

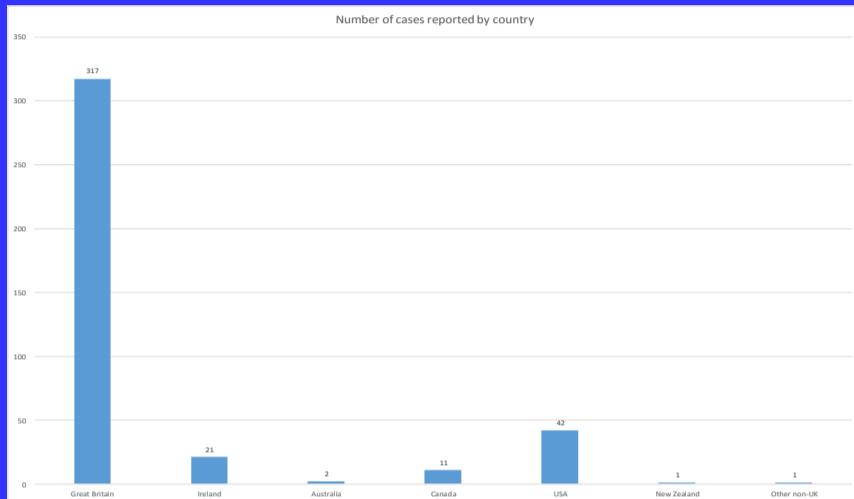
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## Background

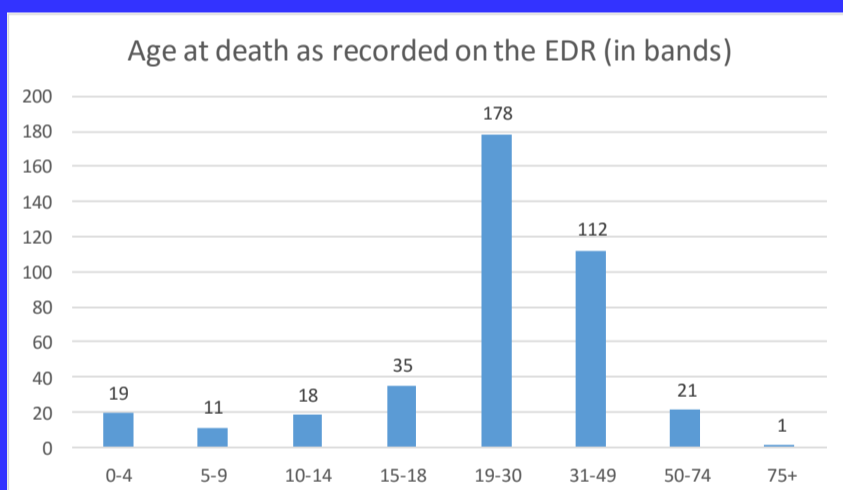
An on-line Epilepsy Deaths Register (EDR) was set up by SUDEP Action (UK) in March 2013 to gather information about Sudden Unexpected Death in Epilepsy (SUDEP) which can be used to help reduce epilepsy related deaths and to improve public awareness of SUDEP. The EDR has been designed to enable family, friends or professionals to report a death. Demographic and descriptive data, including free text comments, of the circumstances leading to death, is collected to build a complete picture of the lifestyle and choices made by the person who died.

## Results

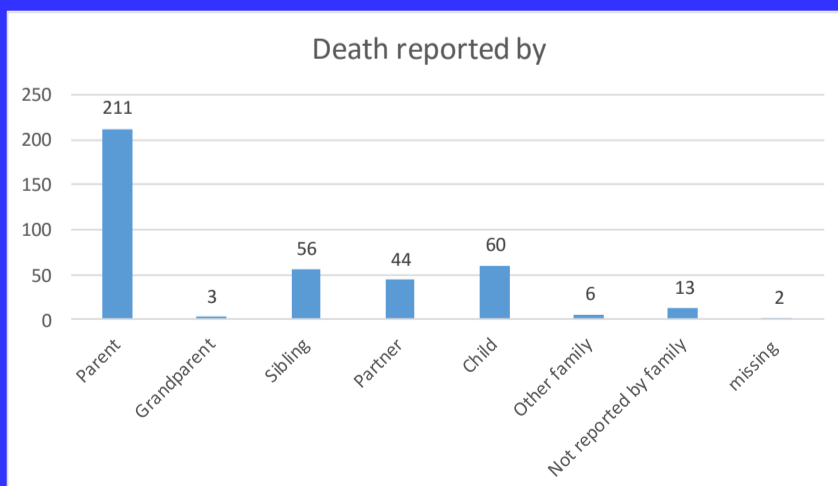
395 cases were reported from 5 countries between March 2013-March 2015. The majority of cases reported are from the UK, with 13% of cases from North America.



Over half of the cases reported are male (59%), with a broad age range (1—80). There is a peak between 19 and 30, reflecting findings from other studies



Almost all cases (97%) were reported by family, with 56% being reported by parents, and 26% were reported by partners or siblings, and 79% of deaths occurred at home.



## Medication

- 215/244 reported that epilepsy medication was prescribed
- 68/231 reported that the deceased sometimes forgot to take their medication
- 98/233 reported that the deceased had worries or concerns about taking their medication

*"She did not like the way the new medication made her feel. She said they made her feel "drunk" She called her doctor several times and spoke to a pharmacist about the medication the day before her death."*

## Specialist Care

- 146/203 had an appointment in the 12 months prior to death
- 46/203 had an appointment more than 12 months prior to death

## Cause of Death

- 67% (261) of cases reported having a death certificate issued.
- 133/261 recorded SUDEP as a cause of death

## Emergent themes from free text comments include:

Gaps in knowledge of the risk of SUDEP, from both families and health care professionals:

*"...feel that if we had been told about SUDEP and how we could have helped reduce the risk or even prevent it, then R could still be here".*

*"We were invited to speak to T's GP, who was sympathetic but seemed unaware that people could die from epilepsy".*

## Gaps in Service or Support:

*"After T's death I learned that the consultant was aware of SUDEP but believed patients should not be told of the risks".*

## The impact of death from SUDEP:

*"I will never come to terms with losing my son who was a strapping healthy young man who had no problems other than suffering from seizures which were kept reasonably under control..."*

## Conclusions

The first two years of data collection from the EDR highlights a number of key points:

- Young people aged 20-30 years appear to be at most risk
- Parents are keen to report the death of their child
- There are still gaps in knowledge about SUDEP which need to be addressed

Additionally, the data provided by the EDR will be a valuable supplement to the registers of people monitored in EMU therefore providing a wider range of risk groups