

Genetic Data of Deceased People: Solving the Gordian Knot

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Abstract : Genetic data of deceased persons are of great interest for both biomedical research and clinical use. This is due to several reasons. On the one hand, many of our diseases have a genetic component; on the other hand, we share genes with a good part of our biological family. Therefore, it would be possible to improve our response considerably to these pathologies if we could use these data. Unfortunately, at the present moment, the status of data on the deceased is far from being satisfactorily resolved by the EU data protection regulation. Indeed, the General Data Protection Regulation has explicitly excluded these data from the category of personal data. This decision has given rise to a fragmented legal framework on this issue. Consequently, each EU member state offers very different solutions. For instance, Denmark considers the data as personal data of the deceased person for a set period of time while some others, such as Spain, do not consider this data as such, but have introduced some specifically focused regulations on this type of data and their access by relatives. This is an extremely dysfunctional scenario from multiple angles, not least of which is scientific cooperation at the EU level. This contribution attempts to outline a solution to this dilemma through an alternative proposal. Its main hypothesis is that, in reality, health data are, in a sense, a *rara avis* within data in general because they do not refer to one person but to several. Hence, it is possible to think that all of them can be considered data subjects (although not all of them can exercise the corresponding rights in the same way). When the person from whom the data were obtained dies, the data remain as personal data of his or her biological relatives. Hence, the general regime provided for in the GDPR may apply to them. As these are personal data, we could go back to thinking in terms of a general prohibition of data processing, with the exceptions provided for in Article 9.2 and on the legal bases included in Article 6. This may be complicated in practice, given that, since we are dealing with data that refer to several data subjects, it may be complex to refer to some of these bases, such as consent. Furthermore, there are theoretical arguments that may oppose this hypothesis. In this contribution, it is shown, however, that none of these objections is of sufficient substance to delegitimize the argument exposed. Therefore, the conclusion of this contribution is that we can indeed build a general framework on the processing of personal data of deceased persons in the context of the GDPR. This would constitute a considerable improvement over the current regulatory framework, although it is true that some clarifications will be necessary for its practical application.

Keywords : collective data conceptual issues, data from deceased people, genetic data protection issues, GDPR and deceased people

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