

Ethical Values and Legal Principles of the Big Data Use in Health

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Abstract

Let's imagine a world where our health data drives our lives and our work. Is that pure science fiction? The application of Big Data to the healthcare industry offers a multitude of opportunities and transforms the way our information is managed; indeed, from now on, a major part of the patient's medical file is dematerialized. What means *Big Data*? There is no one fully accepted definition of Big Data. The Recommendation of the International telecommunication Union (Rec. ITU-T Y.3600 (11/2015) define Big Data as a “paradigm for enabling the collection, storage, management, analysis and visualization, potentially under real-time constraints, of extensive datasets with heterogeneous characteristics”. Advantages of using Big Data in health are (San Segundo et Soler, 2017): 1) Promoting the sustainability of the health system; 2) A better quality of the health care; 3) A better adaptation of drugs; 4) New ways of doing medicine (personalized medicine, preventive, private, participatory). 5) Care for chronically ill and disabled people; 6) Fight against fraud and abuse. This presentation is focusing on the top 10 ethical & legal issues of using Big Data in health, such as: 1) Data Ownership and Safety; 2) Informed Consent; 3) Privacy and Confidentiality; 4) Fairness and Justice; 5) Risk of Discrimination; 6) Trust; 7) Autonomy; 8) Patient Empowerment; 9) Utility; 10) Human Rights and Dignity. Although we are still far from the dystopian world of Gattaca, the invasion of Big Data in the health field and the problems associated with their use are nevertheless very topical.

Keywords: Big Data; Ethics; Health Information; General Data Protection Regulation (GDPR)