

## First Seizure Registry

The **EpiNet** First Seizure Registry is a multi-centre registry that has been established so that neurologists and epileptologists anywhere in the world can follow patients who are seen after their first epileptic seizure. It is for patients who are seen following a first seizure of any type, regardless of whether or not they are seen in a First-Seizure clinic.

We hope that it will be used to systematically record information on all patients who **are** seen in First-Seizure Clinics. The registry can also be used to record information on patients who are eventually diagnosed with an alternative diagnosis, as well as patients who have actually had more than one seizure by the time they are seen in the First-Seizure clinic.

We would like investigators to do the following:

- create a record for the patient in **EpiNet** in the standard way, and select "First Seizure registry" on the demographics page; investigators will be asked to record if the patient was seen in a special First-Seizure clinic;
- record the type of seizure the patient experienced, or the nature of the attack if it was not an epileptic seizure;
- update the record whenever the investigator sees the patient again; in particular we would like investigators to record:
  - whether the patient has further seizures;
  - whether the patient starts an AED; if the patient does so, we would encourage the investigator to consider enrolling the patient in one of the **EpiNet-First** trials, or to enrol the patient in the First-AED registry;
- update the record at least once per year.

As with all records in **EpiNet**, the individual patient data will be controlled by the person who is listed as the Primary Investigator for that particular patient (usually the person who created the record.) Each investigator will be able to extract data for their own patients at any time. However, the registry has been established so that "real-world" data from large numbers of patients can be analysed. Only de-identified data will be shared with other investigators. This de-identified data contained in the registry will be able to be analysed at various times. All investigators who have contributed patient data will be acknowledged in any publications that result from these studies.