Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

CHAPTER 5

The Emergence of Voluntary Citizen Networks to Circumvent Urban Health Data Sharing Restrictions During Pandemics

INTRODUCTION

After the past three industrial revolutions, the fourth one, where use of information and communication technologies (ICT) technologies is emphasized, has accelerated our global transformation. Today, it is not unusual for different institutions and agencies to use a wide range of computing technologies in their decision-making and operations. Technologies such as artificial intelligence, big data, blockchain technologies, machine learning, cloud computing, and others such as natural language processing have become very popular. One sector that has greatly benefitted from such is health, where through the use of the said technologies, it is now possible to collect and process massive datasets, thus leading to advanced surveillance and monitoring, diagnosis, treatment, and drug manufacturing among other benefits. These have been even more instrumental in the present days when the whole world is experiencing one of its lowest moment, courtesy of COVID-19 pandemic. Use of these technologies allowed for quicker identification of the virus strand and for faster sharing of information on the virus to various global agencies for quicker actions to be taken. On the same, the use of these technologies, especially AI, machine learning, and natural language processing, through some startups, BlueDot—based in Canada, and Metabiota—based in California, the United States, was able to an earlier prediction of the next location where the virus would spread after Wuhan (Metaboita, 2020; Heaven, 2020; Allam et al., 2020). Furthermore, these technologies have become particularly handy in helping various stakeholders involved in the fight against the coronavirus in making decisions on issues such as quarantine, self-isolation, preventive measures, screening, and many others (Pringle, 2020).

With all these technologies, the common denominator is the availability of data, and without these, or when such are unreliable, low scale, compromised, or delayed, the analysis, insight derived and decision made, would undoubtably be less impactful. But, while this is the case, there is evidence that the world is amass with data from different sources, especially with the infiltration of smart phones, and availability of numerous social media platforms. There are some open databases that allow free access to data. With all these, in the case of COVID-19, startups engaged in providing more insights are observed to access data from those sources, including airline ticketing and from governments of different countries, and with these, they are able to run simulation and predictive algorithms to come up with conclusions guiding policy orientations. On this, while the outcomes from such computations are impressive and with far reaching impacts on the health frontier, the numerous challenges with data collection, storage, management, access, and distributions still linger. In the present case of COVID-19, for instance, it has become clear that some crucial data such as the actual number of those affected, the trends of spread and the number of those in self-isolation and quarantine are not available to the extent desired. Thereby, it would be a daunting task to quantify or predict the number of those who are to be infected by the virus and in which geographical location. In such circumstances, it has become relatively hard for authorities to pursue watertight preventive measures that would see the spread reduced.

These obstacles on data need to be rectified urgently if substantial steps on the fight against the virus are to be won. On this front, this chapter proposes a paradigm shift where data collection and sharing will not follow

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the traditional models that are mired with the shortcomings but proposes an alternative one. In this case, the model being fronted is the volunteered geographic information (VGI), which emphasizes on having open data banks, with the public being allowed to freely share data. On this, Langley et al. (2017) note that with VGI, it increases the propensity for collaboration in matters relating to data, including with nonscientists like the general public who usually share massive amount of data via social media platforms. With the model gaining popularity, it would be easy to capitalize on the increasing popularity and numbers of smart devices and hence end up with an enriched database that can enhance the information and insights concerning the pandemic.

While VGI has the potential to positively influence the global health database, it would be significant to ensure that the restriction in data sharing is overcome such that the data can be shared in real time. This has not been the case as reported by Hamade (2020), and when that happens, there has been the challenge of lack of granularity making it hard for one jurisdiction to comfortably access and use data from a different jurisdiction. This is observed as among one of the hindrances that need to be addressed while recalibrating the standards and protocols that guide data sharing (Allam, 2019a, Allam, 2020a, Allam, 2020b, Allam, 2020c, Allam, 2020d; Allam and Jones, 2020). But even before this, there is a discourse on how that standardization can be done. It is worth noting that in the case of emergencies, as in the present case of COVID-19, one cannot wait as the situation is dire with far reaching impacts. Therefore, there is need for goodwill from all stakeholders and governments to voluntarily allow unsolicited data sharing, by overriding existing restrictions. This way, as is expressed by Romm et al. (2020), it will be possible to urgently track and trace suspected cases of the virus and, thereafter, initiate the most appropriate medical approach; whether quarantine, isolate, or hospitalize individuals depending on their health status. In view of this background, this chapter is dedicated to the exploration of whether it is feasible to adopt the VGI model during times of disaster like now, especially in this current era where the advanced computational technologies are ubiquitous.

DATA SHARING CONCERNS

The idea of data sharing, especially in the present scenario when COVID-19, has caused havoc across the globe that cannot be overemphasized. But such efforts need to be complimented by reactionary approaches aimed at helping to overcome some deep-rooted challenges that have curtailed free sharing, use, and distribution of data. In view of this, there is a substantial amount of literature dedicated to discussing primary challenges that are associated to data. Among those challenges identified include those of privacy, security, ethics, transparency, volume, and storage to name a few. The concern over those challenges is even further accentuated by the increasing technological advancement, where with some modern technologies, it has become increasingly possible for different agencies and individuals to unlawfully access private data. Tiell (2016) of Accenture affirms this and further expresses that as the amount of data increases, and the means to generate and collect such also in inexpensive ways, the privacy concerns become live. In this case, it becomes relatively hard to convince potential sources to freely share their data, as they fear that such would be compromised, especially for-profit gains. The fear also arises as it is evident that in most cases, such are stored by third parties, especially large ICT corporations that have the technological capacity to collect and store large amounts of data (Allam, 2018a, Allam, 2019b, Allam, 2020d, Allam, 2020e; Allam and Newman, 2018). The fears are compounded by the fact that these parties can, in some instances, share the data in their possession for their own selfish interest, or as tools for target marketing. Such would go against the letter and spirit of VGI, which is based on the principle of transparency and ethical use of collected data (Blatt, 2015). This fear often results in artistic manifestations, as shown in Fig. 5.1.

While those challenges persist, in the recent past, there have been spirited efforts to reverse the situation, especially through the formulation of a series of legal frameworks, standards, and protocols that would guide data management, access, and sharing. In this regard, it is possible to point some practical examples. For instance, in the European region, there is a legal framework dubbed Nordic Data Sharing Framework (Salokannel, 2013) aimed at ensuring that certain procedure, rules, and laws are followed while sharing data. Another example is the Cyber Security Information Sharing Act (CISA) (2015) that was passed in 2015 by the US Senate. Other such frameworks include the General Data Protection Regulation (GDPR) (2016), Trusted Data Sharing Framework, and the Data Sharing Code of Practice that borrows from section number 121 of the Data Protection Act passed in 2018 by the European Parliament (2018). With these, plus a myriad other based on different parts the world, those are observed to provide some reprieve when it comes to sharing of data, especially which has the potential to expose private information. With adequate safeguards and platforms, it has become possible to

FIG. 5.1 Artistic manifestation showing unease over constant scrutiny.

overcome data silos, which most existing databases have maintained, with a bid to overcome existing restriction and filter any unauthorized communication. With such frameworks and protocols, it is a daunting task to allow for free data sharing and leave alone open access of the databases.

Besides overcoming the silos, reworking on the existing standards and protocols allows existing databases to be enriched, and this is affirmed by the quality of insight derived after analyzing the data. This does not imply that they are insufficient in their current form, but eliminating silos is the surest way of enhancing them. This is true as most of the information being sought, in most cases, especially those related to health need to be diversified, regarding issues such as geographical location and demography. For instance, in the current case of COVID-19, compelling insights can only be achieved if analysis is done with data that capture details from different geographical locations—countries, cities, and establishments. But, still, the existing frameworks are not enough; as already, due to their divergence in relation to different issues, it has become hard to have an agreement on the conclusion being drawn in different countries. For instance, China, which was the first to experience the outbreak of the coronavirus, has been accused, especially by the United States, of giving falsified data and information, especially about the emergence of the virus, the spread, and its impact (Crowley et al., 2020). According to Moorthy et al. (2020), the fight against COVID-19 needs to be addressed from a point of sincerity and transparency, especially in regard to data sharing; hence, they emphasize that all concerned agencies and governments need to ensure the authenticity and urgency of sharing the data. By doing this, the world would prevent a repeat of the 2002 severe acute respiratory syndrome (SARS) outbreak, where China was accused of delaying information on the outbreak, thus making it hard for identification and subsequent diagnosis and control of the virus (Cao et al., 2019). The World Health Organization recommends the approach taken during the 2016 Ebola virus outbreak where there were concerted efforts from different agencies and government and, thus, saw the virus contained before it could spread further beyond the three affected Western African countries (Wojda et al., 2015). With that, the current case of COVID-19 requires an open database where all participating institutions, governments, and other stakeholders can easily access the data. However, as of now, this protocol has not yet been established or communicated, but the severity of the virus demands that protocols be adopted and communicated in a clear fashion such that a solution on the virus can be formulated before the global health, society, and economy reach a tipping point.

OVERCOMING DATA SHARING AS A PSYCHOLOGICAL TRAIT

Through the numerous technological advancement that the world has been experiencing since the turn of the fourth industrial revolution, the amount of data being generated has continued to increase. There before, due

to scarcity and complexity of technological tools, and the exorbitant costs of collecting, storing, analyzing, and distributing data, researchers and other data users had to face numerous challenges. Similarly, during those periods, the need for data was not as expounded as it is today; hence, people, organization, institutions, and even government could comfortably survive without data. But today, things have changed, and it has become paramount to have access to data to position oneself as a key player in this competitive world. Luckily, the infiltration and accessibility of mobile devices such as phones, cameras, and wearables have come in handy in ensuring that massive amount of data is available. Similarly, the availability of these devices has been complimented by the availability of diverse social media platforms, and fast Internet has made the generation and sharing of data even more ubiquitous. But, as has been shared comprehensively in the sections earlier, these advancements have attracted substantial challenges, especially those related to privacy, security, transparency, and ethics that have been seen to curtail the freedom, the scale, and volume of data sharing. Indeed, Bezuidenhout and Chakauya (2018) highlight that most people are now apprehensive to share their data for fear that such would be exploited to disfranchise and disadvantage them. Even in high ranking government levels, there is apprehension that some of the technologies that have been developed are maliciously crafted to enable agencies and governments to extract private data from individuals and institutions without their consent.

Some of the issues that have brought about this apprehension range from the profit value that has been attached to data, with large ICT organisations seen to be increasing their activities, including heavy investments in R&D to come up with cutting-edge technologies and devices to help them collect and store data. With such technologies, those are observed to seek increasing revenues, as most governments and institutions are constantly contracting startups with capacity to collect and store massive data on different issues. Such data have also become very popular for target marketing and those with capacity to collect gain financially by sharing insights with marketing institutions. But, further from that, the main concerns with access to data are increasing incidences of terrorism activities such as recruitment and planning. There are also fears of extortion and sabotage of personal privacy among other issues. Such have been seen to sometimes overshadow the original intents such as prevention of crime, increased efficiency in service delivery, medical purposes, improvement of liveability and resiliency of cities, and reduction in some bureaucracies and bottleneck in service delivery to mention a few. While in such scenarios, the existing data sharing frameworks and protocols have been seen to be adequate by proposing data anonymization and encryption, technology advancement is seen to enable reidentification, thus warranting the need for even more stringent measures. When all these challenges are compounded, as noted by Waithira et al. (2019), it becomes relatively hard to convince people to freely share their data, as already the levels of mistrust on agencies handling data are high and thus are seen to create psychological barriers to data sharing. This reality is not conducive for a world that is prone to numerous challenges like the present case of COVID-19, which urgently requires any available data to be analyzed to help in manufacturing vaccines, drugs, and relevant preventive tools and measures.

Though such psychological barriers may exist, it is now possible to talk through and win the public confidence on data sharing. This would be achieved by employing emerging technologies such as blockchain technologies and quantum cryptography, which have shown to be reliable in safeguarding the anonymity of individuals (Allam, 2018b; Allam and Jones, 2019; Naz et al., 2019; Shahab and Allam). As shared by Hölbl et al. (2018), blockchain technology is particularly popular currently due to its qualities such as scalability, immutability, decentralized, secure, reliable, and transparent. Such qualities are sought by those willing to share their data through trusted platforms. Therefore, while these technologies are relatively in their infancy stages and are being tested in different areas, they give a glimpse of hope in overcoming the apprehension caused by the increased leakage of data and the challenge of being traced back.

Availability of such technologies, especially in moments like now when the challenge of COVID-19 is stressing and disrupting the core of the global systems, may inspire some paradigm shift in people and encourage them to voluntarily share data. This is pegged on the fact that even in times of distress, people are not readily prepared to share their data if they are not assured of its privacy and security. This is well recognized in the General Data Protection Regulation (GDPR) (Ketola et al., 2020), which emphasizes that data especially that with potential to directly or indirectly lead to identification of a natural person need to be handled with extra care. Doing this prevents scenarios where data are traced back to their source. That is, using technologies such as machine learning and reversing the process of data

sharing such that one can identify individuals involved in the designing, generating, and sharing of the data. The Imperial College London (2019) calls that process the "reverse engineering" of data, and it shows how much progress the technology has brought in the global arena and, thus, increases the apprehension that people have on sharing data, as such new technologies have the capacity to override the anonymizing and encrypting ones that have been relied upon to prevent identification of persons. Therefore, as is the view of Crutzen et al. (2019), institutions and agencies and any stakeholder involved in data need to restrict themselves to only the data they require to conduct their research work. This strategy of data minimization ensures that as much as possible, only little data that can be utilized to identify an individual are available. Such strategy of data minimization needs to be enhanced with advanced data sharing protection mechanisms, thus inspiring data handlers to share data they have ownership of.

ON VOLUNTEERED GEOGRAPHIC INFORMATION AND CITIZEN SCIENCE

While there are diverse viewpoints on data sharing and the need for stringent measures to safeguard the same, especially to overcome the psychological barriers that is created by the public not trusting the whole system of data management, some cases are different. For instance, the present case of COVID-19—its spread, infectiousness, and havoc it is causing on the health sector, the social fabric and the economy have triggered an urgency on the citizen to voluntarily share data, with a hope that it could warrant the survival of people. On this, it has been observed that a majority of people in different parts of the world are willingly presenting themselves to health facilities, and in some countries, they are willingly collaborating with government agencies (UNHCR, 2020) to voluntarily share information on the coronavirus. Same trends of voluntary data sharing have been observed with popular celebrities drawn from different backgrounds who are sharing their coronavirus health status with the world. Promising enough, these are also willingly complying with the medical requirement for quarantine and self-isolation, so that they can not only safeguard themselves but also cut the spread link, thus, protecting potent contact they would infect. On the government level, similar cases of citizen science are being demonstrated. On this, it is unusual for high-ranking government officials to disclose their health status to the public, but with the coronavirus, traditional knowledge is being shattered. For instance, in different jurisdictions, top officials such as the German's Chancellor Angela Merkel publicly shared their coronavirus status and voluntary submitted to the self-quarantine rule (Delfs and Donahue, 2020). In another case, the Prime Minister of Canada was unhesitant to disclose that his wife had tested positive, leading both of them in self-quarantine (Gillies, 2020). Same case with the British Prime Minister, Boris Johnson, who made a video to share the unfortunate news that he had contracted the virus and was henceforth working from his isolation room (BBC News, 2020) and later hospital.

In view of the earlier background and examples, it then verifies that the VGI model of data sharing can become a strong approach that can be used to enrich the available datasets, more so to overcome global, modern challenges. In the case of COVID-19 pandemic, availability of an open access dataset enriched with data from the length and breadth of the world would enhance steps being made in finding a short-term and long-term solution to the health crisis. From such a dataset, anyone now has the potential to track how the virus is spreading and areas, or regions that require concerted efforts such as supply of test kits, personal protective equipment, food and medical supply, and other essentials. Similarly, information from such datasets can inform governments on steps to take regarding travel ban, lockdowns, and other necessary measures that can prevent the spread of the virus. Likewise, similar approaches could be used in the future to address other global challenges such as terrorism and future pandemics.

The advantage on this is that with modern technologies, and availability of smart devices, it is possible for data to be sourced from different quarters in real time and in an inexpensive fashion. This is perhaps well represented in the rich assortment of wearable tech available today, represented in Fig. 5.2.

But, on this, there also need to be systems and mechanisms in place to ensure that the data shared are filtered such that only factual, time-sensitive, and comprehensive ones are admitted into those datasets. This way, the quality of insight drawn from analyzing such data would be assured. And, while this is pursued, issues such as privacy and security that hold backs voluntary data sharing need to be fully addressed to assure the public of the trust and transparency.

DISCUSSION AND CONCLUSION

The discussion in the previous section, in an expounded way, demonstrates that most of the urban challenges can be, in a larger margin, solved by analyzing the massive

FIG. 5.2 Common wearable technology and portable devices.

data being generated from different quarters. In particular, with the increasing penetration of smart mobile devices, sensors, and other smart devices, which has the potential to link to an existing network, the amount of data being generated and shared is massive, and such can be exploited to develop long-lasting solutions. One such scenario where data have been handy is the present case of COVID-19 pandemic, where through data, its spread, its infectiousness, and its impacts have been made known to the public. Such were shared by BlueDot and Metabiota, some of the modern startups that use data, and through advanced technologies, such as natural language processing and machine learning, they were able to predict some of the geographical location that the virus would spread next from Wuhan, days before first cases were reported in those regions. In addition, it is through availability of data from different locations and sources that health officials, governments, and researchers and other stakeholders are able to establish the manifestation and impacts of the coronavirus in respect to demographic factors such as age, gender, preexisting health condition, neighborhoods, and others. But, from the global happening, where despite spirited efforts and measures like quarantine, self-isolations, lockdowns, and others that have been instituted have not been successful in preventing the virus from spreading. This means that more data require to be collected and analyzed, especially in laboratories and in other medical fields to comprehensively come up with a solution that can help in containing the outbreak.

Regarding the earlier call for more data, there are now some steps that have already been made, especially in coming up with smartphone applications that have the potential to track and report on the infected people. With these Apps, and relying on the concept of citizen science, there is optimism that people can voluntarily continue to share more data, which would ultimately be very useful in advancing research on how to contain the virus. In this front, some of the Apps that are already in use include the COVID-19 tracker that is dedicated to tracking all aspects of COVID-19 with the perimeters of the United Kingdom (Wakefield, 2020). In China, where the virus broke first, giant companies such as Alibaba Group and Tencent are said to have taken the challenge of fighting the virus spread by incorporating coronavirus trackers in their existing Apps. For instance, Alibaba incorporated a color QR code in Alipay App dedicated to identifying those suspected to have contracted the virus. Those whose color turns red after the QR code is scanned then can use the company's messaging App (DingTalk) to seek medical services (Li, 2020). The same approach of using QR code is also available in WeChat App (owned by Tencent) (Voa Student Union, 2020), and such are said to be playing a significant role in ensuring the virus is contained in the country. In the United States, the government is discussing with social media giants such as Facebook, Twitter, and Google to help track whether people are maintaining social distance (Porterfield, 2020). The emergence of these, and many other, Apps dedicated to track the virus across the globe is aimed at enhancing data collection mechanism, especially focusing on the voluntary sharing. The success of such Apps will help in complimenting the existing data collection mechanism, with the main goal focusing on having enriched databases that can be used to give insights on the global virus status.

While those efforts geared toward increasing voluntary data sharing are necessary, the need to strengthen data security and privacy should simultaneously be enhanced, thus assuring those sharing their data, including private ones that such would not land in

hands of malicious people, will not in any way be used beyond their intended purpose. Such efforts would not only help in breaking the psychological barrier but would also increase the confidence and trust that the public has with data-oriented institutions and agencies, and ultimate effect would be increased volumes of data shared. This, coupled with modern technologies, as is discussed above would in turn lead to improved service delivery, lead to improved liveability status, and increase urban digital solutions. The same, especially sourced from health devices and wearable technologies, would help in formulating solutions for medical problems such as pandemics, help in improving diagnosis, and help in surveillance and monitoring to name a few. Availability of big data would also help in optimal use of resources, reduction in pollution, and speeding up efficiency in service delivery.

While there is evidence that there are some emerging, positive changes in the data landscape scene, more study is still necessary to explore how such changes are impacting different sectors, especially on social and economic frontiers. The need for this is based on the fact that, in the recent past, data are argued to be the "new oil" of this modern time, and wide scale acceptance of the concept of VGI would only lead to an increased amount; thus, it would be expected that social and economic sectors would change for the good. But, while that is the same, it is also known that some organizations have been increasing their investments in the ICT so that they can profit from data management (Yigitcanlar and Bulu, 2016); hence, the expected positive changes in the aforementioned sectors may not be actualized, or in the scale commensurate with amount of data shared. With further study, it would be possible to establish such and recommend some of the proactive actions that can be taken to ensure the public truly benefit from their actions to accept the call to voluntary share their data.

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