

The Epilepsies – Definitions

Epilepsies: a group of diseases where epileptic seizures are the prominent presenting feature

Rare epilepsies: an epilepsy with incidence < 5 in 10,000 population, either defined as epilepsy syndrome or aetiologically driven epilepsy

Complex epilepsies: an epilepsy requiring multidisciplinary management through care pathway or comorbidity, with or without known aetiology, e.g. surgically treatable epilepsies needing a high level of multidisciplinary expertise (including VEEG analysis, functional and/or structural neuroimaging, etc.)

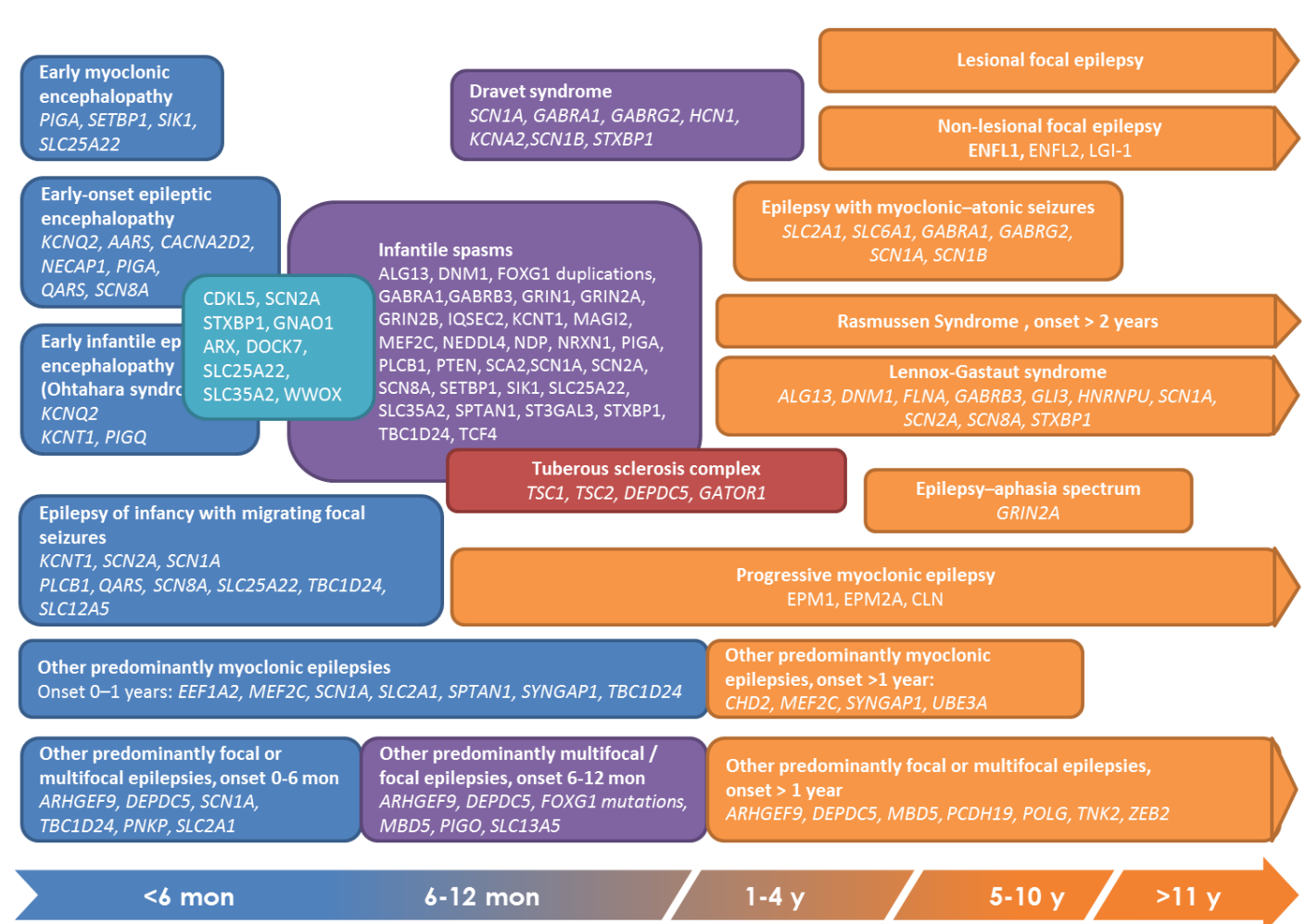


Figure 1: Scope of diseases

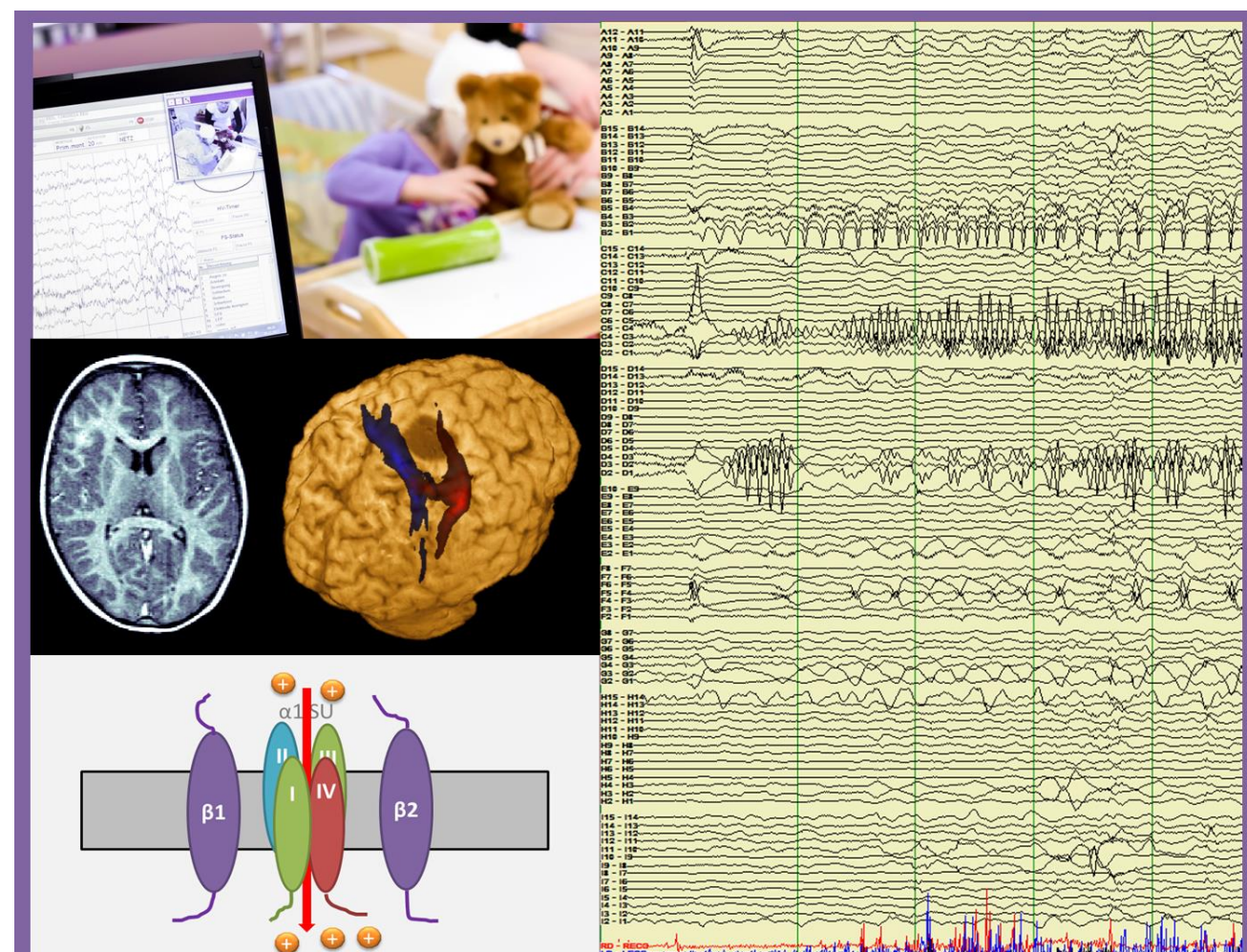
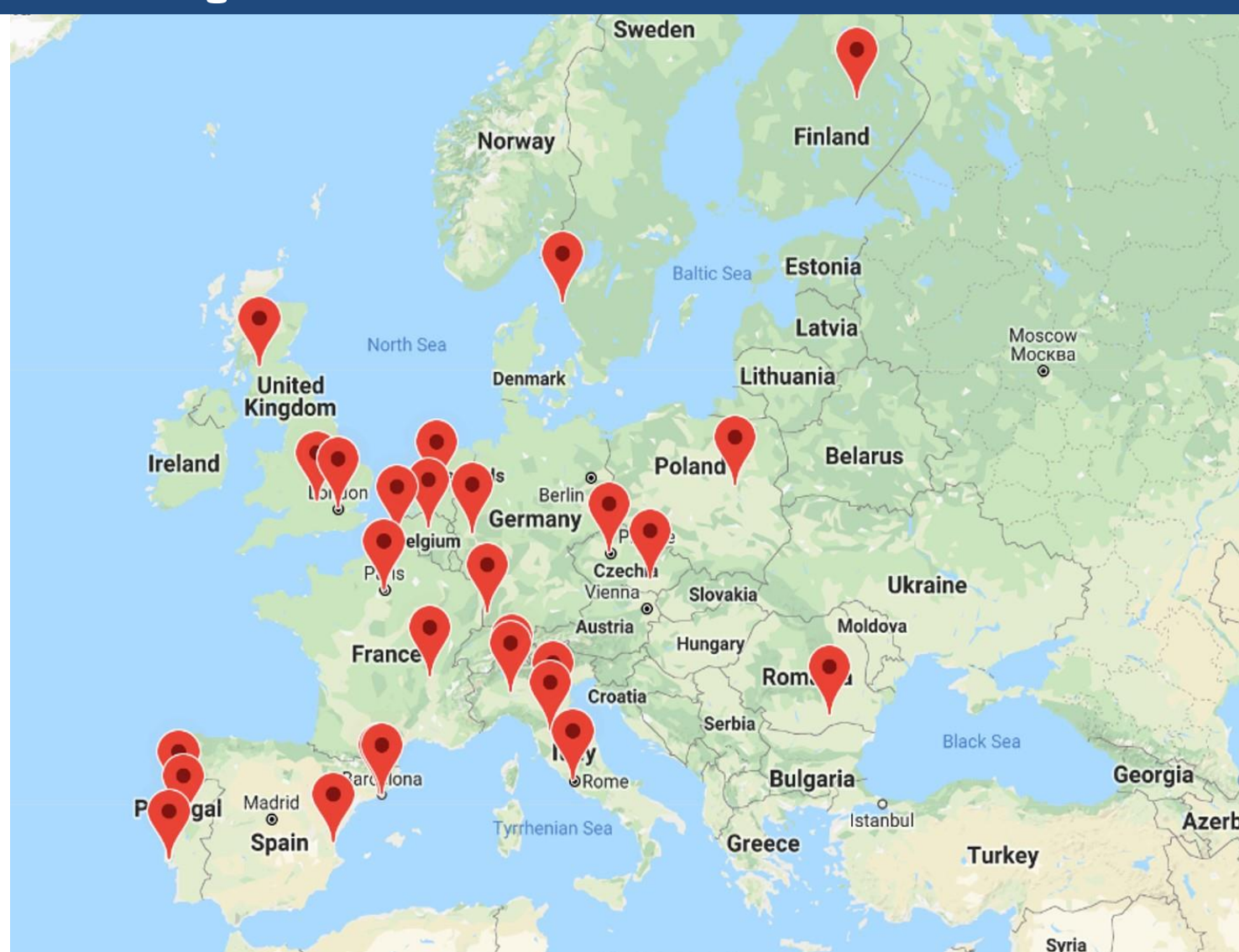


Figure 2: Aspects of investigation of the epilepsies

Members of EpiCARE

- **Lead:** Professor J Helen Cross, Great Ormond Street Hospital, London
- 28 core centres in 13 European countries
- Existing networks with relevant centres participating include:
 - Neurophysiology (SCORE, Dianalund)
 - Neuropathology (European Epilepsy Brain Bank, Erlangen)
 - Neonatal Seizures (University Maternity Hospital Cork)
 - E-pilepsy (Lausanne, Salzburg)



Management Structure

Management Board: representation from all core centres, participating European patient/family organisations, e.g. Dravet Foundation, Tuberous Sclerosis Alliance, Matthews Friends

Steering Committee: leads of the work-packages (core networks), overseeing the day to day management

Scientific Advisory Board : independent member representation from key organisations affiliated to rare and complex epilepsies

Ethics Committee: advisors independent to the project; to specifically advise on clinical trials, treatment outcomes and genetic evaluation

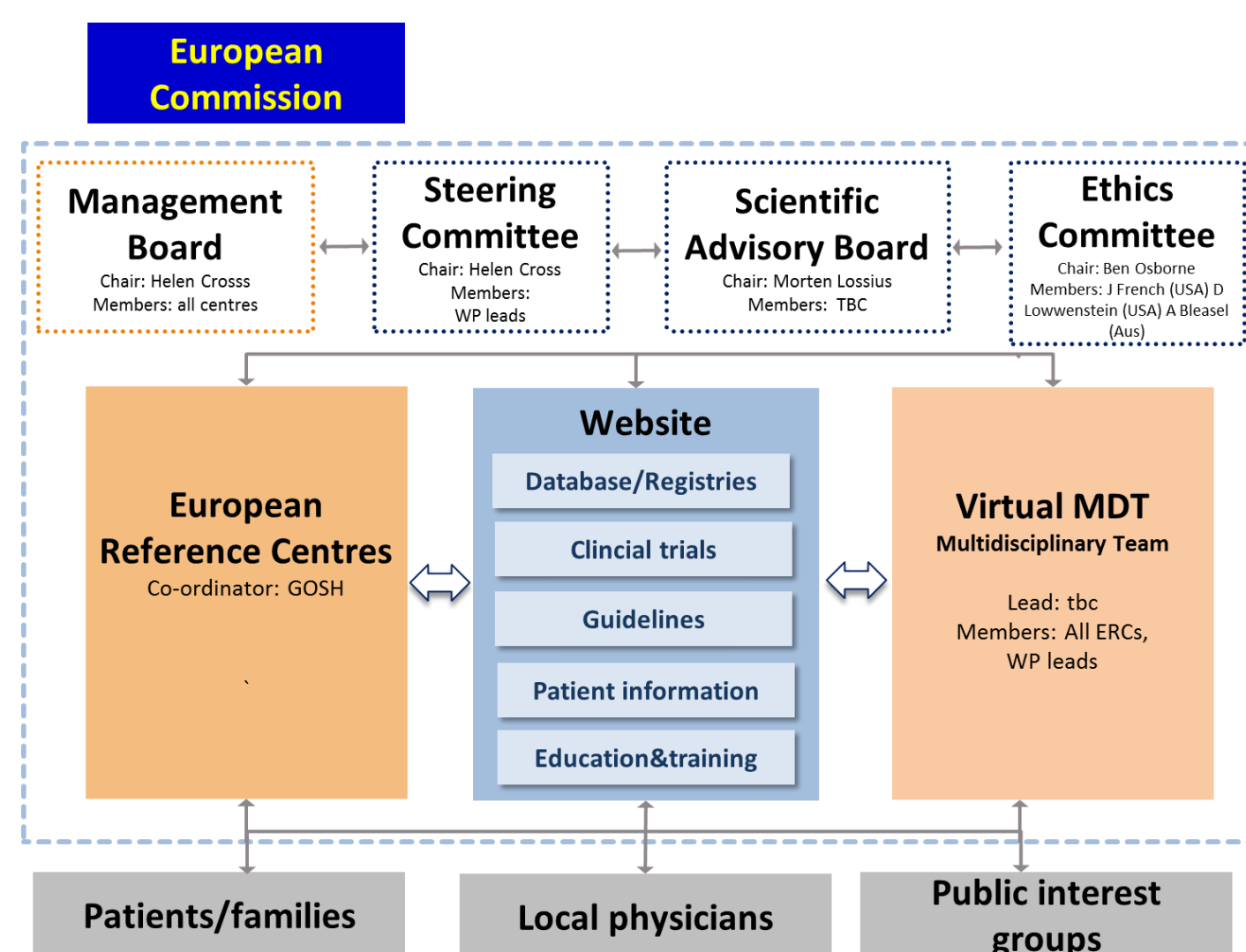


Figure 3: Management structures of EpiCARE

Working Groups

Series of **vertical workpackages**, aimed at developing **diagnostics** and **therapeutics**, working to advance e-care promoting continued local service delivery in order to harmonise care for the rare and complex epilepsies.

Build on existing network relevant to the specialised care of individuals with the rare epilepsies.

Horizontal subnetworks consolidating **registries**, **guidelines**, and **education** (of professionals and patients).

Focus of the work is **clinical care and health delivery**, enabling **collaborative research**, with the ability for **monitoring outcomes** and **clinical trials** with the ultimate aim of improving outcomes and quality of life.

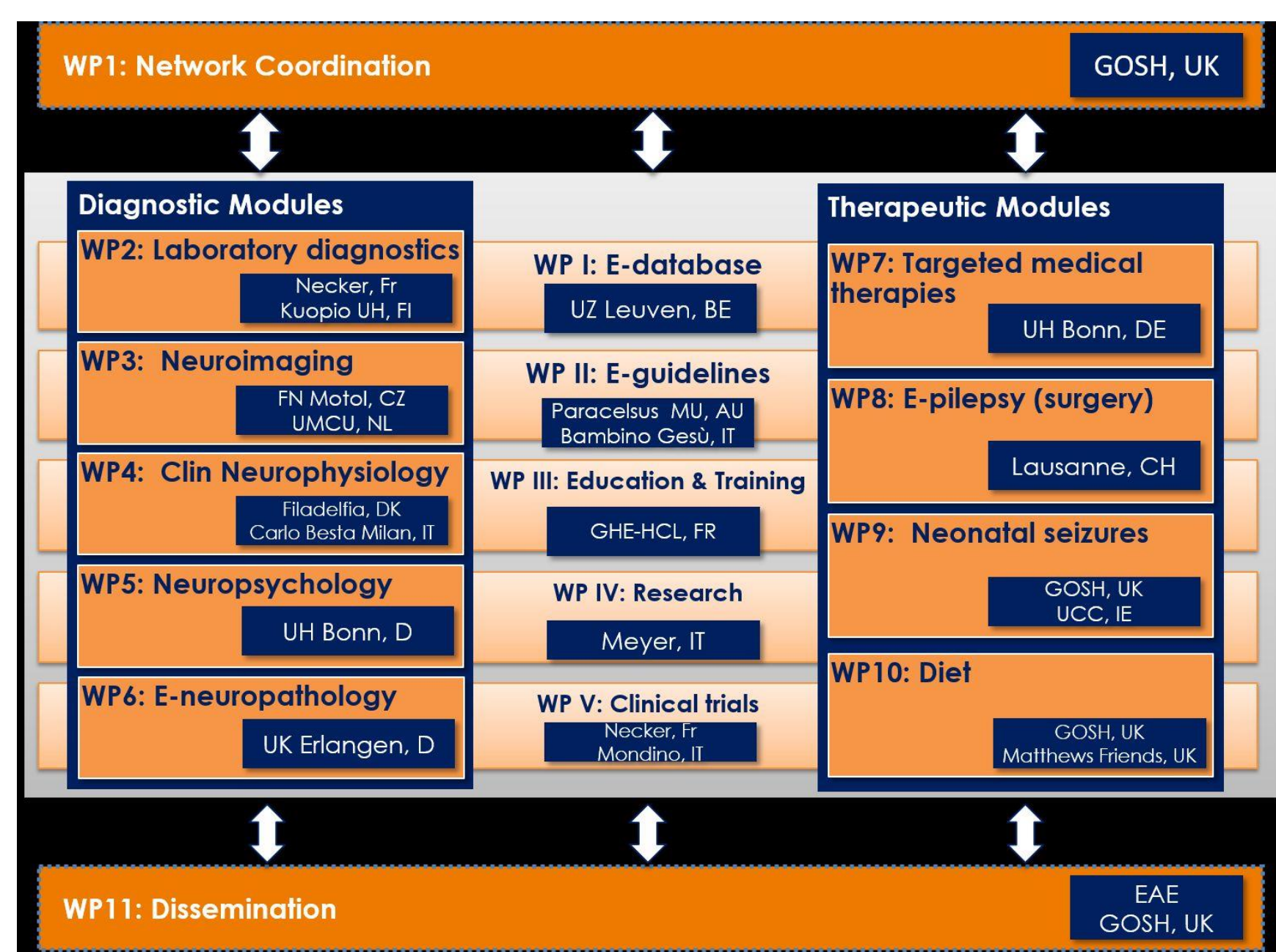


Figure 4: Structure of network

Vision and Objectives of EpiCARE

“Our vision is to develop and deliver highly-specialized diagnostics and care to improve diagnosis and outcome in individuals with rare and complex epilepsies in Europe.”

Objectives of EpiCARE

- To **improve accessibility of detailed diagnostics** to individuals of all ages with rare and complex epilepsies across Europe, including clinical evaluation and investigation
- To **develop treatment protocols** and **monitor standardised outcomes**
- To **improve awareness of, and accessibility to treatment protocols** for physicians and individuals with rare and complex epilepsies across Europe
- To **enhance educational activities** and training opportunities across Europe by interchange across the network
- To enhance opportunities for **registries**, **collaborative research** for the benefit of individuals with rare and complex epilepsies across Europe

Project Milestones

Picture 5: Annual EpiCARE Meeting



- June 2017: EpiCARE launch meeting
- October 2017: Project Coordinator appointed
- October 2017: EpiCARE website launched: www.epi-care.eu
- 9 - 10 March 2018: 1st Annual EpiCARE Meeting in London
- 26 March 2018: First patients added and first panel launched in Clinical Patient Management System (CPMS)

Oversight:

- Steering Committee: monthly meetings
- Management Board: twice a year meeting
- ePAG: bi-monthly meetings



Picture 6: ePAG group meeting

Key Achievements 2017-8

WP2 – Laboratory Diagnostics

- Documentation of availability of diagnostics across network; **care pathway** established

WP 3 – Neuroimaging

- **Work toward broadening availability post processing tools;** continuation from E-epilepsy
- **Participation in MELD project**, a multi-centre collaboration for brain lesion detection utilising machine learning for presurgical evaluation (<https://meldproject.github.io>)

WP 4 – Clinical Neurophysiology

- **SCORE**, a computer based system for standardised EEG reporting and classification, available to all centres across EpiCARE

WP5 – Neuropsychology

- **Working group** established, evaluating changes to online assessment tool

WP 6 – E-Neuropathology

- Standardised **collection of brain pathology specimens** across Europe
- Guidelines developed for histopathological examination of epilepsy surgery specimens, & standard operating procedure for the transfer of specimens

WP7 – Targeted Medical Therapies

- **Working group** established, plan for key diseases over next 12m

WP 8 – E-pilepsy (Surgery)

- Continued monthly **epilepsy surgery case discussions** (22 cases discussed over 12m).

WP 9 – Neonatal Seizures

- **BabyLink** online platform, a web based IT platform for streaming neonatal EEG on a 24-hour basis, developed with SOP

WP10 – Dietary therapies

- **Working group** formed, centres with dietary therapy listed on website

WP I – E-database

- **Core dataset established;** RedCAP to be utilised

WP II – E- Guidelines

- **Existing management guidelines collated** for rare epilepsies. Task force was established to evaluate existing guidelines and devise new ones.

WP III – Education and Training

- Set of **criteria developed to endorse courses** for rare epilepsies.

WP IV - Research

- Existing consortia; 3 further grant applications resultant
- Partnership being developed with **Human Brain Project** to develop infrastructure
- Organising partner of **EpiXchange 2018**, epilepsy research conference

WP V – Clinical Trials

- Working group established with move towards eCRF