

How Confidential is Health Information? The Blurred Boundaries between the Right to Data Protection and a Better Health Care

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‘And whatsoever I shall see or hear in the course of my profession, as well as outside my profession in my intercourse with men, if it be what should not be published abroad, I will never divulge, holding such things to be holy secrets’.² Although not being legally binding, the Hippocratic Oath is an important document for workers of the medical profession and it explicitly underlines the relevance of confidentiality in the field. The obligation to protect health data and information has been further confirmed in several legal texts as well as by courts and tribunals. It is relevant to mention the case law of the European Court of Human Rights in this regard.³

While it is fully agreed that the protection of health information is a basic requirement, sharing some data might be essential in order to develop research activities that could lead to major findings and to better health.⁴

It is therefore necessary to establish where the limits should be drawn between the right to data protection and the need to enhance research and development in this field. The legal framework of data protection has been shaped by the recent case law of the Court of Justice of the European Union⁵. Most importantly, the new Data Protection Regulation brings new elements that deserve to be mentioned.

To address this topic, the paper will be organised in three main parts. First, a historical analysis of confidentiality in the health care sector will be undertaken. Different legal texts

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² Hippocrates of Cos, *Ancient Medicine. Airs, Water, Places. Epidemic 1 and 3. The Oath. Precepts. Nutriments*, translated by W. H. S. Jones, Loeb Classical Library (Cambridge, Harvard University Press, 1923), p. 301.

³ Judgment of the European Court of Human Rights of 25 February 1997 in Case *Z v Finland*, Application No 22009/93; Judgment of the European Court of Human Rights of 17 July 2008 in Case *I v Finland*, Application No 20511/03.

⁴ Editorial, ‘Data Protection: Balancing Personal privacy and Public Health’ (2016) 4 *The Lancet* 1; Menno Mostert, Annelien L Bredenoord *et al*, ‘Big Data in Medical Research and EU Data Protection Law: Challenges to the Consent or Anonymise Approach’ (2016) 24 *European Journal of Human Genetics* 956; Debbie a Lawlor and Tracey Stone, ‘Public Health and Data Protection: An Inevitable Collision or Potential for a Meeting of Minds?’ (2001) 30(6) *International Journal of Epidemiology* 1221.

⁵ Judgment of the Court of 8 April 2014 in Case C-293/12 *Digital Rights Ireland and Setlinger e.a.*, EU:C:2014:238 ; Judgment of the Court of 13 May 2014 in Case C-121/12 *Google Spain and Google*, EU:C:2014:317 ; Judgment of the Court of 6 October 2015 in Case C-362/14 *Schrems*, EU:C:2015:650.

have been developed in Europe and beyond and different courts and tribunals have had the opportunity to address this issue.

Second, the particular situation of the former Data Protection Directive as regards the field of health related data will be considered. Importantly, the divergence between legal regimes among Member States will be addressed. Although this legislative text was an important step in the field, the need for enhanced coherence made the reform of the data protection package inevitable. However, the legislative procedure made apparent opposed views on what the new instrument should look like. More specifically, the European Parliament felt that the balance should swing towards the data protection aspects whereas, according to the Council and some lobbying parties, the balance tilted in favour of an increased research activity.

Third, the novelties that the Data Protection Regulation introduces will be highlighted. First, it will be interesting to assess whether the switch from a directive to a regulation has contributed to a homogenisation of the field in the European Union. Moreover, three elements seem particularly interesting in the new Regulation considering recent developments in the law and policy of the European Union: the informed consent criteria, the right to be forgotten and the international transfers of health data.