital health for infectious disease outbreaks, observed from COVID-19 and previous examples. In assessing the strengths and limitations of existing practices of governing digital health for infectious disease outbreaks, this article particularly examines 'informal' digital health to build upon and consider how digitised responses to addressing and governing infectious disease outbreaks may be reconceptualised, revisited, or revised.

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## Introduction

In April 2020, amid the first wave of the COVID-19 pandemic and while many populations across countries were living under stay-at-home orders and other forms of lockdowns, Meta Platforms/Facebook CEO Mark Zuckerberg spoke reassuringly of a new 'superpower' in the face of this global public health crisis. Though the 'world had faced pandemics before' as highlighted by Zuckerberg, 'this time, we have a new superpower: the ability to gather and share data for good. If we use it responsibly, I'm optimistic that data can help the world respond to this health crisis and get us started on the road to recovery' (Zuckerberg, 2020).

Situated in the early weeks of the pandemic, Zuckerberg's comments and representation of the capacities to gather and share digital data as a new *superpower* against pandemics in many ways crystallised heightened interests in how Big Data sources and digital innovations, particular in smartphone technologies, could be harnessed to respond to and govern the scale and severity of COVID-19. During this same month, in the UK, the CEO of NHSX, the unit of the UK's National Health Service (NHS) tasked with digital innovation and data sharing, published a blog which

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highlighted the huge challenge of COVID-19 for the NHS but further underscored ‘the power of data in a pandemic ... to provide a single source of truth about the rapidly evolving situation’ (NHSX, 2020).

Many digital health operations, which initially proliferated to respond to and to mitigate the disease’s impacts, were seen to have faltered in aims to contain the spread of SARS-CoV-2 and to bring the pandemic to a close (the World Health Organization (WHO) stated in May 2023 that COVID-19 was no longer a global health emergency). Rather than providing relief from the multifaceted impacts of the pandemic, many of these digital ‘silver-bullets’ (Roberts & Kostkova, 2021) and data-driven responses have been fragmented, uncoordinated, and contested on political and scientific grounds. Many of these responses have been largely state-led and have rolled out unevenly across *digital divides* of individuals within states and across states. Meanwhile, evidence for the overall effectiveness of many of these interventions is questioned. The use of evolving digital technologies throughout the pandemic has been problematised by concerns over user adoption and uptake, interoperability of systems and technologies, privacy, legislation regulating the deployment of such technologies, and the role of Big Tech, including Apple, Google, and Meta/Facebook in the design and implementation of the technologies responding to the pandemic (Ada Lovelace Institute, 2020; French et al., 2020; Samuel et al., 2021; Sekalala et al., 2020).

National examples as the pandemic continued have also illustrated many shortfalls and overestimations of the success of digital interventions launched to contain COVID-19. In the first two years of the pandemic in the UK for example, £76 million was spent on developing the NHS COVID-19 contact-tracing app. As part of the larger NHS Test and Trace programme in which the operating budget for the first two years of the pandemic totalled £37 billion, the app failed in its central objective of avoiding further national lockdowns in the UK, despite the ‘unimaginable’ costs of these state-led digital interventions (National Audit Office, 2021; UK Parliament Committees, 2021). Moreover, as vaccinations against COVID-19 spurred forward the lifting of public health measures to contain COVID-19, irrespective of vaccination rates and effectiveness especially over the longer-term, countries including Canada, Denmark, the Netherlands, and Singapore suspended or sunset digital contact-tracing apps, in the absence of any clear conclusions on their overall impact as key pandemic response technologies. In Iceland, despite high digital interconnectivity, high citizen compliance with pandemic regulations, and high uptake of the government’s Rakning C-19 contact-tracing app, it was later found that in the larger context of pandemic management, Rakning C-19, in the words of an Icelandic government official ‘wasn’t actually a game changer for us’ (Johnson, 2020).

Building upon these reflections, this article investigates how practices of governing digital health for infectious disease outbreaks can be reconsidered, reconceptualised, and revisited in order to contribute and inform better responses to future public health emergencies. It will do so by presenting a critiquing reflection of approaches to conceptualising, understanding, and implementing digital health interventions for disease outbreaks, observed from COVID-19 and considering previous examples. Research on various digital technologies and interventions has flourished throughout the pandemic (Blasimme & Vayena, 2020; Roberts & Kostkova, 2021; Samuel et al., 2021; Sharon, 2021). However, critical assessments of larger practices and processes which guided digitised responses to disease outbreaks remain largely overlooked in critical and contemporary global health and digital health literature. Considering how such practices could be revisited and potentially improved via new pathways and collaborative avenues is important in the context of the sizeable and impactful role which digital technologies are expected to play in responding to future outbreaks and pandemics (Al Knawy et al., 2022).

Governance, including within health, has long been partitioned in terms of its level of formality (Duda, 2020; Kooiman, 1993; Ledeneva, 2018). Actions directly representing or coming from specific entities tend to be referred to as ‘formal’, compared to ‘informal’ actions which are those not purporting to be from or representing an established entity. The lines between formal and informal governance are inexact, debated, and blurred. Terms for ‘informal’ (Duda, 2020; Kooiman,

1993; Ledeneva, 2018), either conflated or distinguished depending on the context and publications – and not always defined, although frequently contested – might include ‘unofficial’, ‘non-official’, ‘unrepresentative’, ‘aformal’, ‘non-formal’, ‘unprofessional’, ‘bottom-up’, ‘ad hoc’, and ‘voluntary’.

Within the often-presumed separation of formal and informal in practice, even when not clearly delineated in principle, the following section introduces and analyses the evolution of ‘formal’ digital health approaches for addressing and responding to infectious disease outbreaks. It traces the expansion and influence of these practices which have aimed to aggregate maximal new data sources and to integrate evolving technologies as sentinels for identifying and tracking infectious disease threats. This section examines some pitfalls and shortcomings of these evolving formal digital health practices in seeking to detect and prevent infectious disease outbreaks. These concerns lead to the next section describing ‘informal’ digital health for infectious disease outbreaks, noting (as with formal approaches) the strengths and limitations of considering informality in such contexts. The section after uses the COVID-19 pandemic as a point of reflection and example to identify informal practices, operations, and processes of digitally governing the disease’s spread and management, with case studies of Thailand and Taiwan illustrating. In doing so, variances in the identities, activities, and placements of those involved in these informal digital health approaches are considered. This material leads to a description of the effectiveness of informal digital health approaches, which are relatively overlooked, for governing digital health interventions during infectious disease outbreaks, concluding with the need to combine formal and informal approaches.

## **Formal digital health for infectious disease outbreaks**

### ***Digital infectious disease surveillance***

Some have conceptualised COVID-19 as the first pandemic of the ‘datafied society’ (Di Salvo & Milan, 2020). Yet digitised approaches to the regulation of infectious disease outbreaks neither were born of, nor originate within COVID-19 contexts. Rather, these histories of evolving and intensifying digital interventions extend several decades prior to COVID-19 within global health and digital health work of the late 20th and early 21st centuries.

While the regulation and control of infectious disease outbreaks among populations dates back to early human communities, the origins of modern infectious disease surveillance programmes originated several centuries ago. The collection, logging, and assessment of health and population data first emerged as a central feature of government concerned with the health, livelihood, and social implications of plague and other diseases in expanding population centres. Throughout this period, the accrual and processing of numerical and demographic health data by the time periods’ equivalents of clinicians, statisticians, and epidemiologists and the ‘avalanche of statistical numbers’, (Hacking, 1982) became ‘an essential function of the modern state in the battle against emerging epidemics and pandemics’ (Roberts, 2019a, p. 97). At national levels, such practices intensified within clinics, hospitals, and scientific laboratories, ministries of health, and governmental agencies. At the global level, the founding of the World Health Organization (WHO) in 1948 ushered forward renewed and broadened expectations for coordinated disease surveillance and the sharing of epidemiological and outbreak data.

From the founding of the organisation, WHO as a primary actor and coordinator for global health standards has worked in tandem with member states to codify and establish pathways for communicating and sharing outbreak information. Data were often supplied by member states in attempts to monitor and regulate infectious disease outbreaks and the spread of pathogens across borders, with a particular focus on maintaining the continuity of international trade and commerce networks. Building upon previous international public health and sanitary conventions, WHO adopted several iterations of the International Health Regulations (1969), in which cholera, yellow

fever, and plague were made mandatory notifiable diseases should any outbreaks occur within the jurisdictions of member states (Gostin & Katz, 2016).

Despite these moves to coordinate information and data-sharing towards enhanced infectious disease outbreak monitoring and regulation, efforts to identify, report, and respond to outbreaks were often hindered. In many of these cases, formidable political challenges existed, frequently related to sovereign concerns over the impacts of reporting an outbreak. This was exemplified by the crisis which ensued after the WHO reported an outbreak of cholera in Guinea in 1970, despite the fact that no prior notification of the event had been provided or confirmed by the Government of Guinea, producing an outcry so severe that some states threatened to withdraw completely from the WHO (Weir & Mykhalovskiy, 2012).

As well, formalising new standards for outbreak reporting and data sharing often also lacked scientific and technological capacities and infrastructure to identify and rapidly share requisite information. National governments and WHO were soon beleaguered by the onset of a new *epidemic of epidemics* (Bartlett, 2014) including Ebola, Lassa, Congo-Crimean and Marburg haemorrhagic fevers; HIV/AIDS; and human and animal influenzas (Roberts, 2019b). Since 1980, partly due to improved techniques, over 30 new human pathogens have been detected, of which 75% have originated in animals and have subsequently crossed transmission thresholds into people (WHO, 2022). Moreover, these new pathogens have emerged alongside a range of re-emerging diseases including measles, polio, mpox, Legionnaire's, and noroviruses. During this time period, one human pathogen (smallpox) and one animal pathogen (rinderpest) were successfully eradicated through actions including concerted data sharing and disease surveillance operations.

Meanwhile, advances in digital interconnectivity, technological innovation, the transitioning of Web 1.0, 2.0 and 3.0, as well as the Big Data and Big Tech 'revolutions' have sought to markedly transform infectious disease surveillance practices through new abilities to collect, aggregate, analyse, and report on 'oceans' of new digital data. At the core of these digital transformations in risk assessment practices are interests which seek to quantify and process constantly generating Big Data sets via algorithms in order 'to minimize or eradicate uncertainty' (Rouvroy & Berns, 2013, p. 11).

The initial shift and transition toward digital and open-source infectious disease surveillance information can be traced to the expansion and commonality of desktop computers in the era of Web 1.0. Government, medical practitioners, and public health officials were increasingly able to upload, share, seek, and obtain disease surveillance and epidemiological data on outbreaks where they had previously been stonewalled by reticent national governments or difficult access to locations. The Programme for Monitoring Emerging Diseases (ProMED-mail) – an online, publicly accessible web platform for infectious disease surveillance launched in 1994 – and provides early evidence of the potential gains from digitising surveillance and assessment activities for occurring and potential disease outbreaks (Carrion & Madoff, 2017). Such technology has been widely credited for its sentinel role in communicating information on new outbreaks occurring around the globe including advanced reporting on Severe Acute Respiratory Syndrome (SARS), Middle East Respiratory Syndrome (MERS), Ebola, and the early spread of Zika (Carrion & Madoff, 2017).

From the early launch of ProMED-mail, the 'digital turn' of infectious disease surveillance practices has continued and intensified, occurring alongside the emergence, and spread of new pathogens. Further prominent examples include the Global Public Health Network's (GPHIN) identification of an 'atypical pneumonia' via scanning of open-source media reports circulating in Southeast China in late 2002, months in advance of the official notification to the WHO of a new acute respiratory virus (SARS) by the Chinese government (Dion et al., 2015). Following the 2002–04 SARS outbreak and the role of GPHIN in providing key surveillance reporting in the absence of state-sanctioned and confirmed epidemiological data during outbreaks, interest expanded within global health in how such digital health surveillance technologies could be

integrated and formalised into mainstream global health operations to identify, respond to, and reduce impacts from infectious disease outbreaks.

### **Big Data, Big Tech, and their discontents**

Heightened interest to leverage digital data to better survey and respond to outbreaks gained further global focus following the ratification of the revised International Health Regulations (2005). Within these revised regulations, WHO officially authorised access to sources of information and reports beyond those provided by member states in order to supplement the assessment and evaluation of potential outbreaks occurring in member states (Article 9.1). This effectively paved the way for integrating new open-source, digital technologies, and sentinels to bolster the surveillance and reporting of infectious disease outbreaks, from both formal authorities such as governments and informal sources such as crowdsourced material and syndromic surveillance systems including GPHIN.

Processes of digitisation then continued to iteratively shape and inform surveillance operations of infectious disease outbreaks as the topic climbed up national and global health security agendas in the early twenty-first century. In fact, 'recent advances in algorithmic calculation, big data analytics, and artificial intelligence promised to change the way governments, institutions, and individuals understand and respond to health concerns' (Duclos, 2019, p. 55). In 2008, Google entered the expanding arena of digital health risk assessment and disease surveillance by launching *Google Flu Trends*, (GFT) which aimed 'to mine massive amounts of past data (about online search behaviour and doctor visits) and to extract patterns that could be used to predict future viral activity' (Duclos, 2019, pp. 55–57), particularly around seasonal influenza patterns.

At the time of launch, 'GFT has been the most significant attempt by a giant data mining corporation to transform global health ... and further offered an entry point to examine how big data analytics, specifically algorithmic detection and related data-mining techniques, may intervene in population health on a global scale' (Duclos, 2019, pp. 55–57). Reflective of the assumed predictive and transformative capacities of Big Data, the founder and former tech lead of GFT claimed that Google's newly established digital disease surveillance technology was able to predict patterns of influenza more rapidly than traditional disease surveillance and reporting systems, including the USA's Centres for Disease Control and Prevention (CDC) (Ginsberg et al., 2009).

Following the launch of GFT, digitised and datafied approaches to tracking and understanding outbreaks continued to expand and proliferate. Amid the 2014 West Africa Ebola epidemic, another digital, open-source surveillance technology *HealthMap* which used Google software and mapping technologies, gained global attention for bold claims about its capacities to aggregate data and to produce real-time intelligence of outbreaks. Combined with automated assessments and scanning of a range of open-source online data, *HealthMap* claimed to have successfully identified reports of a mysterious haemorrhagic fever circulating in Southeast Guinea, nine days prior to official notification of the presence of Ebola in Guinea by national public health authorities (Milinovich et al., 2015). Without fully investigating or verifying these claims, global media outlets celebrated the capacities of these new digital disease forecasting technologies, stating how 'an algorithm detected Ebola before official alerts', or how 'an online tool nailed the Ebola epidemic' (Associated Press, 2014; Schlanger, 2014). These accolades further enforced beliefs that in the digital era, Big Data was now 'a new organisational necessity for crisis response and management' (Erikson, 2018, p. 316).

Following closely upon a wave of globalised infectious disease outbreaks, including five designated public health emergencies of international concern (PHEIC) from 2014–2020, the COVID-19 pandemic has represented a new plateau in the unleashing of digital and Big Data-driven responses to a global public health emergency. Throughout the pandemic '(d)ata collection and processing via digital public health technologies have been promoted worldwide as strategic remedies for mitigating the COVID-19 pandemic' (Gasser et al., 2020: e425). Both datafication and digitisation have been applied across a scope of pandemic response operations, including symptom

checking technologies, quarantine compliance processes, and flow modelling (Gasser et al., 2020). As concerns with capacities to identify and track a rapidly spreading virus were underscored by public health authorities in early 2020, Storeng and De Bengy-Puyvallée (2021) conceptualised the onset of the ‘Big Digital Contact-tracing experiment’, whereby over one third (at least 70) of the world’s countries launched digital contact-tracing technologies, mostly via handheld mobile and smartphone technologies. In the UK, the launching of the NHS COVID-19 contact-tracing app – as a central component of the NHS Test and Trace response to the pandemic following months of delay and re-design – was hailed as part of a ‘world-beating’ COVID-19 testing system (Briggs et al., 2020).

In exchange for the uptake of these digital interventions, populations around the globe were emphatically reassured that these technologies would be central to controlling COVID-19, identifying, and tracing cases, and exiting lockdowns (Roberts & Kostkova, 2021). The rollout of these digital surveillance and monitoring systems occurred largely through two formal pathways. First, during the pandemic’s early stages, digital interventions designed and implemented largely by national governments were seen prominently through the initial creation of *centralised* digital-contact tracing apps (European Parliament, 2020). Second – later, more prominently, and more controversially – partnerships were forged between national governments and Big Tech corporations in order to make many faltering programmes ‘work’. A significant example was the Apple/Google joint development of an application programming interface (API). It supported the function of many of the digital contact-tracing technologies piloted by countries including the UK, Canada, Japan, New Zealand, jurisdictions in the United States, Russia, and many EU member states. Many questions emerged and still linger regarding the effectiveness and impact of these established and increasingly formalised digital interventions, with mounting scholarship pointing to the outright failure of these technologies as pandemic response instruments (Government of Australia, 2022; Polzer & Goncharenko, 2021; White & Van Basshuysen, 2021).

Meanwhile, further scholarship critiques ‘Big Tech fixes’ for ‘Techno-optimism’ and ‘Big Data disasters’ surrounding outbreaks and public health emergencies (Martin McDonald, 2016). Such work analyses the effectiveness and implications of digitising the surveillance and response to public health emergencies. It also scrutinises key formal actors, namely state governments, and Big Tech corporations in developing and implementing these interventions. In the contexts of COVID-19, Martin McDonald (2020) has conceptualised ‘technology theatre’, whereby intense focus is attributed to technological interventions during a crisis ‘instead of a holistic solution to address complex policy issues’ (2020, p. 1). Technology theatre, as conceptualised by Martin McDonald (2020) has been instrumental in understanding the uneven terrains of investment and neglect in many governments’ reactive responses to the pandemic, and to the formalisation of partnerships between states and Big Tech during crises.

Further critical accounts have been key in moderating perceptions of success which have abounded following many digital interventions led by states, Big Tech actors, and the expanding interplay of both. Google Flu Trends, for example, initially made bold claims as being a new sentinel of disease surveillance which would be enacted by a multinational tech company. Despite this initial promise, the project faltered in its forecasting activities and following a series of huge overestimations in influenza patterns in the coming years, eventually closed in 2015, itself a victim of what has been termed ‘big data hubris’ (Duclos, 2019; Lazer et al., 2014). Assessments of the ‘gaps in the gaze’ (French, 2014) of these approaches and claims of what Big Data and Big Tech ‘can do’ for global health surveillance therefore provide cautionary tales for the ‘successes’ of many digital interventions observed during acute public health episodes and public health emergencies.

Further critiques can also be noted regarding the claims that HealthMap ‘detected Ebola before humans did’. Erikson (2018, 2019) highlights how the digital disease sentinel missed the first circulating reports of ‘patients with Ebola-like symptoms’ fever in Guinea which were published in French, as HealthMap largely scanned and analysed bulk English-language data sources. Erikson (2019, p. 512) underscores that ‘HealthMap’s ability to simply note disease incidence did not directly translate

to an ability to treat people with the virus, which was a complex challenge.’ Aside from early reporting of an unusual disease occurrence, there is little to suggest that HealthMap’s role was significant in identifying or mitigating the spread of the Ebola epidemic across Guinea, Liberia, and Sierra Leone or that these early reports were actually integrated into national or global response operations to contain the outbreak. Erikson (2019) has also emphasised that this situation does not take away from the value of a global disease visual technology like HealthMap. Rather, the technology is interesting in and of itself to examine the capacities to aggregate and present critical outbreak data in real-time and with a method digestible for a range of online users including researchers, responders, medical practitioners, and the general public. Once more, however, the case of HealthMap and Ebola, as asserted by Erikson (2019: p. 512) serves to ‘highlight a fetishization of a technology and an overstatement of its capabilities’ particularly during public health emergencies.’

Similarly, for COVID-19, authoritative or lasting accounts of the effectiveness of a range of formal digital interventions, most notably digital contact-tracing via apps, continues to be thin. Yet, as global vaccine rates against SARS-CoV-2 increased and the risks from restrictions began to be perceived to be higher than the risks from the virus, many high-income states sunset or suspended digital data collection and contact tracing operations and apps with little public discussion on any future reactivation, or on how such technologies can be securely dismantled. These technologies’ rollouts, most of which were part of formal agreements between state governments and Big Tech actors including Apple and Google, have further exposed, entrenched, and accentuated health inequalities and inequities across countries which existed before the pandemic (Ada Lovelace Institute, 2020; Watts, 2020).

Even within countries labelled as ‘success stories’ in combatting and containing early waves of COVID-19 through coordinated responses which sometimes included digital health interventions, unforeseen implications have eroded public trust in government during crises and have facilitated the rise of discrimination, violence, and stigma. This was illustrated in South Korea where digital contact-tracing was used to link infections to a series of LGBTIQ + nightclubs in Seoul during the first waves of the pandemic, leading to the forced outing of LGBTIQ + people in the area, heightening stigma and causing a public backlash against an already marginalised community (Shin & Lee, 2020). Elsewhere, in Germany in 2022, public outcry followed revelations that German police had unlawfully accessed data from the *Luca* contact-tracing app in order to investigate a crime which had occurred in the city of Mainz, emphasising the concerns made by some civil society groups throughout the pandemic regarding government and law enforcement access to personal data collected for combatting COVID-19 (Deutchewelle, 2022).

This section has presented a critiquing overview of the emergence and expansion of digital health practices for monitoring and responding to infectious disease outbreaks. Owing to advances in technological innovation, digital interconnectivity, and the volume, variety, and speed of new data sources, the analysis has highlighted how these technological innovations have been iteratively incorporated into formal global health operations over the past several decades. Much has occurred due to global health actors and organisations, including state governments which have been uncritically ‘assisted’ by Big Tech corporations, in efforts to control and contain public health emergencies. As analysis has shown, numerous pitfalls and shortcomings exist for formal digital health practices used increasingly to monitor and respond to outbreaks. Mobilising these technologies during COVID-19 did little to provide clarity or confidence for the claimed successes or overcoming the challenges posed by these formal digital health interventions. In the wake of COVID-19, key questions and concerns continue to remain surrounding the expense, equality, effectiveness, and privacy of many of these formal digital interventions (Anglemyer et al., 2020).

### **Informal digital health for infectious disease outbreaks**

Given the examined concerns of digital health interventions leading up to and including COVID-19, could approaches other than formal ones enhance or improve the governing of digital health



interventions for responding to disease outbreaks? This section examines conceptualisations of more informal approaches to responding to disease outbreaks and public health emergencies. No resolution is attempted here for governing digital health for infectious disease outbreaks. Instead, the focus is on considering ‘formal’ and ‘informal’ actors and approaches, recognising that this arbitrary division (since formal and informal are really a continuum, not a binary) does not and cannot give a comprehensive picture (Duda, 2020).

For disease outbreaks, informal digital health covers actions by a range of actors without official positions at any scale, whether global, national, subnational, or individual. Numerous attempts are made to group a huge range of informal actors, often without robust delineation from formal ones (Duda, 2020). The area of diplomacy illustrates, which for infectious disease outbreaks can refer to health diplomacy, public health diplomacy, global health diplomacy, medical diplomacy, vaccine diplomacy, and others. Davidson and Montville (1981) and Jones (2015) examine and present the importance of what they call ‘Track Two’ diplomatic approaches, delving into how formal approaches often bypass or downplay informal, localised approaches. Similarly, according to Diamond and McDonald (1996), multi-track diplomacy has nine separate categories: (i) government, (ii) nongovernment/professional, (iii) business, (iv) private citizens, (v) research, training, and education, (vi) activism/advocacy, (vii) religion, (viii) funding, and (ix) communications/media. While recognising the overlaps between who and what might be a formal, non-formal, or informal actor or process (Davidson & Montville, 1981; Diamond and McDonald, 1996; Duda, 2020; Jones, 2015), long-standing phenomena with formal and informal elements include para-diplomacy, micro-diplomacy, and proto-diplomacy.

The need for expanded understandings of cooperation between and across countries, regions and populations has been recognised for disease outbreaks. Katz et al. (2011, p. 510) offer a concise definition conceptualising the informal within global health as ‘interactions between public health actors around the world including host country officials, representatives of multilateral and nongovernmental organisations, private enterprises and the public’ and further assert how ‘the accelerated pace of globalization has dissolved the distinctions between many domestic and foreign issues’ including that of infectious disease outbreaks. Applying digital health for infectious disease outbreaks therefore involves informal actors and processes which engage a variety of proactive communities, people, and entities sharing skills, expertise, and experiences. They expand networks and cooperation for improving and achieving aims for digital health and global health, helping to identify ‘practices that increasingly characterise the more open, networked and less state-centric multilateralism of the twenty-first century’ (Elbe, 2021, p. 659). Yet involving ‘entities’, typically referring to organisations and institutions, can question their informality, given that the existence of the entity makes it formal in some respects and, as such, people acting on behalf of the entity have formal roles and rules (Duda, 2020).

Despite the establishment and existence of informal practices within digital health and global health, attention to and engagement with the scope and impact of these practices remain scant for infectious disease outbreaks. Elbe (2021) is an important exception, covering bioinformational diplomacy and the sharing of genetic sequence data for new pathogens. Here, scientists are identified and situated as significant informal actors regarding the exchange of viral sequence data for enhanced outbreak surveillance. Again, the lack of formality can be questioned since scientists receive funding, are usually employed at an institution or organisation, and have formalised procedures for reporting, validating, and publishing their work. Being part of a formal system does not necessarily make individuals formal actors, but it does dilute their informality by somewhat formalising them. Meanwhile, scientists are often free to pursue their own interests in their own ways collaborating with whom they choose, making them independent and diluting their formality with expectations of informal and non-formal connections, networks, and actions.

Irrespective of these definitional difficulties, less formal contributions appear to be expanding for conceptualising the changing and shifting nature of infectious disease surveillance, forecasting, and reporting. Examples are participatory surveillance (Albrechtslund, 2008) and self-tracking (Lupton,

2014). Research and practice fully recognise the variety of these less-than-formal actors, processes, and venues for digital health for infectious disease outbreaks. Rich and Miah (2014, p. 306) interpret ‘public pedagogy as occurring within informal, digital, social spaces, captures the pedagogical features of technologically mediated health sites’ in order to explore how people learn and teach about health in a digital environment. Informal approaches to health using mobile phones, termed ‘informal mhealth’, are seen as a boon for supporting the health needs of hard-to-reach communities, including in sub-Saharan Africa, as well as contributing to Universal Health Coverage (UHC) (Hampshire et al., 2015; Mariwah et al., 2022). Combining informal and formal approaches to digital health has been examined for identifying infectious disease outbreaks spread by mass gatherings (Nsoesie et al., 2015).

Gaps remain in the practical understanding of how informal digital health is seen in practice and its effectiveness for infectious disease outbreaks. For instance, during the Ebola epidemic, informal health approaches for tracking and responding to the disease involved rumourmongering and word-of-mouth (person-to-person and digitally via social media) dissemination of incorrect practices (Roberts et al., 2017), a situation repeated for COVID-19 (Hartley & Vu, 2020; Naeem & Boulos, 2021). Nonetheless, the next section presents and considers how applying informal digital health approaches to COVID-19 can yield advantages and successes within community and national contexts.

## **Applying informal digital health to COVID-19**

What informal practices, operations, and processes exist and can be presented for digital interventions utilised to contain and mitigate the risks and consequences of COVID-19? What actors are involved in these informal digital operations, what are their roles and positions within and outside of formal processes and entities, and how could their effectiveness for digital health be assessed? Some work (e.g. Mbunge et al., 2022; Narla et al., 2020; Singh et al., 2021) investigates these questions and illustrates potential benefits, as well as difficulties. As with preceding public health emergencies in the digital era, it is claimed that BlueDot, an independent web-based startup that was pioneered in 2003 by Dr. Kamran Khan after the SARS outbreak, which automatically scans thousands of online data sources, was among one of the first sentinels to ‘informally’ identify the outbreak, again nine days prior to official notification (Allam, 2020). For more examples and to support further analysis, two national case studies during COVID-19, Thailand, and Taiwan, are selected here to indicate aspects of the impact of informal digital health practices during infectious disease outbreaks.

### **Thailand**

Long recognised for its sustained investments and improvements in its national health system, movements towards achieving UHC, and in outbreak preparedness, Thailand reported its first case of COVID-19 on 13 January 2020 (WHO, 2022). The country implemented similar measures which were unfolding across the globe at that period in response to the spread of the coronavirus, including the closure of public spaces, workplaces, and educational institutions. Meanwhile, informal, and digitised responses to monitoring and reporting the outbreak were credited for reducing infections and educating the public during the initial state of the emergency in early 2020 (Intawong et al., 2021; Marome & Shaw, 2021; Tantrakarnapa et al., 2020).

In preparation for an upswing in cases following the first reporting of the virus in the country, the Thai government recruited and trained laypersons across the country via online training sessions in the areas of ‘basic knowledge of COVID-19, which included educating the population in how to stay safe, identifying and monitoring members of the community at high risk and in data collection methods and reporting’ (Kaweenuttayanon et al., 2021). This approach rapidly assembled and trained an informal surveillance network which could be immediately

operationalised for the tracing and tracking of COVID-19 in efforts to reduce infections and hospitalisations as the coronavirus began to spread globally (see also Intawong et al., 2021 and Tantrakarnapa et al., 2020).

The importance of community engagement and community involvement as imperative to improved health outcomes has long been recognised in Thai public health programming (Kitphati et al., 2022; Lyttleton et al., 2007; Nuntaboot, 2006). Indeed, early pandemic responses in Thailand sought to operationalise surveillance programmes at differing levels of state and society (Intawong et al., 2021; Tantrakarnapa et al., 2020). Building upon local networks and relationships, these trained health surveillance volunteers educated people about COVID-19 transmission, enacted exhaustive contact-tracing of infected individuals and their networks, and served as strategic interlocutors between accessing vital health data on-the-ground and supplying this information to sub-national and national health authorities to further guide responses to the pandemic. A key point is how digital health approaches featured as important response instruments and informed the surveillance and reporting practices of the Thai COVID-19 health volunteers. Emphasising public hygiene and risk reduction, volunteers were strongly encouraged to collect and upload surveillance data via a COVID-19 data platform, accessed via either Smartphone app or secure website and operated by the public health ministry. In this way, data were collected and aggregated on infected cases, their potential contacts, and groups considered to be high risk (Kaweenuttayanon et al., 2021), which enabled an expanded degree of situational awareness during the early outbreak of COVID-19.

Enabled with digital data collection capacities and often embedded in familiar or local communities, the experiment of training informal health volunteers in Thailand at the onset of the pandemic appeared to be a successful response to the onset of the pandemic in Thailand in early 2020. As Kaweenuttayanon et al. (2021, p. 395) underscored, '[t]he close relationship between the volunteer workforce and members of the communities enabled the smooth functioning of COVID-19 disease surveillance which might have otherwise been considered as an invasion of privacy', particularly via the collection of sensitive health data during a period of national emergency. Through combined approaches of community engagement, manual data collection, and digitisation, these health volunteers 'visited more than 14 million households from March to April 2020, monitoring 809 911 contacts and 64 552 people at high risk, making referrals for a total of 3346 symptomatic patients.' Combining and leveraging informal actors and digital health approaches for data collection and surveillance enabled an initially overall 'robust response of the country to COVID-19, resulting in albeit, limited containment of the virus without the use of a costly country-wide lockdown or widespread testing' (Kaweenuttayanon et al., 2021).

Despite the core of the work being completed by what can be understood as informal actors utilising blended digital and manual approaches, the programme's initiation, operation, and monitoring was completed by an entirely formal actor, the Thai government. It was implemented through the country's formal healthcare system. This example demonstrates the mutual interdependence of formal and informal digital health approaches for infectious disease outbreaks.

## **Taiwan**

At the pandemic's onset, Taiwan received extensive citation and global interest for the array of digital health approaches combined with technological innovation and widespread testing which the country swiftly implemented (Summers et al., 2020; Wang et al., 2020). In fact, throughout 2020 and 2021, Taiwan was often cited as a global success in combatting COVID-19, with media and commentary claims of how Taiwan 'beat COVID-19' and was a 'COVID-19 success story' (Fitzpatrick, 2021; Kennedy, 2022). Key to controlling the onset of COVID-19 on the island, many of Taiwan's tech-driven, Big Data-powered responses were implemented at formal levels of government and as part of larger responses which integrated health systems and government (Cheng et al., 2020; Summers et al., 2020; Wang et al., 2020). Many responses in the country also involved examples of

informal citizen participation which shaped and produced digital responses to regulate and control the spread of coronavirus and the onset of infections and hospitalisations (Lanier & Weyl, 2020; Perng, 2022).

Notably here, Lanier and Weyl (2020) have described the role of civic technology in Taiwan's early responses to COVID-19, discussing how the Taiwanese Government's public release of types of COVID-19 reporting data empowered numerous informal digital health approaches, with one example being mapping the availability of masks. The interface of informal actors, communities, and practices with civic tech in Taiwan's COVID-19 response further saw the development of an array of digital pandemic support technologies across Taiwan including 'chatbots, dedicated mobile applications, interactive data dashboards and voice assistants, developed by individuals, developers, and companies' (Perng, 2022, pp. 5–7).

As a high-tech, digitally interconnected society, informal citizen-led responses to COVID-19 showed how the governance of outbreak risks 'and the programming of digital disease control was not being implemented by the government alone, with other actors working to construct alternative data collection systems or platforms to supplement government strategies' (Perng, 2022, pp. 5–7). In some cases, within the contexts of Taiwanese pandemic response, informal actors and citizens 'have worked voluntarily to reconfigure or recalibrate government systems or analytics for the better protection of collective health; including alternative data sources and reporting developed in response to concerns about mass gatherings and cluster infections' (Perng, 2022, pp. 5–7).

Taiwan, through its integrated and dynamic initial response to COVID-19, leveraged and combined informal and formal processes and digital interventions. These integrated and innovative responses received much early praise for the regulation and containment of the spread of the coronavirus throughout much of 2020. While premature given subsequent developments, Taiwan was regarded as an early success-story and world-leader in containing COVID-19, demonstrating how 'effective prevention and containment of COVID-19 can be achieved without the excessive use of intrusive interventions that upend daily life' (Hsieh et al., 2021, p. 301). As with Thailand, it was a balance of successes and problems, with many aspects of the successes achieved through the formal actor of the government initiating, supporting, directing, and using the information from more informal actors and actions to optimise the impact of digital health interventions to address and respond to COVID-19.

As Hsieh et al. (2021) emphasised, the contested ongoing political status and historical contexts of Taiwan must also be understood as key drivers to its 'whole of nation approach', which united more formal and more informal digital health actors and approaches to respond to COVID-19 (see also Kastner et al., 2022). This national and political context facilitated digital partnerships and exchange between formal and informal actors and networks operating across the island at the pandemic's onset. Hsieh et al. (2021, pp. 304–309) highlight how various country-specific factors led to the close cooperation of central government, local governments, private enterprises, and citizens. These include (see also Cheng et al., 2020; Lee & Lin, 2020) collective lessons learned during the 2002–04 SARS pandemic; democratic deepening and civic society; a perceived lack of support from the WHO; and proximity to China where the outbreak of coronavirus had originated.

## Conclusion

As analysis here has shown, both Thailand and Taiwan demonstrated initial COVID-19 successes through the formal actor of the government leveraging and integrating a range of informal digital health interventions and working in collaboration with networks of informal actors and approaches. Despite these impressive initial gains in limiting infections without imposing national lockdowns, both countries eventually experienced large-scale outbreaks, hospitalisations, and deaths in successive waves as the pandemic continued. Their situations illustrate the limitations of the approaches employed, including the combination of formal and informal digital health

initiatives. One major factor in the later difficulties was the significant formal and informal pressures on the countries to relax internal measures and to avoid closing their international borders (as Australia and New Zealand did) which permitted new variants to enter the countries.

The analysis conducted here of Thailand and Taiwan's engagement of informal digital health approaches during COVID-19 should not be considered in isolation from other states which employed informal or hybrid digital approaches for COVID-19 including in other digitally connected states such as Hong Kong, Singapore, and Vietnam, all of which achieved early gains in pandemic response activities (Bao et al., 2020). The examples of Thailand and Taiwan nonetheless illustrate the value and centrality of informal digital health interventions and actors within the governing of digital health for infectious disease outbreaks. The countries highlight that informal approaches were completed in tandem with formal approaches and that research so far has typically focused on the formal approaches. The latter especially tends to venerate or vilify governments and Big Tech, thereby marginalising assessments and investigations into more informal contributions including within community connections (e.g. O'Connell et al., 2021), and civic tech (e.g. Suzuki, 2022).

As such, for COVID-19 and infectious disease outbreaks more widely, complexities and contextual importance make it difficult to draw firm conclusions about which informal digital health approaches could be generalised or transferable, as well as how and why they work or do not work. Part of the challenge is the difficulty of drawing lines between and being able to define clearly formal compared to informal (and non-formal) digital health initiatives for infectious disease outbreaks as illustrated and discussed within this article. In fact, definitively separating them might not be feasible. It might not even be desirable, given the importance of formal actors and processes in addition to how the formal and informal are shown to merge and meld (Duda, 2020). Bringing them together can enhance effectiveness in other digital health areas through complementing each other, as demonstrated in Thailand and Taiwan. Both informal and formal digital health approaches have advantages and limitations, meaning that using them in tandem could help to fill in gaps and draw on strengths from both areas to guide and inform better future coordinated responses.

Ultimately, neither formal nor informal digital health approaches for infectious disease outbreaks can or should be conceptualised in isolation. Instead, both approaches must be balanced together for piloting, evaluating, refining, implementing, and governing much-needed interventions to monitor and tackle infectious disease outbreaks occurring within and across countries. These challenges within digital health, datafied health, and global health are not new. The key here is to continue to draw on vast past experience in order to do much better than is being done for the ongoing surveillance of and response to ongoing and future infectious disease outbreaks.

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