

## Detailed presentation

In the Big Data Era, where more and more data are being collected and processed (on/from the Internet, through IoT devices, for a service subscription or the purchase of a good), what makes health data special? This question is highly relevant because of the increase of the data diversity to be processed in the health sector (biological signals, environmental data, living habits). This relevance is further more highlighted by private non -medical companies entering the digital health market. Indeed, aware of potential opportunities, the GAFAM (Google, Apple, Facebook, Amazon, Microsoft) have reached the market by offering services such as cloud computing.

Behind the opposition often drawn between the GAFAM and individuals whose data are processed for commercial purposes, one will find multiple disputes and debates focusing on data access, data re-use and the benefit sharing of data processing. Even in France, where the ownership paradigm is contested for personal data, voices are now calling for individual's property rights over one's own data. The reasoning behind is based on the fact that property rights will ensure individuals to benefit from the commercial processing of the data<sup>1</sup>. The criticism then concerns the current legal framework, which would provide privacy protection mechanisms (more or less effective), but would fail to provide tools so that everyone can benefit economically from the risk of intrusion of their privacy by third parties.. As a consequence, the development of an alternative approach to regulation is in debate. Many questions are raised: Are property rights on personal data an appropriate solution? Under which conditions and for what effectiveness? What drawbacks could we expect? Should we consider other legal mechanisms?

Those questions will be at the centre of the proposed workshop.

The workshop's aim is to enlighten the audience on the current legal debates regarding the rights that provide individuals with control over their health data. The aim is, specifically, to question which legal innovations could be fostered to improve effectiveness of those rights, and will include the study of property rights theories.

This workshop will be run as a "forum/debate" among three guest speakers having each different points of view over the subject matter. Ahead of the workshop, the coordinators will present the speakers with two identical questions that they will have to answer during the workshop. After a presentation by each guests' answers, a discussion will be opened with the attendees.

**Contact and information:** Margo Bernelin : [mbernelin@gmail.com](mailto:mbernelin@gmail.com)

---

<sup>1</sup> Jaron Lanier, Gaspard Koenig, Bruno Bonnell, Manuel Carcassonne, Alexandre Jardin, Laurence Parisot, « Nos « données personnelles » nous appartiennent : monétisons-les ! », *Le Monde*, Tribune, 5.02.2018 ; Alain Bensoussan, « Pour un droit de propriété et une monétisation des données personnelles », *Le Figaro Blog*, 28 février 2018, <http://blog.lefigaro.fr/bensoussan/2018/02/pour-un-droit-de-propriete-et-une-monetisation-des-donnees-personnelles.html> ; François-Pierre Lani, « Vers un droit de propriété sur nos données personnelles », *Les Échos*, 5.07.2018.