2nd EPICLUSTER Event
Funding workshop & EpiXchange II Meeting

On December 1st and 2nd 2020, EPICLUSTER's second activity took place. On the first day, the EPICLUSTER leadership and wider stakeholder group met for a workshop on funding. On the second day, EPICLUSTER organised and ran EpiXchange II, a community-building meeting based on the format of EpiXchange I (2018). The meeting brought together various FP7 and Horizon 2020 epilepsy projects with stakeholders to review progress and future directions in key research areas including genetics, biomarkers, therapeutics, co-morbidities and biobanks/resources.

Dec 1st 2020 EPI-CLUSTER Funding, governance and Patient Engagement Workshop
Time: 14:00 – 17:00 CET; By Microsoft Teams (virtual)

Meeting overview The main part of the workshop was on funding for epilepsy. To drive the discussion among leading epilepsy researchers on how we identify, plan, develop and secure large-scale funding in the future. The main target in this regard is Horizon Europe but other opportunities include through partnering with US-based agencies such as NINDS or philanthropy/patient representative groups. The second half of the meeting featured presentations from MULTI-ACT on a framework for our Cluster to improve our governance and ensure the inclusion of key stakeholders.

Attendees There were 25 attendees at the workshop. This included the complete EPICLUSTER leadership group, several of the affiliated members from other projects and patient representatives, members of EBRA and the invited speakers.

David Henshall
Sergiusz Jozwiak
Kristien Aarts
Merab Kokaia
Asla Pitkanen
Simona Borroni
Annamaria Vezzani
Janet Mifsud
Tim Raemaekers
Deborah Bertorello
Elke de Witte
J Helen Cross
Matthew Walker
Eleonora Aronica
Michele Simonato
Martin Brodie
Ulf Tolsch
Francesca Sofia
Laura Lubbers
Françoise Van Hemelryck
Vicky Whittemore
Philippe Ryvlin
Ana Sebastiao
Eleonora Palma
Ann Little
Sanjay Sisodiya
Roland Krause
Paola Zaratin
Andrea Gavazzi

Agenda The first presentation focused on previous and future (HE-Health Programme) funding landscape for epilepsy in Europe and was presented by Tim Raemaekers *(DG Research and Innovation, European Commission)*. The presentation covered recent spending on epilepsy and other brain diseases and examples of recent, successful projects funded by the EC with relevance to epilepsy. Also, likely funding instruments in the coming programme which include NEURON, JPND and HBP. A "Brain Health Partnership" funding instrument could be possible (2025?).

Next, Vicky Whittemore from the NINDS/NIH gave an overview of the organisation of NINDS and funding instruments – *NIH/NINDS funding landscape for epilepsy: now and the future*. There has been steady investment in epilepsy-related projects which is about €200

Mio (per capita, far greater than in EU). A number of large-scale "centres without walls" collaborative programmes have been funded on epilepsy ($94Mio in past 10 years). The Epilepsy benchmarks were also presented which may drive the direction of future requests for proposals.

The next presentation – *CURE epilepsy funding and patient-focused programming* - was from Laura Lubbers, the CEO of the private charity CURE Epilepsy. They have raised over $70Mio and offer regular funding calls for junior and more established investigators over 1 – 3 year time frames. Focus is on transformative ideas for prevention and disease modification. They are open to any countries.

Simona Borroni spoke next – *Promoting and funding patient-focused research* - President of Gruppo Famiglie Dravet, European Dravet Federation on the challenges and achievements of a smaller, patient-specific charity and how they have raised funding. They typically raise ~€150,000 from donations per year. The contribution of families was strongly emphasised and their expectations for the outcomes and value of research supported by such organisations. In particular, the need for more transparency with project progress and outcomes from scientists. Addressing these gaps is important to achieve impact for patients and ensure support for research continues.

Finally, Francesca Sofia spoke on *Championing the cause of epilepsy through education and engagement of people with epilepsy in research* about the importance of engaging people with epilepsy to ensure sustainable funding and urgency. Also, how patients ("e-patients") are more empowered now in promoting what matters most to patients. There is a sense that other neurological diseases (e.g. Multiple sclerosis) are further ahead than the epilepsy field in incorporating "champions" into research programmes and stigma and lack of public awareness remain major issues in epilepsy. One initiative is the IBE Academy for patients to upskill them to be active and empowered.

Summary of discussion and priorities

Tim Raemaekers/EU Horizon 2020 brought challenges as we (epilepsy) had to compete directly with other fields since there were no disease-specific topics. This will not change under Horizon Europe. Indeed, draft text for the early Health calls indicates that only "mental health" is specifically called out. We must think creatively about how to organize so we can compete. TR was challenged on the extent to which co-design was meaningful in the design of the programme. TR assured that this was extensive and open. Some further clarification around the possible Brain Health Partnership was raised and whether this would replace or be instead of a "Mission". Ultimately, it depends on member states wanting this. Increasingly, patient involvement in design of studies will be important in Horizon Europe. Discussion also focused on approaches to lobbying. A subsequent comment on statistics around funding was made around Tim Raemaekers presentation. Specifically, that the figure for epilepsy (~€200 Mio) is misleading because this is based on any project that had relevance to epilepsy and not projects specifically focused on epilepsy. In fact, we think the amount of funding that went from Horizon 2020 to epilepsy is actually disproportionately low relative to disease-burden/DALYS. Other discussion covered the issue of the need to better embed patient values in the design of research.

MULTI-ACT

The second part of the Workshop focused on EPICLUSTER's governance and patient engagement and maximising the impact of research for patients. The first presentation was by Paola Zaratin. The presentation provided an overview of MULTI-ACT and emphasised that multi-stakeholder involvement is key to sustainable healthcare research and alignment of R&I with societal benefits – Responsible Research & Innovation (RRI). This will be a key requirement for the next Horizon Europe programme for success. Andrea Gavazzi then followed with a baseline analysis of EPI-CLUSTER. Several strengths were identified but also gaps. Deficits in key areas included participatory governance and patient/stakeholder engagement. Recommendations were provided for how to address these deficits. Finally, Deborah Bertorello covered what it means to capture the patient's voice to meet RRI goals. The tools available to EPI-CLUSTER include a digital toolbox containing patient engagement plans, activities and measures of success.

Summary of discussion and priorities

The MULTI-ACT presenters were asked about how epilepsy community compares to other major brain diseases in terms of degree to which research is co-designed with stakeholders/patient groups. At least for MS, this is very embedded, with codesign from the beginning and with industry, although acknowledged this is still early. The ideal research "ecosystem" is a challenge for most, however. EPICLUSTER has linked with patient representatives/experts but this can be improved. The EpiCare network was mentioned as a great example of an epilepsy network with very active participation of patient experts (15 patient engagement groups). Many of these patients are motivated to be more engaged with research. FS raised the point that the shift toward patient engagement in research brings, however, challenges in that demands from researchers to include patients in projects is outpacing the available experts and the community is too stretched. There is a need to educate more e-patients. This will be time-consuming. MULTI-ACT seeks to mitigate this aspect by making sure patient expertise is used when needed. Another point raised is that EPICLUSTER could bring forward a "white paper" that might delineate the issues around patient and stakeholder involvement in research. Last, the ILAE/IBE have managed to get the WHO to pass a resolution on epilepsy and neurological disorders. This now needs to be translated into action, including the importance of research. This puts responsibility of member states to support research on epilepsy.