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Growing Concern During the COVID-19 Pandemic: Data Privacy

COVID-19 Salgını ile Birlikte Artan Endişe: Veri Gizliliği

Fedayi YAĞAR[a]

[a]Kahramanmaraş Sütçü İmam University Faculty of Economics and Administrative Sciences, Department of Health Care Management, Kahramanmaraş, TURKEY

ABSTRACT The aim of the study was to examine data privacy which has become a subject of debate with the COVID-19 pandemic. While evaluating data privacy, it is considered that there is a balance between data privacy and public health in a pandemic crisis, where latter outweighs the former. Therefore, mostly the period following the pandemic was focused and which significant issues to be taken into consideration in terms of eliminating the possible negative impacts of data policies implemented today were discussed in the study. Firstly, mobile applications (such as TraceTogether and PEPP-PT) or technological infrastructures developed to track patients and provide their filings in South Korea, Taiwan, China, Europe and Singapore were explained. Increased concerns about data privacy have been expressed with such approaches. Four main matters were determined to be considered with regard to the technological applications being used as a part of COVID-19 response efforts. These are: 1) Complying with regulations and international health guidelines, 2) Having transparent data collection and processing conditions, 3) Using anonymized mobile geodata, and 4) Conducting data quality and security controls. It is believed that paying attention to these matters will be beneficial after the pandemic or while developing new applications. In addition, together with the consideration of these issues and preparation of the necessary infrastructure, it has been seen that telemedicine applications can be an important power in the fight against COVID-19. It is emphasized that it can make an important contribution in controlling outbreaks and preventing unnecessary use of health services.

Keywords: COVID-19; data privacy; mobile applications; telemedicine

ÖZET Bu çalışmada, COVID-19 ile birlikte tartışma konusu hâline gelen veri gizliliği konusu incelenmiştir. Veri gizliliği ile ilgili değerlendirmeler yapılırken, bir pandemi krizinde veri gizliliği ve halk sağlığı arasında bir denge olduğu, bu dengede halk sağlığı kısmının ağır bastığı yaklaşımı dikkate alınmıştır. Bu sebeple yapılan bu çalışmada, daha çok salgın sonrası süreç düşünülmüş, günümüzde uygulanan bu veri politikaları ile birlikte oluşabilecek olumsuz etkileri azaltmak için hangi önemli noktaların dikkate alınması gerektiği değerlendirilmiştir. İlk olarak Güney Kore, Tayvan, Çin, Avrupa ve Singapur'da hastaları takip etmek ve filyasyonu sağlamak için geliştirilen mobil uygulamalar (TraceTogether ve PEPP-PT gibi) veya oluşturulan teknolojik altyapılar açıklanmıştır. Bu gibi yaklaşımlar ile birlikte veri gizliliği konusunda artan endişeler ifade edilmiştir. COVID-19 ile mücadelede kullanılan teknolojik uygulamalarda 4 temel hususa dikkat edilmesi gerektiği belirlenmiştir. Bunlar: 1) Düzenleyici uygulamalara ve uluslararası sağlık yönergelerine uyulması, 2) Veri toplama ve işleme koşulları açık olması, 3) Anonimleştirilmiş mobil konumlandırma verilerinin kullanılması, 4) Veri kalitesi ve güvenlik kontrollerinin yapılmasıdır. Salgın sonrası süreçte veya geliştirilecek yeni uygulamalarda bu hususların dikkate alınmasının fayda sağlayacağı düşünülmektedir. Ayrıca bu hususların dikkate alınması ve gerekli altyapının hazırlanması ile birlikte, teletıp uygulamalarının COVID-19 ile mücadelede önemli bir güç olabileceği görülmüştür. Salgınların kontrol edilmesi ve gereksiz sağlık hizmetleri kullanımının engellenmesi noktasında önemli bir katkı sağlayabileceğine vurgu yapılmıştır.

Anahtar Kelimeler: COVID-19; veri gizliliği; mobil uygulamalar; teletıp

As of late December 2019, coronavirus disease-2019 (COVID-19) has emerged in Wuhan, China, known as COVID-19 that adversely affects many countries in the world.[1] According to a report published on February 11, 2020 by the Chinese Center for Disease Control and Prevention, it took 30 days for the disease to spread from Hubei to all over the country.[2] The World Health Organization soon announced this disease as a public health problem at a global level.[3]

Correspondence: Fedayi YAĞAR
Kahramanmaraş Sütçü İmam University Faculty of Economics and Administrative Sciences, Department of Health Care Management, Kahramanmaraş, TURKEY/TÜRKİYE
E-mail: fedayiyagar@hotmail.com

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The COVID-19 is an immediate and spreading threat where clinical and epidemiological characteristics are still being documented.[4] Efforts still continues to find a specific solution (such as drugs or vaccines) for the disease. The capabilities (such as healthcare system capacity) of countries play an important role at this point. In their study, Kandel et al. analyzed the response efforts of 182 countries against the pandemic.[5] Some actions to be taken in order to effectively respond to the pandemic were briefly explained. These actions are as follows:

- Taking into consideration population density and not allowing crowds;
- Raising public awareness on issues such as hand hygiene to protect public health;
- Strengthening laboratory capacity and effectively detecting suspected cases;
- Effectively managing emergency logistics - as a country, plans are ready, capacities are checked, constantly updated and prepared for any emergency;
- Investing in human capital - increasing investments in the fields (such as economists, communication specialists and data scientists) required to provide education in a timely, complete and quality manner;
- Ensuring multisectoral coordination and cooperation at both national and international levels;
- Access to primary health care services (such as maternal health and immunization services) should be provided and the healthcare system should be able to provide continuity services.

According to Wang et al., the most fundamental action to be taken is to inform and guide the public accurately.[6] For example, the Deputy Minister of Health and Welfare of Taiwan regularly updated the public through briefings (on where and how to wear face masks, the importance of hand-washing, etc.) broadcasted from the President's office and also online and this had a major impact in ensuring public participation. It is also very important to have a committee dedicated for the outbreak. For example, the Taiwanese government established the National Health Command Center in 2004, a year after the SARS outbreak. This committee became a part of a disaster management center serving as an operational command platform to ensure direct communication among central, regional and local authorities focusing on outbreak response efforts. This committee is thought to have played an important role in Taiwan's success in its COVID-19 experience. The same approach was also the case in Turkey. The Ministry of Health has been the sole authority sharing regular and up-to-date information to prevent information pollution and the Scientific Committee has had great influence over the decision-making process enabled Turkey to be more successful compared to many other countries.

THE USE OF TECHNOLOGY IN COVID-19 RESPONSE EFFORTS: PATIENT DATA COLLECTION

Countries introduced different technological applications to better monitor patients and to trace contacts. For example, in Singapore, the Ministry of Health introduced a new application by March. Expressed as "TraceTogether", this application works by considering the Bluetooth connection. Through these connections, tokens are exchanged between the phones and generally these tokens are transferred to a central server. Phone owners do not know who they belong to. Here, infected individuals register to the system precisely and can create a list of these people and their contacts in the government. At this point, it can be said that the data privacy of the infected people is provided less. The biggest challenge in this application is the possibility of malicious actors to falsely claim to be infected.[7] The Pan-European Privacy-Preserving Proximity Tracing (PEPP-PT) application, which was developed jointly by Google and Apple in Europe, is known to be quite similar to TraceTogether.[8]

Taiwan has initiated special approaches in order to protect public health and quickly took action to detect cases, to limit them and to allocate resources. In this process, Taiwan decided to consolidate national health insurance and migration and customs databases. A large database was created, taking into account the travel history of individuals and case symptoms. With this approach, QR code scanning was carried out and classifications were made to min-

imize the level of contagiousness, taking into account the last 14 days of individuals. In this classification made according to risk levels, the last level (high risk ones) were quarantined in their homes. Individuals who were under quarantine were followed up with their phones. Individuals in the low-risk group were sent messages explaining their status via SMS (short message service).[6]

With the MERS outbreak in 2015, South Korea amended its Infectious Disease Control and Prevention Act. This amendment granted relevant institutions (Ministry of Health and Welfare and Korea Centers for Disease Control and Prevention) the power to collect certain data, to conduct profiling and share these profiles in case of a new outbreak. The data that can be collected included personal identification information; medical and prescription records; immigration records; card transaction data for credit, debit, and prepaid cards and transit pass records for public transportation. Later on, with the COVID-19 outbreak, the Korean government developed a customized app for quarantined individuals and required them to report their health status on a regular basis with aggregated location data. These data were also used in modeling efforts to locate potential sources of community transmissions. The focus of this application was tracing infected individuals and also those who had been in contact with an infected individual. The data can be shared with central, municipal, or local governments, national health insurance agencies, and health care professionals and their associations.[9]

Chinese officials made it compulsory to use an application developed by Ali Baba on smartphones. The basis of this application is QR codes in different colors. With this approach, the places visited by individuals are tracked and security inspections are carried out frequently. The main purpose here was to restrict individuals' freedom of movement on certain issues, such as access to offices or using public transport.[10]

DATA PRIVACY CONCERNS RAISED WITH COVID-19

In order to emphasize the importance of personal data protection, an explanation has been made by the European Data Protection Board, with an emphasis on combating COVID-19. In this disclosure, the General Data Protection Regulation is taken into consideration and certain article are highlighted. The point that draws attention to this explanation was the evaluation made on article 9. According to this article, considering the public interest (for public health), it is stated that the data can be used for specified purposes in order to prevent serious threats to health. It was also stated that the rights and freedoms of the data subject are protected and the right to data protection is taken into account.[11] Despite such statements, there is growing concern about data privacy. For example, in some countries (such as Israel, South Korea and China), it is stated that personal mobile phone data is used to both inform individuals and track their movements. Human rights organizations, social media, various civil society actors and public opinion surveys have started to emphasize certain points. These points are; ethical problems can arise, potential loss of privacy may arise and in this case may cause concerns over civil liberties.[12] For example, some problems arose with regard to the application in South Korea where the profiles of infected people were accessed and leaked. Privacy of some of these people were violated and they were subjected to public shaming. Restaurants, stores and other businesses visited by infected people experienced job loss.[9]

In the United States, Google and Apple have recently announced that they are developing a tracking app together. To minimize privacy concerns, the two tech companies focused on Bluetooth-based proximity detection. The application is designed to hold the most information on users' phones instead of servers. In some states, such as California, state laws may provide some protection for data privacy, but not every state has laws or regulations. At this point, it is hoped that technology companies will have good intentions, do not abuse data or violate confidentiality.[13]

In the world of 2020 where a huge amount of data is consumed, omnipresence of hot spots and digital surveillance devices can further exacerbate these concerns. China, the country most affected by COVID-19, was reported to make use of data collected from sensors located everywhere and health control practices to prevent the spread of the disease. According to the report published by the New York

Times, the transparency of how this data will be supervised, how it will be controlled and whether it will be reused or not is not specified sufficiently.[11]

Telemedicine is one of the practices employed for patient care. For example, two possibilities are currently available for patients in the United States: The first one is direct-to-consumer telemedicine with private providers mostly relying on out-of-pocket or private insurance payment and the second one is free solutions (for example, WhatsApp, Skype, or Facetime).[14] The United States Department of Health and Human Services recently liberated the HIPAA eligibility rules for the COVID-19 outbreak. Many free or low-cost apps have become available, including Apple Facetime, Facebook Messenger video chat, Google Hangouts video, and Skype.[15] Research conducted by Mann et al. states that telemedicine visits increased from 102.4 daily to 801.6 daily between March 2 and April 14, 2020.[16] It has been stated that the use in emergency health services has increased a lot (683% increase). Ohannessian et al. also emphasized their hesitation that with the increase of this approach, the confidentiality and security requirements of national health data will not be complied with.[14] Similarly, in their study, Leite et al. stressed that data privacy and protection were a critical issue to telemedicine and that this issue had been raised as a significant challenge by academics and practitioners.[17]

Starting to use artificial intelligence and collecting data in this way can have negative effects. For example, fear of "big brother" style control may occur. It is expected to use data to fight the virus. The point to be emphasized here is that any institution is prevented from using this data for different purposes. If the applications used are not secure, this data can be collected individually and used by any company or hostile government.[10] It is of paramount importance to not let such approaches come out. Otherwise, the public may lose confidence in its government and be lax in following public health recommendations, which may result in undesirable health outcomes.[18]

CONCLUSION

The topic of data privacy, which has become a matter of debate with the COVID-19 pandemic was discussed and the recommendations based on researches were presented in the present study.

DATA PRIVACY: WHAT TO DO TO EASE CONCERNS?

It is critical to act early to contain the spread of a highly infectious disease such as COVID-19.[9] Data collected so far on COVID-19 suggests that nearly half of all infections develop even before symptoms like fever or persistent cough show. For this reason, it is not enough to quarantine people only after they start showing symptoms. It is necessary to act rapidly to find the contacts of a confirmed COVID-19 case to reduce infections. That is how the chain of transmission can be broken.[8] As this approach became more widespread, many countries launched similar applications (like TraceTogether and PEPP-PT), which raised concerns about data privacy. So, what can be done to ease these concerns?

Complying with regulations and international health guidelines. When the pandemic is over, the legal system to be established based on these principles could be further refined to facilitate the use of aggregated data rather than individual-level data to deter misuse of the data.[9,19]

Transparent data collection and processing conditions. Not ensuring this transparency could undermine the trust of the public. In this case, individuals may not consider the recommendations regarding public health (the probability of follow-up may decrease) and then come up with a more negative situation in terms of health outcomes.[11] People must know that their personal data is secured by a public institution, this data will be pulled back once the outbreak is over and not be used for any other purpose.[10]

Using anonymized mobile geodata. Solutions that minimize data must be developed. For example, opting for a Bluetooth-based solution rather than directly collecting geodata of individuals could be a more beneficial approach. Throughout the entire process, no one (other users who were in close contact, local healthcare officials, the central server, etc.) learns the identity of the user since it is not linked to application identity. Geodata cannot be saved or stored at any point during the process. The "TraceTogether" application developed in Singapore and the "PEPP-PT" application criticized in Europe are good examples for this approach.[8]

Data quality and the lack of security controls. With the use of personal digital devices, weaknesses in data integrity may occur. This can lead to errors, which can have a major impact on large-scale predictive models. Furthermore, biases in datasets, insufficient or ineffective de-identification and data breaches can become major causes of distrust in public health services.[11]

TELEMEDICINE: IT CAN BE A MAJOR POWER IN COVID-19 RESPONSE EFFORTS

Disasters and outbreaks bring many challenges to healthcare services. Provided that relevant regulations on data privacy are respected and necessary infrastructure is in place, telemedicine could be a great option for physicians to evaluate patients. Credentialing across hospitals, state licensing, payment and regulatory structures, and program implementation all take time to work through, but health systems that have already invested in telemedicine are can save on resources by automizing the general tracing processes of epidemiology researchers.[9,20] It can also be used to reduce face-to-face clinical visits of patients with chronic patients and to meet their ongoing health needs.[21] Telemedicine was shown to be helpful in previous outbreaks of SARS and Ebola and in preventing the use of unnecessary healthcare services.[14]

They can also be of help in reducing the psychological impacts of these outbreaks. For example, a variety of telemental health services were offered in China following the COVID-19 outbreak. State and academic institutions offered psychoeducation, as well as counseling services through online platforms (helpline, WeChat and Tencent QQ, etc.).[22] Likewise, according to Calton et al., physicians' asking patients about their mental states can have a positive effect on patients.[15]

In the study carried out by the French Ministry of Health, regulations were made in the National Health Insurance for the infected individuals and a decree was issued allowing the reimbursement of tele-expertise and video teleconsultations. The decree was aimed to allow follow-up of mild confirmed cases from home, screen and detect suspected patients, limit the number of individuals grouping in waiting rooms and decrease unnecessary travel for medical consultations.[14] On the other hand, it is safe to say that there is not enough labor force to carry out such practices. At this point, physicians, who are quarantined and fit for working, can also be considered as workforce, or as pointed out by Greenhalgh et al., individuals with mild and non-complicated symptoms can be managed through the phone.[4,20] Using telemedicine in this way can allow it to be separated into patients who need medical supplies.[21]

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Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Authorship Contributions

This study is entirely author's own work and no other author contribution.

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