



The GDPR, secondary research purposes and global data sharing— one-wheel too many

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The article of David Peloquin, Mike DiMaio, Barbara Bierer and Mark Barnes, ‘Disruptive and avoidable: GDPR challenges to secondary research uses of data’ (<https://doi.org/10.1038/s41431-020-0596-x>) in this issue provides the first-in-kind legal analysis of the real-world difficulties that the European Union General Data Protection Regulation (GDPR) presents for biobanking, databanking, and global data sharing in secondary research activities. The interpretation of the GDPR has raised concerns, misconceptions and unclarity regarding scientific research, in particular with medical and genomic data.

The application of the European Union General Data Protection Regulation (GDPR) is approaching its 2 years anniversary in May 2020. Some parties suggest that the GDPR is too vague, some suggest that it is too strict. There are lot of views and opinions, but they are generally too abstract in argumentation to present, let alone solve any real issues. Thus, the article of the US colleagues is most welcomed as it provides a pragmatic analysis of the legal situation. Their major claim is that the GDPR has posed major challenges to the secondary uses of data and associated biospecimens without appreciably improving privacy protection. The authors go through various positions and interpretations regarding legal grounds for processing, potential contextual approach to anonymous data, consent, non-EU-data transfers and research exemptions. They demonstrate how broad consent as one viable option to balance the interest of information and future needs of research, elaborated for a longtime, seems to have been diluted by narrowing interpretations.

In January 6, 2020 the European Data Protection Supervisor issued a Preliminary Opinion on data protection

and scientific research, and called for more dialogue between research community, data protection authorities and ethics review boards as he sees that “there is no evidence that the GDPR itself hampers genuine scientific research” [1]. However, the reality is different and many have witnessed, me included, insurmountable legal obstacles to share data globally. In Science November 22, 2019, director of US National Institutes for Health (NIH) Francis Collins implies that “the regulation has turned out to be a serious impediment to research”, endorsed by many others in the same article [2]. This is because in many cases there is simply no plausible legal ground for data transfer from EU to non-EU countries.

The value of the article in this journal lies in the fact that the authors David Peloquin, Mike DiMaio, Barbara Bierer and Mark Barnes as practicing lawyers know what they are talking about.

Compliance with ethical standards

Conflict of interest SS is Director of THL Biobank, legal counsel to many projects, and negotiates international datasharing agreements.

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