

# The adult profile of SUDEP using the Epilepsy Deaths Register

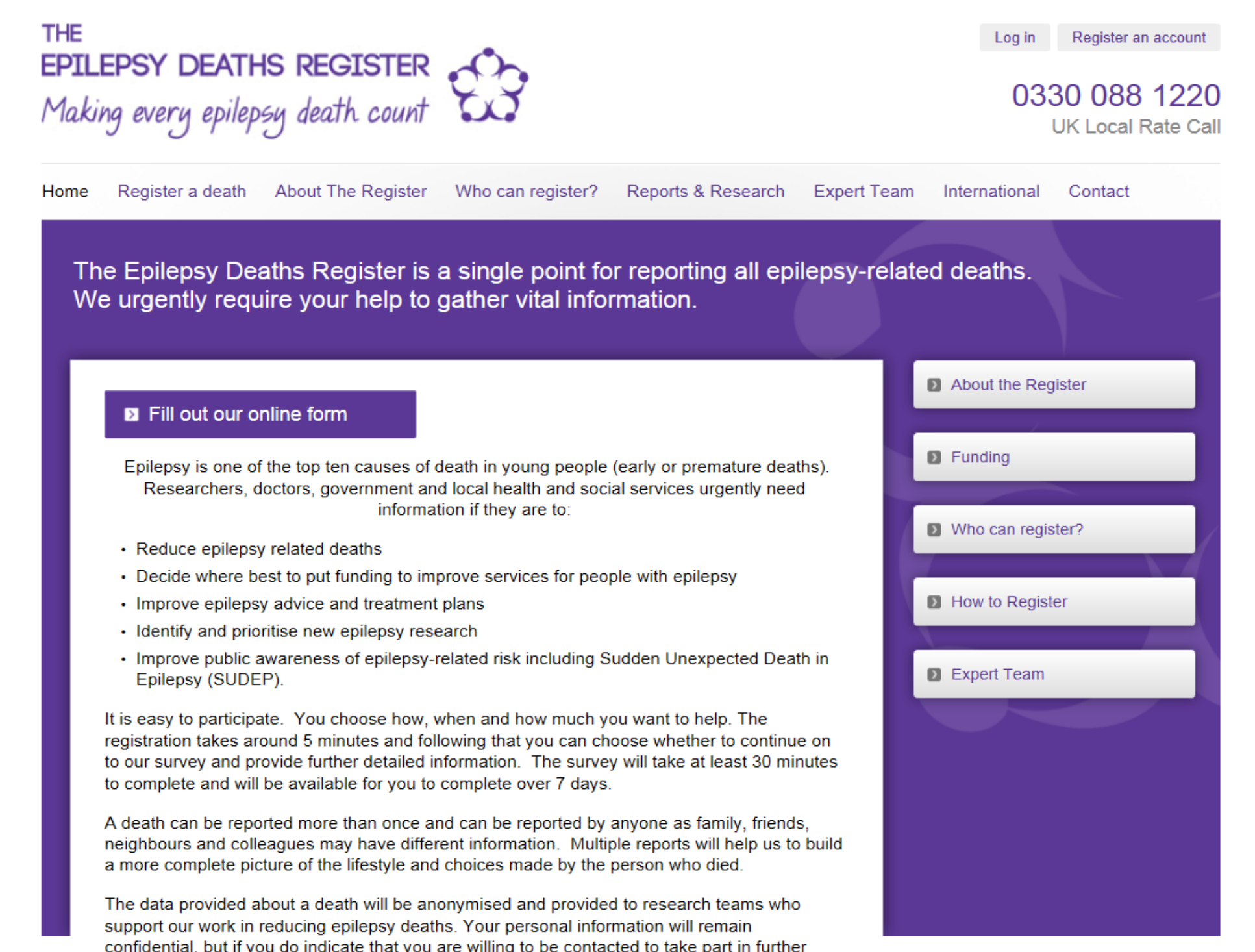
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**There is no ‘standard’ sudden unexpected death in epilepsy (SUDEP). Currently attention is mostly paid to the minority of people at the highest risk – but this misses most deaths. Every person with epilepsy is at some risk; we sought to identify the median profile of reported SUDEP.**

## The Epilepsy Death Register

Three epilepsy deaths occur each day in the United Kingdom<sup>1</sup>. The Epilepsy Death Register (EDR) provides a different perspective, complementing population studies that preferentially identify clinical data but not fully encapsulate the background of a person with epilepsy. The register is voluntary, can be completed by family and clinicians with no time limit to when the death can be registered. The survey contains questions on the epilepsy, demographics and circumstances prior to and after the death. All deaths are recorded and death certificate, post mortem and coronial reports are collected where available. [Epilepsydeathsregister.org](http://Epilepsydeathsregister.org)

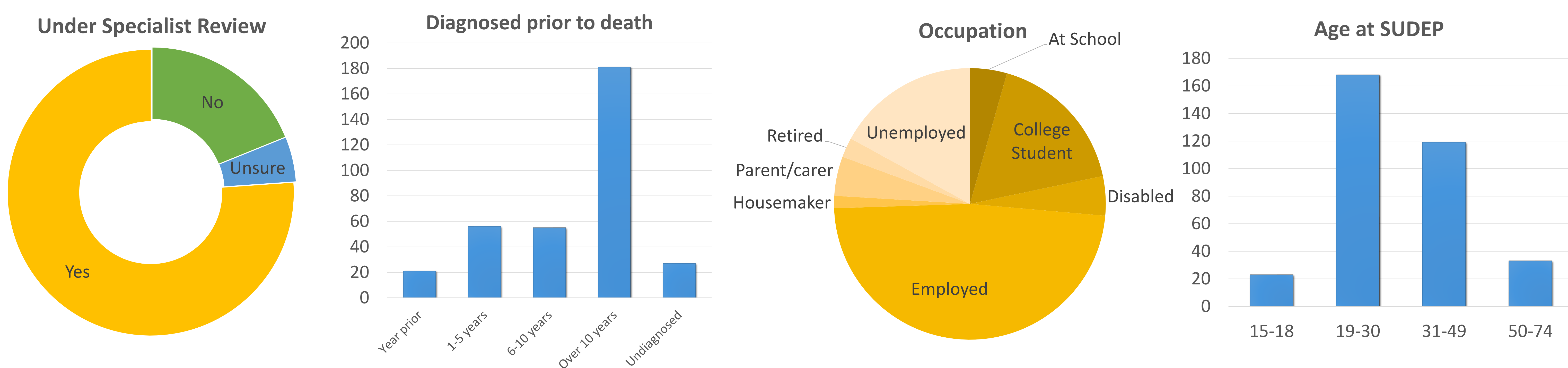


## Methods

There were 726 EDR entries submitted up to June 2018. Adults, aged 15 and above, from any country with a post-mortem supported diagnosis of SUDEP were reviewed. Deaths from other causes such as status and trauma were excluded. 349 complete, individual entries were combined to produce a profile of the composite, median adult patient with a SUDEP.

## Results

The “typical” death would be in a male (58.5%) aged 19-30 (48.7%). They live in the family home (73.3%) are currently in work (45.6%). They were diagnosed more than 10 years ago (53.5%), taking anti-epileptic medication (90.1%) and under the care of a specialist in epilepsy (76.2%). The majority were not known to forget medication and had not had a recent AED change. Their death was unwitnessed (81.0%) and they were found on their back (57.4%).



**SUDEP occurs in otherwise well people with epilepsy. SUDEP should be discussed and safety checks embedded for everyone rather than just targeted at people at higher risk**

## Talking about SUDEP

Discuss early, discuss often<sup>2</sup>. Half (56%) of the families of our ‘typical’ patient did not know that epilepsy could kill. If you are squeamish about discussing death – reframe this as a safety discussion. We recommend the SUDEP and seizure safety Checklist. Outpatient clinic is the most appropriate venue for enduring and person-centred advice.