

First Anti-Epileptic Drug Registry

The **EpiNet** First Anti-Epileptic Registry is a multi-centre registry for neurologists and epileptologists anywhere in the world to follow patients who start a first anti-epileptic drug (AED) to control their seizures.

We encourage all **EpiNet** investigators to create records in this registry for all patients who are not participating in the **EpiNet-First** trials.

We would like investigators to do the following:

- create a record for the patient in **EpiNet** in the standard way, and to select "First AED registry" on the demographics page;
- record the drug and dose started, and the intended target dose;
- indicate why they chose the particular AED;
- update the record whenever they see the patient again; in particular we would like investigators to record:
 - changes in doses of the AED;
 - whether the patient has had further seizures;
 - whether the AED has been changed, and if so, the reason(s) for the change, and the new AED commenced;
 - whether the patient has troubling side effects.
- 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 compared with data obtained for patients recruited into the **EpiNet-First** trials (or other randomised controlled trials in patients with newly diagnosed epilepsy.)

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.