



The EMIF Colloquium – reaching out to local researchers



[Watch video on EMIF Colloquium 2014](#)

The colloquium took advantage of the meeting location, in the Barcelona Biomedical Research Park, to combine communication within the international EMIF team and contact with local research leaders. EMIF participants could inform a broader audience of the objectives of the project and disseminate their first deliverables. As part of the Innovative Medicines Initiative (IMI), EMIF is keen to communicate activities and progress to a wider audience.

“Having all three EMIF Topics together in Barcelona was a great opportunity for communication within EMIF and to open a dialogue with the research community of Catalonia. The colloquium was an ideal way to achieve that,” says Bart Vannieuwenhuysse, of Janssen Pharmaceutica and Coordinator EMIF.

The EMIF partners were welcomed and the Colloquium opened by Miguel López-Botet, Director of the Hospital del Mar Medical Research Institute, and Joaquín Gea, Dean of the Faculty of Life Science and Health of Pompeu Fabra University, both in Barcelona. They commented on the potential and on the technical and social challenges of handling the large quantities of health care data accessed within EMIF, adding that insights provided by EMIF will enable researchers and health authorities to see the bigger picture.

Bart Vannieuwenhuysse gave an overview of EMIF and its objectives. The EMIF Vision is “to be the trusted European hub for health care data intelligence enabling new insights into diseases and treatments”. The word ‘trust’ is crucial. Without the trust of partners, patients and the general public the vision will not be realised. Success with EMIF will open the way for researchers in many other diseases to gain insights from vast quantities of health care data. The ultimate objective is a virtuous circle



in which data generated at the point of care will inform research that will improve the treatment of the individual at the point of care.

In the colloquium, five leading scientists from the Catalonian medical research community explained their activities. These ranged from making dementia a European priority to the collection of data from up to 80 percent of the regional population and processing that data both to inform research and to improve the effectiveness of local mental and physical health services.

Dawn Waterworth, of GlaxoSmithKline and Co-lead of EMIF-Metabolic, presented on 'using real world data to combat global obesity'. Ann Martin, Principal Scientific Officer in the Innovative Medicines Initiative (IMI) Office, explained the funding of IMI, from public and private (EFPIA) sources and its objectives in funding projects such as EMIF.

The presentations were followed by a Question and Answer session chaired by Simon Lovestone of Oxford University and Co-coordinator of the EMIF project. The session featured wide participation and highlighted important points.

More on the EMIF Colloquium

Watch
presentation of Bart
Vannieuwenhuysse 

In his presentation, Bart Vannieuwenhuysse reported that EMIF now has 57 partners from 18 countries, with 47 academic research units, smaller enterprises and patient organisations joining ten pharmaceutical companies in the search for new knowledge. The large mass of data accessible within EMIF represents around 53 million lives. The Metabolic and Alzheimer's Disease Research Topics also hold smaller data cohorts with much greater detail. He added that 150 of the 260 researchers in EMIF had come to Barcelona, creating a great opportunity for networking.

Watch presentation of
Dawn Waterworth 

Dawn Waterworth, of GlaxoSmithKline and Co-lead of EMIF-Metabolic, presented on 'using real world data to combat global obesity'. Ten years ago, the occurrence of Type 2 Diabetes, related to obesity, was virtually unknown in people under 30 years of age. Today even teenagers are presenting with the condition. Research to tackle this epidemic requires the multidisciplinary approach that EMIF offers.



Watch presentation of
Jesús Rodrigo 

Jesús Rodrigo, Executive Director of CEAFA (the Spanish Alzheimer's Disease patient organisation) and a member of the Alzheimer Europe Board, spoke on 'making dementia a European priority'. In particular, he explained progress being achieved by Alzheimer Europe in pushing for political action to make dementia a priority.

Three presenters explained the use of real patient data in research centres in Catalonia.

Watch presentation of
Alberto Lleó 

Alberto Lleó, of the Memory Unit in the Neurology Department of the Hospital de Sant Pau in Barcelona, pointed out that with the longest life expectancy for women in Europe (85.5 years) and the fourth longest in the world for the total population (82.5 years), Spain both has a great responsibility and opportunity for addressing Alzheimer's Disease.

Watch presentation of
Ferran Sanz 

Ferran Sanz, of the Pompeu Fabra University, described the Research Programme on Biomedical Informatics (GRIB), which is using data from the Parc de Salut Mar. GRIB is collating data from two general hospitals, three emergency rooms, one mental health care provider, one social health care provider and 13 primary care teams covering a population of 325,000. The work contributed to the development of IMASIS, a multi-centre hospital clinical information system covering 1.6 million patients. Part of this data, relevant to Type 2 Diabetes, is available in EMIF in an anonymised form.

Watch presentation of
Bonaventura Bolívar 

Bonaventura Bolívar, Scientific Director of the primary care research institute IDIAP Jordi Gol, reported on SIDIAP. This database was created in 2010 with the Catalan Institute of Health to collect data using standardised e-records software at 274 primary care centres and 3,400 GPs and other complementary sources. The data represents over 5.8 million patients. The SIDIAP team is working to add value to this data.

Watch presentation of
Josep Maria Argimon 

Josep Maria Argimon, Director of the Catalanian Agency for Healthcare Quality and Evaluation, spoke on 'Collaboration for better health care — the importance of public-private partnerships'. He emphasised the need for large quantities of health-linked data to facilitate medical research and said this is a key recommendation of the European Commission. VISC+,



he explained, is a public-private partnership project that will link all the information of the Catalan health care system, anonymously and securely, to foster and accelerate innovation in research.

Watch presentation of
Ann Martin 

Ann Martin, Principal Scientific Officer in the Innovative Medicines Initiative (IMI) at the European Commission spoke on the same topic. She explained the funding of IMI, from public and private (EFPIA) sources. IMI is now linked with 764 academic research teams and 433 in the pharmaceutical companies, 146 small and medium enterprises, 17 regulators and 25 patient organisations. She described some of the other IMI projects as well as EMIF and reported that IMI is working for faster regulatory approval so that innovations can benefit patients sooner.

Questions and answers

Watch Q&A session 

The presentations were followed by a Question and Answer session chaired by Simon Lovestone of Oxford University and Co-coordinator of the EMIF project. The session featured wide participation and highlighted important points.

The data sets used in Catalonia were first developed for clinical purposes and there were challenges using the data for research. One way to lessen this was to explain the value of the data to the providers, such as local GPs. They then provide data that is more accurate and complete; which also improves the value for clinical purposes. In addition, confidentiality must be stressed.

The involvement of patients and patient organisations is critical in gaining support for the use of such data in research. They need to understand the benefits that can come from using the data. It also helps if the data providers can see a potential benefit for their own work, rather than just an extra task.

Discussing the ethics and the limit for the use of health data in research, Simon Lovestone referred to a recently published paper in which he was involved. This describes a governance model prepared together with patients for the reuse of mental health data and would enable researchers



to contact individual patients as potential recruits for trials.

Large consortia with a wealth of data, such as EMIF, provide an effective means of tackling complex conditions such as AD and obesity.

Closing the event, Bart Vannieuwenhuyse quoted Paul Janssen, the founder of Janssen Pharmaceutica, saying we need to get beyond the data, because “the patients are waiting.”

