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Ethical, legal, and social issues related to the retrieval of personal information through digital contact tracing apps: Lessons from Japan

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Abstract---During the COVID-19 pandemic, digital contact tracing apps were developed and operated in various countries. They were partially effective in preventing COVID-19 transmission and fairly allocating finite healthcare resources such as hospitals. However, the functionality of digital contact tracing apps considerably varied among different countries. While one of the differences included technological development capabilities, a more prominent difference was that although digital contact tracing apps promoted public health benefits and the efficient use of finite healthcare resources, they also potentially increased the risk of personal information leakage or misuse of the app users' data. Higher app-mediated intervention facilitates the prevention of infectious disease transmission; nevertheless, it also increases the risk to users' privacy.

Keywords---ethical, legal, social issues, personal information, digital contact tracing apps.

Introduction

During the COVID-19 pandemic, digital contact tracing apps were developed and operated in various countries. They were partially effective in preventing COVID-19 transmission and fairly allocating finite healthcare resources such as hospitals [1, 2]. However, the functionality of digital contact tracing apps considerably varied among different countries. While one of the differences included technological development capabilities, a more prominent difference was that although digital contact tracing apps promoted public health benefits and the efficient use of finite healthcare resources, they also potentially increased the risk of personal information leakage or misuse of the app users' data. Higher app-

mediated intervention facilitates the prevention of infectious disease transmission; nevertheless, it also increases the risk to users' privacy [3].

While defining the functionality of digital contact tracing apps, potentially conflicting ethical norms between the principles of beneficence and respect for autonomy should be considered before making decisions and reaching a consensus at the national level. Additionally, the actual operations of the apps must be conducted in compliance with the legal norms of the community.

However, during the recent COVID-19 pandemic, the countries possibly had limited time to fully consider Ethical, Legal, and Social Issues (ELSI) before making decisions regarding the functionality of the app [4]. Consequently, some countries developed apps that were either ineffective in preventing the spread of infectious diseases owing to privacy risks or had a high degree of intervention without sufficient public consent.

In Japan, the Ministry of Health, Labor and Welfare (MHLW) developed and released the "COVID-19 Contact-Confirming Application (COCOA)" in June 2020 and widely encouraged its use by the public [5]. COCOA had the following three functions: 1) registration of positive PCR test results; 2) notification of contact with a COVID-19-positive person; and, 3) guidance to a consultation center in case of contact with a COVID-19-positive person. The description of COCOA on the official website of MHLW is presented below:

"This application enables users to receive notifications about possible contact with positive COVID-19 cases after approval from the individual user by utilizing the short-range communication function (Bluetooth) on smartphones. It ensures privacy by preventing users from identifying each other. Users can receive quick support from local public health centers, including test visits if they know that they might have been in contact with positive cases. The more users use this app, the more effective it will help prevent the spread of infection."

COCOA uses the same privacy protection technologies as those of Apple and Google, allowing users to freely choose whether or not to use it and preventing the determination of users' device location data beforehand [5]. Therefore, COCOA involves maximum consideration of the privacy risks of app users. As of November 2022, COCOA had 41 million downloads, and 58% of all users responded to a survey stating that they were "not particularly happy with COCOA" and that there was nothing in particular that they felt good about while using the app. Moreover, only 37% of all the respondents were aware that COCOA did not use the personal information of users [7]. The summary report by the "Collaborative Team on the Operation of the Contact-Confirmation App COCOA" is presented below:

"The lack of clarity on how to effectively call for behavior change and specific measures for those who received COCOA notifications and the lack of information necessary for active epidemiological studies led to the evaluation by infectious disease control specialists and health center operations that the system was inadequate."

“The technology provider was unable to present the possibility that the contact confirmation application system could be a solution to what was considered an issue at the time on the part of experts in infectious disease control, such as approaching the younger generation, which is more active, and alerting contacts when the number of infected cases increases. The experts in the field of infectious disease control were not able to explore the possibility of using the technology to solve their problems because of the evaluation that the technology could not be used for existing countermeasures.”

While considering public health measures for future infectious disease pandemics, it is important to re-examine laws regarding the handling of personal information and assess public opinion on the balance between public interest and privacy risks to achieve balanced and ethical policy-making and administration.

In several countries, social research was conducted on the ethical dilemmas concerning public interest and privacy risks in the management of infectious diseases using mobile device applications or other information technologies [8–10]. In this context, in June 2021, we conducted an internet-based survey of the general population in Japan to determine their attitudes toward the use of digital contact tracing apps to prevent the spread of infectious diseases, such as the COVID-19 pandemic, in Japan. In this survey, we assumed that the following functions were added to the current COCOA: 1) automatic registration of COVID-19-positive persons to the MHLW database; 2) location tracking and notification functions; and, 3) introduction of infection prevention measures based on information of the app users’ movement. Thereafter, the respondents were asked how hesitant they would be to using an app with each of these additional functions. The percentages of those who answered “definitely do not want to use” or “feel great hesitation to use” were 27.3%, 31.4%, and 33.6% for functions 1, 2, and 3, respectively.

Notably, we found that if adding these three functions to COCOA reduced the number of new infections by half, hesitation to the use of this app would be reduced to a minimum. Paradoxically, respondents showed a rather high level of resistance to using the apps when offered a discount on their cell phone usage in exchange for the addition of the respective functionality options. Our survey results suggest that at least in the case of an event that threatens the entire nation, such as the recent COVID-19 pandemic, contributions toward health benefits on a group basis, such as the prevention of infection transmission, are more valuable than individual financial benefits and can even overcome concerns regarding privacy risks and data leaks [11]. In September 2022, we conducted another survey using a conjoint analysis method, in which respondents were asked to rank their preference for specific combinations of app functions; nevertheless, we obtained results that led to the same conclusion as that of our first survey.

The respective governments are required to impose a strategy to cope with difficult situations, such as in the event of an infectious disease pandemic or other emergencies, including major disasters and wars. Contact-tracing apps can help protect the lives and health of many people in such contingencies. However, when a particular organization utilizes personal information retrieved through an

app, it is, in principle, subject to the consent of individual users based on a voluntary purpose. Even if a utilization method that significantly contributes to public interest is proposed, it would not be appropriate for the government to implement the strategy without public consent if there is no consensus on who will utilize users' personal information and for what purpose. Moreover, although operational feasibility may be enhanced through various legislations such as contingency bills, we believe that such legislation should also exist on the premise of public understanding and consent. The COVID-19 pandemic provided an important opportunity to learn ELSI lessons regarding the nature of public administration in information gathering, the authority of the state, and social consensus-building procedures. We hope that this event will be researched academically, and recommendations for future contingencies will be proposed by different sectors.

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