The value of personal data in the digital society

As citizens we must be concerned about the value of privacy, a fundamental asset

One year ago, the Silicon Valley company 23andme, which analyses DNA to determine genetic predisposition to certain diseases or to find out who someone's ancestors were, signed an agreement worth millions of dollars with the pharmaceutical company GSK to give it access to its database, containing more than five million genetic profiles. It is an example of exponential business in which personal data are the main assets, which clearly shows the interest in the monetization of genetic data. Thus, as well as the traditional random selection of participants, more costly in time and resources, there is now a new trend that makes the users of direct-to-consumer genetics companies participants in biomedical research, promoted by private enterprise in order to develop new drugs and treatments.

With the data stored in this base, correlations can be established between sets of data and with other different types of databases, through the development of mathematical algorithms that make it possible to determine patterns and predict behaviours. The combination of genetic with sociodemographic data looks like an opportune decision in the eyes of its founders. Whether out of curiosity or desperation, the company 23andme has become a resource for finding relatives and criminals.

As citizens we must be concerned about the value of privacy, which is a fundamental asset. We cannot remain indifferent to the use of our data, and we are important for the public authorities, private companies, and for the synergies between them. Personal data feed business initiatives and models in personalized medicine, ageing, and for developing more efficient healthcare systems. They are scientific and economic policy decisions, to which much of the research in Europe is addressed, and which produce knowledge, power, profits and social benefits. Turning our backs on the power of properly managed

data would be detrimental. We would deprive ourselves of advantages for our health, quality of life and for the coming generations. Cancer treatments, now more personalized, have been developed thanks to research with biological samples of human origin stored in biobanks that citizens donate altruistically.

These days everyone is talking about the evils of FaceApp, the application that satisfies digital narcissism and which, besides showing us our aged digital image, can do anything with our data, such as selling them to third parties. The data are exploited and monetized in a free-market society in which we have ceased to be anonymous in order to be re-identifiable. Our digital identity is an object of desire.

The company Cambridge Analytica managed to modulate the voting intentions of up to 87 million Facebook users in order to help Donald Trump to become the president. Although we only found out recently, this identification of vulnerable profiles who were led to believe they were taking decisions freely took place between 2012 and 2016! This example shows us that it is necessary to take care of our personal data because they are what we are and they include data about health, political opinions, sexual orientation and genetic data.

The Law of Personal Data Protection and Guarantee of Digital Rights (2018) establishes the right to digital education, and we must be taught how to identify what we are exposed to, and to be critical. The Reuse of Public Sector Information directive was passed to ensure its proper management. The decision to give it value is firm and we, the possessors of such highly prized raw materials, are obliged to look after them and to take free and informed decisions about a common asset that deserves our complete respect.

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Published in EL PAIS the 24th of August 2019 (Tribune Section): https://elpais.com/ccaa/2019/08/24/catalunya/1566667062_032847.html