



## **Terms of Reference**

The Organisation of Paediatric Epilepsy Networks in the United Kingdom (OPEN UK) is a UK clinical network connecting all NHS health boards and trusts providing care for children with epilepsies, regional epilepsy networks and a UK Working Group.

### **OPEN UK aims**

To unite children's local, regional and national epilepsy services and networks to improve integrated care for children and young people with epilepsies by:

- Encouraging collaboration and sharing of local, regional and national ideas, pilots, and resources
- Being a national resource and professional UK body to which other organisations may come for information, support, data and strategic or clinical input
- Facilitating links to local, regional and national funding bodies

### **OPEN UK Working Group Membership**

- A nominated lead representative for each regional or national epilepsy network
- A nominated ESN representative with quality improvement role for each regional or national epilepsy network
- BPNA representative
- BACD representative
- Epilepsy12 Clinical Lead

Each region or group to manage the nomination of a lead within their own structures. Leads and ENS representatives will declare any conflicts of interest.

### **OPEN UK Meetings**

- OPEN UK Working Group to meet 3 times per year
- An annual conference style meeting badged as "Epilepsy12 & OPEN UK" focusing on paediatric epilepsies quality improvement

### **Leadership and administration**

- Chair, elected by the group with a 3 year term of office
- Deputy chair, elected by the group with a 3 year term of office
- Quoracy for key decisions is at least 50% of Working Group participation
- OPEN UK web pages hosted by Epilepsy12 with a list of meeting dates, current regional leads/ENS links and a hyperlink to respective regional network websites, where available
- RCPCH-based Epilepsy12 project team to support meeting organisation, membership, minute taking, website information, mailing lists
- Annual report to BPNA and to the regional networks



## **Funding**

- Costs of admin support, travel and daytime accommodation for 3 meetings per year to be funded via the RCPCH through the Epilepsy12 project team.

## **Epilepsy12/OPEN UK Epilepsy Specialist Nurse (ESN) QI facilitator role**

- Epilepsy12 will additionally fund an ESN QI facilitator within each OPEN UK region to support quality improvement and the work of the Epilepsy12 audit. Each ESN QI facilitator will be nominated from within their respective OPEN UK region. The role will include:
  - Attendance at UK Working Group meetings as per membership detailed above
  - Funding for travel to Epilepsy12 operational events
  - Attending regional epilepsy network events and facilitating Epilepsy12 updates and quality improvement initiatives
  - Troubleshooting and supporting the RCPCH-based Epilepsy12 project team with local clinical and/or participation issues

There will be a limited annual budget per network region to support these QI activities.