



Domain Ambassador for human immunogenetics and health ethics

What:

Increasing the awareness and implementation of Open Science and especially Open Data in human immunogenetics, genetics, bioethics and research ethics communities, through participation in meetings and education schemes in these domains. Fostering data sharing in these fields and making the values underpinning Open Science an essential elements of consideration. Communities targeted are European Federation for Immunogenetics, European Society of Human Genetics and several structures involved in bioethics and research ethics, especially through a UNESCO Chair. Finding ways of managing the tension between data sharing and individual protection in health domains is a common challenge that can be tackled with various tools and strategies.

Who:

Anne Cambon-Thomsen, French medical doctor specialised in human immunogenetics, now health ethics and Emeritus Research Director at CNRS.

Biography:

Anne Cambon-Thomsen is a French medical doctor specialised in human immunogenetics and health ethics, now Emeritus Research Director at CNRS in an epidemiology and population health unit of Inserm and University of Toulouse and a societal platform "Ethics and biosciences". She has a strong record of past activities in human immunogenetics research, ethics and scientific bodies, European and international projects and more recently in Open Science. She co-leads a working group on "Ethics, regulation and society" of the French plan of genomic medicine and was the first leader of the Common Service ELSI of BBMRI-ERIC, the European infrastructure on biobanking and biomolecular resources. She was member of the CCNE (French National Consultative Bioethics Committee), the European Group on Ethics in Science and New Technologies, the "ethics and policy" Committee of the international consortium of cancer genomics (ICGC) and chaired the deontology and ethics Committee of INCa (National Cancer Institute) and was research integrity officer at University Toulouse III. She co-leads the SHARC IG of RDA, is member of the local council on open science at Federal University of Toulouse and member of the network of international experts on Open Science of the French national plan on Open Science.

Scientific Domain:

Human immunogenetics and health ethics

Your Promotion and Networking:*International*

December 2022: Finalisation of the FAIRplus project: "[Cookbook](#)" and "[education programme](#)"

November 2022: UNESCO Chair "Science, ethics and society": [Ethics and Open Science](#)

August 2022: Conférence EPITER: Epidémiologie et santé publique : frontières technologiques et éthiques ([summary](#))

June 2022: Annual Conference of the European Society of Human Genetics (ESHG): Ethical values in relation with Open Science and FAIR data principles applied to human genetics research

May 2022: Annual Conference of the European Federation for Immunogenetics (EFI): Recognition of scientific contributions in immunogenetics in the era of Open Science

National

December 2022: Local seminar for the Public Health research local community ([report](#))

December 2022: University course on Ethics of Open Science in Master Programme "Open science & reproducible science" (University of Marseille)

November 2022: French Society of Archivists "Concilier ouverture, protection et conservation des données": Speaker in round table discussion on "[Archivage et protection des données comme outils de l'intégrité scientifique](#)"

October 2022: Public lecture on Open Science in the framework of an Association of dissemination of science (Assoscience): [Science ouverte qu'est-ce que c'est et où en est-on?](#)

Anne and her activities are also [featured on the RDA Website](#).

Your Connection to RDA WG/IG or CoP:

- RDA Plenary P19 : (Seoul) virtual participation to 2 sessions as speaker (SHARC IG and Output and impact session)
- EOSC activities in relation with Health data: I followed the EOSC life workshop on "[Sharing sensitive data](#)" (27 September 2022)

I am especially active in the following RDA groups:

- [Artificial Intelligence and Data Visitation \(AIDV\) WG](#) where I am co-pilot of a deliverable on informed consent
- [Sharing Rewards and Credit \(SHARC\) IG](#) where I am a co-Chair; we have done a survey on the ways to recognise Open Science activities

Country:

France