Paradigm Shift in the Concept of Privacy:
Data Managing in the Age of Digital Revolution

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Preface
According to the International Association of Privacy Professionals (IAPP), privacy is “the right to be let alone, or freedom from interference or intrusion”.1 While privacy then can be considered a right, is also a part of freedom.

Introduction
Digitized Society
We live today in a time of digital revolutions and big data. Data and digital devices are almost everywhere around us. For most, it is difficult to end the day without touching any digital device including smartphones, tablets, or computers. Moreover, our use of these devices is generating a large amount of data every single moment. Essentially whether you like it or not, when you visit any website, new data is created by your movement within that site. The data is used for improving user experiences and promoting digital marketing. However, how many are really aware of the almost automatic acquisition of our data? In my case, the answer would be “Yes,” but perhaps I pay it little mind; whenever I open a website and find the box declaring the use “cookies,” for example, what I usually do is simply push the “accept” button. I assume this is true of many others as well. Because it is hard to realize how valuable our private data is for others, we frequently feel little concern about companies using them.

Problem, Countermeasure, and Question
As a result of the digital revolution and our attitude towards the use of our personal information which is made less cautious by the companies’ lot of efforts, our personal privacy is being eroded. Yet, I believe that an individual’s freedom of privacy must outweigh the freedom of businesses. Political regulations for building a healthy social structure are needed, and in fact, some public sectors have begun to take action to tackle the problem. For example, the General Data Protection Regulation (GDPR) was introduced in the European Union on May 25th, 2018,2 and the California Consumer Privacy Act (CCPA) became effective on January 1st, 2020.3 I think more and more appropriate regulations should be enacted worldwide. The following are the key factors to be considered:

- Individuals have the freedom to know what kind of information they provide, the purpose of the data collected, and how it will be used
- Individuals have the freedom to reject providing their data and request
companies to stop collecting it and delete it from their database. Our personal data is potentially valuable. Proper political regulations should defend our privacy from capitalist pursuits for maximum profit. We need rules so that citizens can protect their personal data. But, can we apply the same theory to all types of data in today’s world? How about our personal health-related data?

**The Digital Revolution in Healthcare**

Before discussing the questions above, it’s important to consider the dramatic impact digital technologies may potentially have on the field of healthcare. Developed technologies are transforming practices in both science and medicine, for example:

- Artificial Intelligence (AI) can help doctors quickly detect cancers.
- AI can assist doctors in deciding the best treatment for each patient.
- Big data can help researchers create new drugs more efficiently.

New computer technologies are helping doctors perform better diagnosis and treatment, and are fostering new forms of research in various ways. Moreover, forms of disease prevention may also achieve a giant leap forward with the use of big data and AI. In everyday life, for example, digital watches or smartphones can send alerts to say, “Take a break and let’s walk around!” or “Why don’t you spend 10 minutes jogging every day?” based on data collected about an individual’s lifestyle.

However, as is so often the case, transformation is easier said than done. For more precise prevention, especially, a large amount of high-quality data needs to be collected. The data should be continuous, which means that it has been taken over a long period of time. In an ideal situation, an individual’s health data should be connected and linked back to the individual. Such data might include medical history recorded at hospitals or clinics, lifestyle and genetic background. With the collection of lifelong big data from individuals, it might become easier to locate the risk factors for various diseases and generate targeted preventive medicine, which will lead to improving population health overall. In Japan, for example, a health data collection system has not yet been developed, while countries such as Estonia and Portugal are already making advancements in this direction. In the future, the development of technology will make such data collection easier while there are increasing demands for preventive medicine to support aging societies around the world. Then, the questions arise once again, how should we deal with health data? And, what about our privacy in healthcare?

**Problem**

Some people would claim that healthcare is a realm where their privacy matters the most. They are afraid of allowing their personal information to be distributed and for others to have access to it. However, as discussed earlier, collecting data and data analysis may lead to public health benefits. The more data we have, the more academic evidence will be accumulated, which will likely be beneficial to an individual’s health as well as the population. There remains an unresolved dilemma between the right to privacy and the potential for public good.

**Proposition**

A paradigm shift needs to be brought about in the concept of privacy to tackle one of the challenges of our time. According to today’s news, privacy seems like something to “protect,” which is partly unsuitable for what is happening in the field of healthcare with the digital revolution. If many individuals decide not to release their health data, healthcare will fail to develop the ways it is projected to. I do not think it is a good idea to make a strict regulation and try to protect health privacy, in the ways that today’s world leaders have been doing to deal with the social injustice mentioned earlier. Instead, we should give individuals an incentive...
so that they voluntarily choose to provide personal health information which is potentially valuable. What we need is a complete data managing ecosystem that enables both privacy protection and research promotion at the same time. A key idea is giving something back in return for an individual’s personal data.

I. How to Collect Health Data

- First, all the individuals are given their own ID when they are born
- All health data are linked to the individual’s ID and securely kept in a national database
- If you go to the hospital or clinic, the results will be kept as personal data linked to the ID
- The government develops a national “genome data bank”
- If you are willing to share, you can add your lifestyle-related data, for example, walking time/distance and sleeping time in daily life can be measured by your smartphone. You can scan your meal with your smartphone, and the nutrition status will be automatically estimated

For this first phase to be achieved, all the Electronic Health Record (EHR) recorded at hospitals or clinics must be integrated. Individuals can see their Personal Health Record (PHR) on a government-run website at any time.

II. Who Keeps Health Data

- A national organization that is totally non-profit keeps the data
- The data is secured by various technologies

The most important thing is to protect all personal data with strengthened cybersecurity. A portion of the national budget should be spent on maintaining this second phase.

III. Who Has Access to Health Data

- Whoever wants to use the data can ask for access
- They must clarify the purpose of using the data by explaining their research project
- If the research project is approved, they can buy the dataset from the organization. The price depends on the dataset
- The dataset is anonymized and processed to make it impossible to identify individuals
- The dataset is processed depending on the research question
- The data users are registered with their ID, and no one else has access to the data
- The data users are expected to write academic papers to create evidence
- Individuals have the freedom to reject to disclose their data at any time

For many researchers, universities, and various stakeholders in healthcare, the national health database would be very attractive. The process of confirming research projects must be carried out rigorously by paying attention to privacy and ethics. It would be the hardest part to process the dataset before handing it to others.

IV. How to Use the Money Acquired through “III”

- Data users pay money for the dataset to the data managing organization
- The money is used for maintaining big health data
- The money is used for investing in data collecting
- The money is also used for the service of “V”

It will cost a lot to maintain a huge national database. Besides, it is necessary to invest in services in areas where there are currently little resources.
V. A Benefit to Individuals who Provide their Health Data

- Individuals enjoy benefits depending on the levels of their data disclosure
- Individuals receive reports and get advice for better health

For example, if they decide to disclose their lifestyle data, they can receive a detailed lifestyle recommendation. If they further open their genome data, they can know about their congenital risks for diseases and the possible ways to prevent them.

Discussion and Conclusion

What is unique with this new data managing ecosystem is that individuals who provide their personal information can get something in return, which also gives them an incentive for providing data. They can enjoy the latest evidence which is built upon the personal data they provided. This is something we cannot find within the current privacy-protecting political movement. Throughout this brand-new data managing ecosystem, the concept of privacy can be expanded and redefined so that it includes the freedom of deciding what to do with one's own valuable information, which makes everyone realize the value it potentially holds.

In the case of the private sector in the field of healthcare, such as 23andMe, I think governments should defend health data privacy by making strict rules, in the same way as regulating web data companies. Moreover, with the new health data ecosystem, people will be less likely to give their personal health data to outside companies.

Facing the time of the digital revolution, the amount of any type of data will continue to grow more and more worldwide. Data and data analysis have the potential to generate profit, and our personal information is therefore valuable. Our freedom of privacy is endangered, and that is why we need to call on governments to make vigorous rules. However, at the same time, with the new data managing ecosystem in the age of medical big data, individuals should realize their own value, and privacy can be recalibrated so that it incorporates the concept of freedom which lets everyone decide how to deal with their personal data. In further future, more people will choose to control their personal information even when they view a website. Freedom to control our own data will become more common among us.
References