Does Government Own Your Health Data?

A Case Summary of 2022 Taiwan Constitutional Court Decision

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Abstract—We all know personal health data is increasingly valuable; however, what is left behind is who can legitimately claim the ownership of the data and what rights and interest the owner can claim. A Taiwan Constitutional Court decision rendered on August 12, 2022 on one of the largest health databases in the world – the Taiwan National Health Insurance Database – provides us a real case on how the information privacy and data ownership issues, such as secondary uses, right to opt-out, and good governance mechanisms, can be argued, proposed, and regulated.

Keywords-Health Data; Seconary Ues; Information Privacy; Data Governance; Constitutonal Court; Taiwan.

I. INTRODUCTION

The Taiwan National Health Insurance Database (NHID) is a centralized and comprehensive database maintained by the National Health Insurance Administration (NHIA). The database contains a tremendous collection of over 70 billion health records from the country's 23 million population over the past 27 years [1].

While the original intent of creating the database was for health insurance management, such as payment, reimbursement, and quality improvement, the ever-lasting accumulating datasets, including patient demographics, medical diagnoses, treatments, prescriptions, and medical images like computerized tomography (CT) and magnetic resonance imaging (MRI), make secondary uses of the NHID incredibly valuable and appealing for both academic and commercial purposes. According to an NHIA's survey, more than 8,600 research papers have been published by using data from NHID [2].

The COVID-19 pandemic has accelerated the digitalization of health service delivery, and so does the commercial use of NHID. A Software Development Kit (SDK) program initiated by NHIA in mid-2019, under the My Health Bank (MHB) system (See Figure 1), has created a new channel for linking people's health data with mobile apps developed by private sectors. In other words, with authorization from member users and technical interference supported by the SDK, a third-party app developer now can combine its own user's data, such as running tracks or daily calorie intakes, with their users' personal medical records under NHID, such as cardiovascular diseases diagnose and treatment [1][3]. It certainly opens a route for a wide range of commercially secondary use of data on the NHID, such as chronic disease management or teleconsultation.

The paper is structured into three sections. Section I explains the NHID database and the secondary uses of the data, including commercial purposes, through the My Health Bank (MHB) system. Section II describes the legal disputes and proceedings of the lawsuit, including the plaintiffs' arguments and the defendant's counterarguments. Finally, Section III provides an overview of the Taiwan Constitutional Court decision on the NHID case, detailing the issues addressed and the Court's holdings and prevailing parties.

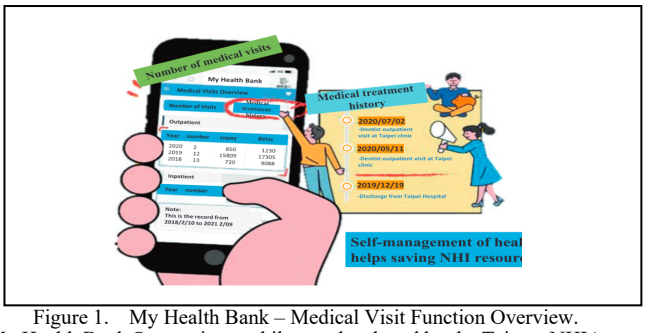

Figure 1. My Health Bank – Medical Visit Function Overview. My Health Bank System is a mobile app developed by the Taiwan NHIA to allow people access to their NHI data. [1]

II. LEGAL DISPUTES OF THE SECONDARY USES AND THE PROCEEDINGS OF THE LAWSUIT

Admittedly, despite the secondary use of NHID, such as research, policy development, public health surveillance, and even commercial innovation is so powerful, its legitimacy has been controversial and disputable under Taiwanese laws. In the spring of 2012, eight citizens from the Taiwan Association for Human Rights sent a cease-and-desist letter to NHIA for stopping providing their NHI data to third parties. The opt-out request was denied by the NHIA and a 10-year lawsuit from the individuals and NGO against the NHIA then began [4]. The plaintiffs argued that they had not granted their NHIA permission for any secondary uses of their NHI data. In addition, based on Taiwan Constitutional Law [5] and Personal Data Protection Act of 2012 (PDPA) [6], they had information privacy right to "opt-out" from the "unauthorized secondary uses".

The main counter-arguments from the defendant, NHIA, were that, firstly, all NHI data sharing with third parties were appropriately encrypted and de-identified, and therefore, there is no concern for data privacy or security. According to Article

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6 of the PDPA, personal [health] data can be processed and used without data subjects' consents, as long as it is for "*statistics gathering or academic research by a government agency or an academic institution for the purpose of healthcare, public health, or crime prevention"* and "*such data, as processed by the data provider or as disclosed by the data collector, may not lead to the identification of a specific data subject*" [6].

NHIA also alleged that, the whole society benefits from the academic research based on using NHID, and the plaintiffs' information privacy right could still be limited under certain circumstances. This was the case that the public interests of academic research and medical development shall trump the plaintiffs' information privacy.

Courts, both lower and appellate levels, essentially supported the NHIA's arguments, and ruled in favor of the government agency. The plaintiffs then had the opportunity to appeal the decision in 2017 before the Taiwan Constitutional Court to challenge the ruling.

III. TAIWAN CONSTITUTIONAL COURT DECISION: 113-HSIEN-PAN-TZI NO.13 JUDGMENT

On August 12, 2022, the Taiwan Constitutional Court held a press conference to announce their decision of the NHID case, the 113-Hsien-Pan-Tzi No.13 Judgment [7]. In this final and landmark verdict, the Grand Justices reversed the earlier judgements from the lower courts, and reaffirmed that the information privacy right under Taiwan Constitution shall include both procedural aspects, like an independent supervisory mechanism, as well as substantial aspects, such as a right to opt-out (The holdings of the Judgement, See Table 1).

TABLE I. THE ISSUES AND HOLDINGS OF THE JUDGEMENT [7]

Issues	**The Court's Holdings and Prevailing Parties**		
	Court holdings	***Petit.***	***Resp.***
Whether the Article 6 of the PDPA is unconstitutional?	No.		V
Whether the current PDPA has no independent supervisory mechanism is unconstitutional?	Yes. Competent Authority is obligated to amend the law within 3 years.	V	
Whether the current rules of NHID's data utilization is unconstitutional?	Yes. Competent Authority is obligated to amend the law within 3 years.	V	
Whether the current practice that people can not opt-out from secondary uses is unconstitutional?	Yes. Competent Authority is obligated to amend the law within 3 years. Otherwise, people can enforce the right directly.	V	

Several impacts on Taiwan's health data use have emerged immediately after the judgment rendered:

Firstly, it is the first time in Taiwan's legal history that the General Data Protection Regulation (GDPR) of the European Union (ER) is cited as a good comparative law model for setting up a data protection supervisory body. In the ruling, the Grant Justices have imposed the obligation to the competent authority for amending the laws within three years. Apparently, the EU GDPR model will be the must-seen reference for Taiwan's legislators.

Furthermore, what constitutes a sufficient "de-identification obligation and process" becomes a hot issue again. Under the Enforcement Rules of the PDPA, the definition of de-identification means "inability to identify specific individuals by coding, anonymizing, and hiding part of personal data or by other means". However, no one really knows what it is. A set of more precise and practical protocols of de-identification, such as the pseudonymization under the EU GDPR or the safe harbor method under the US Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, shall be created.

Finally, the judgment affirmed the right to opt-out for unwilling or unauthorized secondary use of the data. Before the ruling, it was unclear whether the information privacy right under Taiwan Constitution law and judicial interpretations could extend to ex-post determination of personal data control. It is now clear, nevertheless, that the data subject has the final call for its data, not the government. In other words, even though the data is collected, processed, and used by the government, it is the people have the ultimate control over their data.

IV. CONCLUSION: WHAT NEXT STEPS ARE?

While Taiwanese government, in particular the NHIA, has learned its lesson about information privacy and health data governance through the case and the ruling, their impacts are likely beyond the jurisdiction.

On the one hand, the Taiwan Grand Justices have pointed out, in the ruling, that the EU GDPR model shall be a reference for NHIA to amend current regulations and practices. Some Taiwanese privacy scholars have also proposed comparative law examples for Taiwan's data governance reform, such as the England model under the Health and Social Care Act of 2012 [8], or a trustworthy data governance mechanism for developing a better framework [9].

The decision and its further development, on the other hand, may also be a good reference for secondary use of health databases from around the world, such as MyData in the South Korea or Findata in Finland [10][11].

As health data's huge potential is emerging every minute, how to build up a constitutional and more trustworthy regime of health data governance, becomes critical and urgent worldwide.

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