Big Data, e-Health and the Right to be Forgotten
Ana Nordberg
Associate Senior Lecturer
Faculty of Law, Lund University, Sweden

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This paper examines the scope and limits of the ‘right to be forgotten’ recently codified under Article 17 in the General Data Protection Regulation. It will focus on both health and health related data provided outside a traditional health care and medical research setting and address generally patience records and clinical trial data.

Big data, machine learning and artificial intelligence promise to enable great advances in personalised medicine, public health and generally in bio-medical research. Already we start to see a proliferation of e-health, e-fitness and e-wellness services. These are emerging inserted in strategies to optimise and personalize public health services, in particular in the areas of general health information and pre-clinical advice, emergency services triage, pre-screening, long-term monitoring of patients, elderly care, etc.

Some types of e-health services start to be offered by or subcontracted to private entities, such as insurance companies, private clinics, long-term care facilities and e-health care providers. Also in the market, we can already observe emerging a long list of other e-services with health relevance, offered by a variety of heterogeneous commercial enterprises with different goals and business models, but which include inter alia genetic testing, biometric data monitoring, sample analyses and health, wellness and fitness questionnaires. Mostly data flows multidirectional, using a combination of testing devises, ‘apps’ and machine learning tools. Physiologic and psychologic health indicators can also be retrieved from social networks, using e.g. language, speech pattern and biometrics analysis.

Digitalization of medical journals, biobanks, clinical trials and medical research, also offers possibilities for personalised and precision medicine, public health decision making and biopharmaceutical innovation. Since most non-communicable diseases are caused, aggravated or mitigated by social-economic conditions, life-style, cultural factors and socialization habits, comprehensive health data will likely tend to include highly private information.

As recently stressed by the EU Parliament in the resolution on the fundamental rights implications of big data, public health interest in creation and access to health big data will necessarily interface and need to be balanced with the protection of other fundamental rights. Such will be particularly pertinent to consider in cases where the supply and/or creation of such data involves commercial entities and other actors operating outside the scope of the traditional confidentiality protected relationship between a patient and a health care professional or medical researcher.

In this paper the right to request data erasure is analysed in a big data analytics setting, namely the issues of (1) determining whether personal data is personal health data; (2) whether there is grounds to request erasure; (3) exemptions to erasure related to health data; (4) technology issues concerning implementation of erasure requests/decisions; and (5) technologic potential for reducing conflict of rights by design.

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2 European Parliament resolution of 14 March 2017 on fundamental rights implications of big data: privacy, data protection, non-discrimination, security and law-enforcement (2016/2225(INI)).