

# The objectives of the EpiCARE network

1. To improve **access to detailed diagnostics**, clinical evaluation and investigation of patients with rare and complex epilepsies.
2. To **develop treatment protocols** and monitor standardised outcomes of rare and complex epilepsies.
3. To improve awareness and **accessibility to protocols** for physicians and patients with rare and complex epilepsies.
4. To enhance **educational activities and training** opportunities across Europe by interchange across the network.
5. To enhance opportunities for **registries and collaborative research** for the benefit of individuals with rare and complex epilepsies across Europe.



Great Ormond Street   
Hospital for Children  
NHS Foundation Trust

# EpiCARE A European Reference Network for Rare and Complex Epilepsies

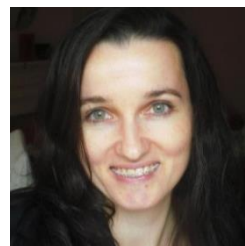
## We are based at:

Clinical Neurosciences Section,  
4<sup>th</sup> Floor, PUW South  
UCL – Great Ormond Street Institute of  
Child Health  
Faculty of Population Health Sciences  
30 Guilford Street  
London  
WC1N 1EH



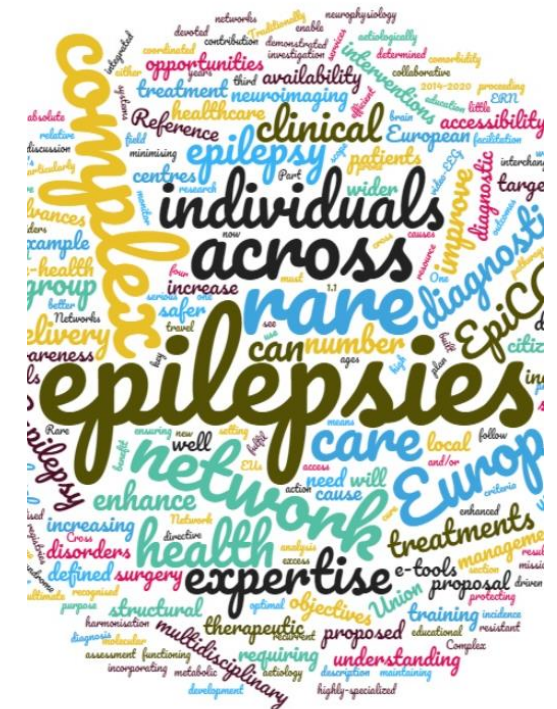
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<http://epi-care.eu>



EpiCARE\_ERN



## A collaboration of 28 specialist epilepsy services in 13 European countries.

- Promoting therapeutic excellence
- Sharing knowledge
- Research

## Who we are

EpiCARE is a network of specialist **centres of expertise in Europe** developed to enhance diagnosis and treatment of rare and complex epilepsies.

Through **cross-country collaboration**, we promote multidisciplinary management across the care pathway. Using **e-tools** and **e-consultancy**, we aim to **improve patient diagnostics and care**, whilst minimising the need for patients to travel.

## What we do

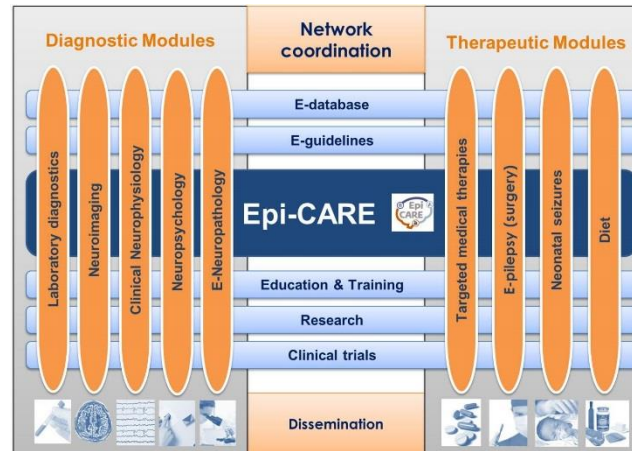
The EpiCARE network functions through a series of vertical workpackages and horizontal subnetworks.

Workpackages aimed at developing diagnostics modules will focus on **laboratory diagnostics, neuroimaging, clinical neurophysiology, neuropsychology** and **neuropathology**.

Workpackages with the aim of developing therapeutic modules will look at **targeted medical therapies, epilepsy surgery (E-pilepsy), neonatal seizures** and ketogenic **diet**.

Running through these workpackages are horizontal subnetworks to consolidate **registries, guidelines**, and **education** of professionals and patients.

The focus of the work will be clinical care and health delivery, the network will enable **collaborative research**, with the ability for monitoring **outcomes** and **clinical trials** in these orphan diseases with the ultimate aim of improving outcomes and quality of life.



**Surgical WebEx case discussion:** 4<sup>th</sup> Wednesday of the month, 6pm CET/5pm GMT

**Non-surgical WebEx case discussion:** 2<sup>nd</sup> Wednesday of the month, 6pm CET/5pm GMT

## Participating centres

- Great Ormond Street Hospital for Children NHS Trust, UK
- University College London Hospitals, UK
- Queen Elizabeth University Hospitals, UK
- Oxford University Hospitals, UK
- University Hospital Gasthuisberg KU Leuven, Belgium
- Motol University Hospital, Czech Republic
- St. Anne's University Hospital, Czech Republic
- Kuopio University Hospital, Finland
- CHRU LILLE Epilepsy Unit, France
- Hospices Civils de Lyon, France
- Hôpital Necker – Enfants Malades, Paris, France
- University Hospital Bonn, Germany
- Epilepsy Center, University Hospital Freiburg, Germany
- RCCS Institute of Neurological Sciences of Bologna, Italy
- Azienda Ospedaliero-Universitaria A. Meyer, UO Neurologia Pediatrica, Florence, Italy
- Fondazione IRCCS Istituto Neurologico Carlo Besta, Milan, Italy
- Fondazione Istituto Neurologico Nazionale Casimiro Mondino, Pavia, Italy
- Ospedale Pediatrico Bambino Gesù, Rome, Italy
- University Medical Center Utrecht, Brain Center Rudolf Magnus, Netherlands
- The Children's Memorial Health Institute, Poland
- Centro Hospitalar e Universitario de Coimbra, Portugal
- Hospital de Santa Maria, Lisbon, Portugal
- Centro Hospitalar do Porto, Portugal
- Alexandru Obregia Clinical Hospital, Bucharest, Romania
- Hospital Sant Joan De Déu, Barcelona, Spain
- Hospital del Mar-Parc de Salut Mar, Barcelona, Spain
- Hospital Universitario y Politecnico La Fe, Valencia, Spain
- Sahlgrenska University Hospital, Gothenburg, Sweden