

# Symposium: Private health data in the cloud



Wednesday 14<sup>th</sup> December

Centre for Genomic Regulation (CRG)  
Barcelona



Those projects have received funding from the European Union's H2020 research and innovation programme under grant agreements No 635290 & 634143

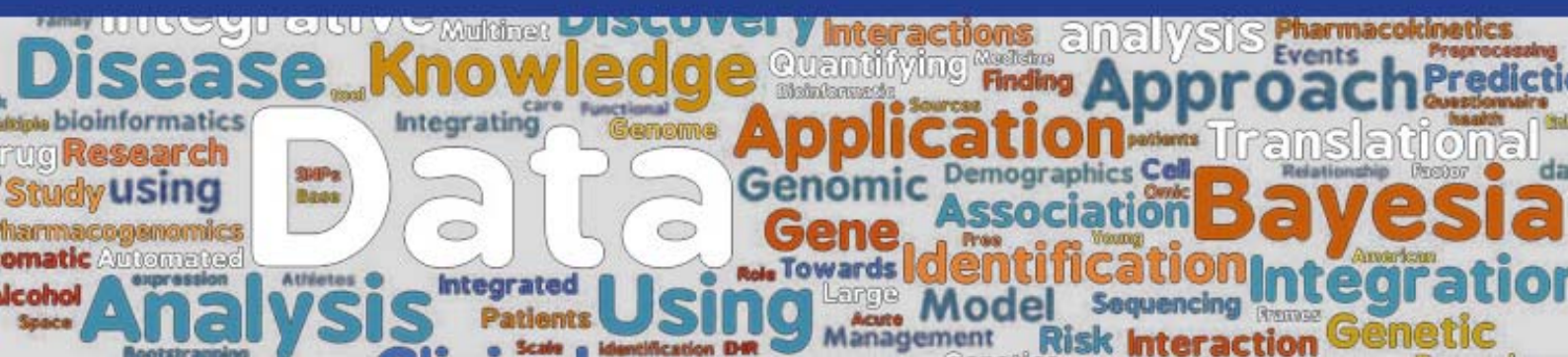


**PanCanRisk**

Personalised Bioinformatics For Global Cancer  
Susceptibility Identification & Clinical Management



**MedBioinformatics**





### Why to Attend?

- 1For an overview ontheimpendingreformsof the data protection rules, and how it affects health researchers.
2. To envisagehowhealth researchers can prepare for the practical implementations required by the Data Protection Act and ensure the inter-operability of the new EU rules with privacy frameworks worldwide
- 3To find newwaystoachievethe right balance between citizens’privacy needs and growth in Europe’s digital economy

### Who Should Attend?

- Researchers and bioinformaticians
- Students
- Data Protection responsables at organizations (universities, hospitals, biomedical institutes...)
- Project Managers
- Biobank managers
- IP Law Experts
- Media Experts
- Patients
- Legal Advisers
- Local and Regional Government
- Patient support groups

### Organised by:

PanCanRisk and MedBioinformatics Consortiums

### Venue and Accommodation

Centre for Genomic Regulation (CRG)  
 Parc de Recerca Biomedica de Barcelona, PRBB building,  
 Dr. Aiguader St. 88,  
 08003, Barcelona (Spain)



## Symposium: Private health data in the cloud



### Overview

The concept of “big data” has evolved in the past few years to illustrate the evolution in the sizes of information-rich datasets in the health and economic fields. For scientific research, the availability of bid –omic datasets of information constitutes a serious ethical issue, as it will be imperative to conciliate data security with the anonymity that is needed to preserve the identity of subjects that are tested at the clinical setting. While data is being produced, analysed and reanalysed at a very high speed, we lack a common ethical and legal framework to facilitate genomic and clinical data, global science collaboration, and responsible research conduct. An international code of conduct should be designed to enable global genomic and clinical data sharing for biomedical research within a human rights framework has been proposed.



### Programme

10:00	Chair'sWelcome and Opening Remarks, <i>Helena Machado</i>
10:15	Ethical and legal aspects of giant database storage, <i>Vincenzo L. Pascali</i>
10:45	Legal horizons in the treatment of genomic data: opportunities, boundaries and gray areas, <i>Ana Marzo</i>
11:15	Data protection in the cloud, <i>FerránSanz</i>
11:45	Health, Big Data and the Cloud: a new challenge for Law, <i>Carlos Romeo</i>
12:15	<b>Round of Discussions</b>
13:30	Chair's Summary and Closing Comments
13:45	<i>Networking Lunch</i>
14:30	Close



### Event Details

**Date:** Wednesday14<sup>th</sup>December2016  
**Time:** 10:00am – 14:30pm

**Venue:** Centre for Genomic Regulation  
 Barcelona, Aula Room, 4th floor.



### Speakers Include:

- 🔗 **Helena Machado**,Research Professor at the Centre for Social Studies, University of Coimbra, specialist on the societal, regulatory and ethical issues associated with the uses of molecular genetics in contemporary modes of governance in medical fields.
- 🔗 **Ana MarzPortera**, Lawyer, Cofounder of EquipoMarzo, Data Protection and New Information Technology consultancy. Partner at Whitan Law & Tech
- 🔗 **FerranSanz Carreras**, Professor of Biostatistics and Biomedical Informatics at PompeuFabra University, scientific staff of the Hospital del Mar Medical Research Institute and Director of the Research Program on Biomedical Informatics
- 🔗 **Vincenzo Lorenzo Pascali**, Researcherinforesnsic genetics.
- 🔗 **Carlos Romeo Casabona**,Professor of Criminal Law at the University of the Basque Country. Director of the Inter-University Chair Provincial Government of Biscay in Law and the Human Genome, University of Deusto and University of the Basque Country



Entrance is free but in order to access the building,  
please confirm assistance by sending your name  
and ID to: [info@pancanrisk.eu](mailto:info@pancanrisk.eu)

Enquiries: +34 636 631 859  
[www.pancanrisk.eu](http://www.pancanrisk.eu)

 @PanCanRisk  
#PrivateHealthData

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