

DATA PRIVACY REGULATION DAY*

Paris
January 17, 2017**

(10 AM - 5 PM)

On May 2016, the EU Regulation 'on the protection of natural persons with regard to the processing of personal data and on the free movement of such data' entered into force and must be transposed into the national law of all EU Member States by May 25, 2018. As stated by the European Commission, 'The objective of this new set of rules is to give citizens back control over of their personal data, and to simplify the regulatory environment for business...The reform will allow European citizens and businesses to fully benefit from the digital economy'. What is really behind this new legal instrument, how it will impact the development of innovation in Europe, how citizens/patients will benefit of it: these are the questions still open.

This one-day workshop organized by the ELSI-LE group of the Europe sponsored Knowledge & Innovation Communities (KIC) EIT-Health will try to shed some light on the consequences of the Regulation implementation. Speakers from European bodies, research institutes, companies, patient organizations and other KICs will present the Regulation and illustrate its impact with practical examples.

EIT Health (<https://eithealth.eu/>) is one of the largest healthcare initiatives worldwide. Its goal is to sustainably advance the foundations of healthcare and thus promote the future conditions for healthier living and wellbeing of people across Europe. EIT Health is leveraging the expertise of more than 140 leading organizations spanning key areas of healthcare such as Pharma, MedTech, Payers, Users, Research Institutions and Universities. Chosen by the European Institute of Innovation and Technology (EIT) to form EIT Health, the consortium offers best-in-class research capabilities, higher education and business expertise. With a budget of 2 billion EUR over the next decade, it will purposefully invest in Europe's best entrepreneurial talents and creative minds to foster the development and commercialization of smart product and service solutions in the health sector, addressing the challenges imposed by demographic change and ageing societies.

*** Supported by EIT Health France**

**** Registration: <https://eithealth.wufoo.com/forms/r1a1vo80amtro/>**

STEERING COMMITTEE

François Hirsch, ELSI EIT-Health & Inserm (France)

Ignasi López Verdeguer, ELSI EIT-Health & "la Caixa" Banking Foundation (Spain)

Date and Venue

January 17, 2017, ICM¹ (Paris 13^{ème})

Programme

Morning: the Regulation

The morning is dedicated to provide detailed information on the new Regulation.¹

Chairperson: **Heidi C. Howard** (EIT-Health ELSI & Uppsala university, Sweden)

9h30-10h00 Welcome coffee

10h00-10h30: Opening session **Alexis Brice** (Director General, ICM – Brain & Spine Institute),
Sylvie Bove (ceo, KIC EIT-Health) & **Jean-Marc Bourez** (Managing Director KIC EIT-Health France)

10h30-11h00²

Mihailis Kritikos, Vrije Universiteit Brussel (VOB) & Scientific Foresight (STOA) – European parliament (Belgium)

*The new Regulation

11h00-11h30²

Tobias Schulte in den Baeumen (Hapag-Lloyd AG, Germany)

*International transfer of data

11h30-12h00²

Guillaume Levavasseur, Adel Health (France)

*Good practices for an ethical use of data

¹ ICM – Brain & Spine Institute - 50/52 Boulevard Vincent Auriol - 75013 PARIS - France

² 20 mins presentation + 10 mins discussion

12h00-13h30 **Networking lunch**

12h15 -13h00 **Networking sessions for EIT-Health partners by invitation only:**
"real life data in sustainable cities", chaired by **Philippe Gesnouin** (*EIT-Health & Inria*);
"sleep condition", chaired by **Christophe Cans** (*EIT-Health & Inserm Transfert*)

Afternoon: The implementation of the Regulation: Ethical tensions

13h30 -15h00 The round-table #1 is dedicated to information and exchange of views on implementing the Regulation in industrial innovation and research

Chairperson: **Emmanuelle Rial-Sebbag** (*ELSI-France EIT-Health & Inserm*)

Pierre-Yves Lastic (*Sanofi, France*)

Per Matsson (*ThermoFisher Scientific, Sweden*)

Stéphane Amarger (*Managing Director KIC EIT-Digital, France*)

Hueseyin Cavga (*SAP Connected Health, Germany*)

Charles Huot (*Temis / Alliance Big Data / #TICSanté-IDF, France*)

Annemiek Heijer (*Eurapco, Switzerland*)

15h00-15h15: coffee break

15h15-16h45 The round-table #2 must illustrate the ethical tensions raised by the processing of personal data: transparency, tracability, right to be forgotten, empowerment.

Chairperson: **François Hirsch** (*ELSI EIT-Health & Inserm, France*)

Lloyd Humphreys (*Patients Know Best, UK*)

David Townend (*Maastricht University, The Netherlands*)

Tristan Fuller (*Ethics and Research Integrity Sector, European Commission DG RTD*)

Gauthier Chassang (*Inserm, France*)

Joan Guanyabens (*HIT Consultant, Barcelona, Spain*)

16h45-17h00: Next steps

Ignasi López Verdeguer (*ELSI EIT-Health & "la Caixa" Banking Foundation, Spain*)