Legal Issues of Collecting and Processing Big Health Data in the Light of European Regulation 679/2016

Authors : Ioannis Iglezakis, Theodoros D. Trokanas, Panagiota Kiortsi

Abstract : This paper aims to explore major legal issues arising from the collection and processing of Health Big Data in the light of the new European secondary legislation for the protection of personal data of natural persons, placing emphasis on the General Data Protection Regulation 679/2016. Whether Big Health Data can be characterised as 'personal data' or not is really the crux of the matter. The legal ambiguity is compounded by the fact that, even though the processing of Big Health Data is premised on the de-identification of the data subject, the possibility of a combination of Big Health Data with other data circulating freely on the web or from other data files cannot be excluded. Another key point is that the application of some provisions of GPDR to Big Health Data may both absolve the data controller of his legal obligations and deprive the data subject of his rights (e.g., the right to be informed), ultimately undermining the fundamental right to the protection of personal data of natural persons. Moreover, data subject's rights (e.g., the right not to be subject to a decision based solely on automated processing) are heavily impacted by the use of AI, algorithms, and technologies that reclaim health data for further use, resulting in sometimes ambiguous results that have a substantial impact on individuals. On the other hand, as the COVID-19 pandemic has revealed, Big Data analytics can offer crucial sources of information. In this respect, this paper identifies and systematises the legal provisions concerned, offering interpretative solutions that tackle dangers concerning data subject's rights while embracing the opportunities that Big Health Data has to offer. In addition, particular attention is attached to the scope of 'consent' as a legal basis in the collection and processing of Big Health Data, as the application of data analytics in Big Health Data signals the construction of new data and subject's profiles. Finally, the paper addresses the knotty problem of role assignment (i.e., distinguishing between controller and processor/joint controllers and joint processors) in an era of extensive Big Health data sharing. The findings are the fruit of a current research project conducted by a three-member research team at the Faculty of Law of the Aristotle University of Thessaloniki and funded by the Greek Ministry of Education and Religious Affairs.

Keywords : big health data, data subject rights, GDPR, pandemic

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