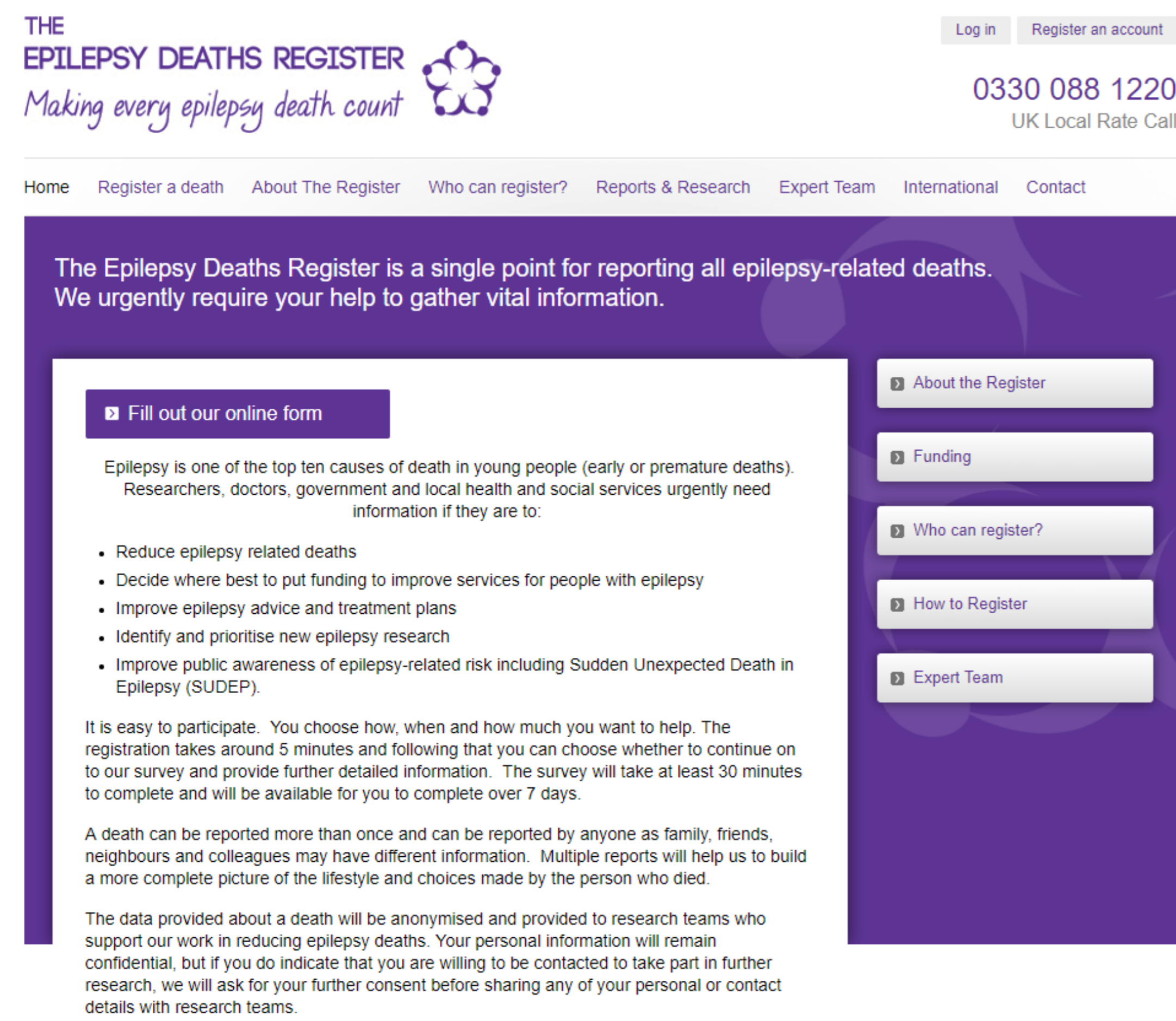


We should be doing more for families who experience an epilepsy associated death

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THE EPILEPSY DEATHS REGISTER
Making every epilepsy death count

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The Epilepsy Deaths Register is a single point for reporting all epilepsy-related deaths. We urgently require your help to gather vital information.

Fill out our online form

Epilepsy is one of the top ten causes of death in young people (early or premature deaths). Researchers, doctors, government and local health and social services urgently need information if they are to:

- Reduce epilepsy related deaths
- Decide where best to put funding to improve services for people with epilepsy
- Improve epilepsy advice and treatment plans
- Identify and prioritise new epilepsy research
- Improve public awareness of epilepsy-related risk including Sudden Unexpected Death in Epilepsy (SUDEP).

It is easy to participate. You choose how, when and how much you want to help. The registration takes around 5 minutes and following that you can choose whether to continue on to our survey and provide further detailed information. The survey will take at least 30 minutes to complete and will be available for you to complete over 7 days.

A death can be reported more than once and can be reported by anyone as family, friends, neighbours and colleagues may have different information. Multiple reports will help us to build a more complete picture of the lifestyle and choices made by the person who died.

The data provided about a death will be anonymised and provided to research teams who support our work in reducing epilepsy deaths. Your personal information will remain confidential, but if you do indicate that you are willing to be contacted to take part in further research, we will ask for your further consent before sharing any of your personal or contact details with research teams.

About the Register
Funding
Who can register?
How to Register
Expert Team

About the Epilepsy Death Register (EDR)

The Epilepsy Deaths Register (EDR) intends to make every epilepsy death count.

The EDR was developed and supported to collect details on factors and events surrounding deaths in epilepsy. The register aims for better understanding of any contributors to the risk of death and works to reduce common factors.

A family member, flat-mate or friend might have information about an epilepsy related death that may not be known to anyone else. The bereaved are able to voluntarily inform the registry about any death in someone with epilepsy.

Even if the death occurred many years ago reports are encouraged, helpful and voluntary to increase knowledge.

This includes deaths reported as or suspected to be:

- SUDEP (Sudden Unexpected Death in Epilepsy)
- any sudden death in someone with evidence of a seizure that cannot be explained
- deaths in people with epilepsy reported as status epilepticus
- accidental deaths in people with epilepsy
- deaths from suicide in people with epilepsy
- deaths reported as cause unknown in people with epilepsy

Introduction

The principal aims of the organisation behind the EDR - are to share information on death in epilepsy and to give support to those bereaved by deaths in epilepsy. SUDEP Action estimate three epilepsy deaths occur each day in the United Kingdom, most of which are potentially avoidable.

Population databases and case-control studies help identify clinical risk factors but may underestimate the rates of SUDEP and deaths related to epilepsy.[1] The 2018 Public Health England analysis of deaths in neurological conditions reveal deaths in epilepsy in England increased significantly between 2001 and 2014.[2]

The reasons behind this concerning change and variations, whether due to awareness in reporting or change in the disease are unclear. The EDR provides a different perspective that complements population sources that may be incomplete and not fully encapsulate important background circumstances.

There have been previous suggestions that closer liaison between professionals and families that have suffered loss may lead to insights that reduce future death rates.[3] Discussion and clarification following sudden loss may help the family with inappropriate feelings of guilt and blame.[4]

Aims

The bereaved reporters are asked about the circumstances prior to and after their loved one's death. They are also asked details as how they have been supported in their grief, and what they were told about the death.

This project aimed to analyse communication prior to and after a death to attempt to assess if information shared could be insufficient or ambiguous.

We wished to ascertain if there was a discussion from the treating teams if the possibility of death in epilepsy was raised prior to death.

We also sought to determine from which service information after death was provided and to assess if there was opportunity to feedback and the ability of support to discuss issues and the timing of this.

Methods

The register is open to all deaths and there is no time limit as to when the death can be registered. The survey is completed online or by phone discussion and takes 30 minutes.

The survey contains questions on illness and demographics in addition to the situational circumstances prior to and after the death. No comparison is made with public records as names and identifying information is removed.

Since SUDEP Action started the EDR in 2013 there have been 454 unique death registrations of people based in the UK. Multiple registrations are treated as one death with the information combined.

This information was extracted from questions regarding awareness and communication of both the epilepsy condition and the cause of death.



Conclusions

There is an enormous amount that clinical teams can do to improve how we communicate SUDEP risk and to help families through the aftermath of an epilepsy-related death. SUDEP can occur early and in people who have not yet been diagnosed with epilepsy.

Families wait many months for an inquest to report and yet – even after this wait - are often left with inadequate answers.

We need to continue to accurately learn on the risks contributing to epilepsy death but recognizing the effect of these deaths on the bereaved should be of equal priority. We encourage all teams to contact the families who have been bereaved, offer your sympathies and direct them towards the register. Many families report that the process of entering the data is partially therapeutic, and by extending registrations we hope to be able to do more to identify modifiable risk factors and support bereaved families.

Future plans

Important research questions that the EDR may contribute in finding answers to are

- How important are social factors and life-style factors
- Why is SUDEP less common in children than adults
- What proportion are in less severe epilepsy
- IS SUDEP associated to particular drug or non-drug treatments / Is it due to sub-optimal care
- Does communication of risk reduce risk-taking behaviours
- Are seizure detection devices and alarms protective / Is night-time surveillance protective
- What flagging mechanisms are effective in targeting people at risk
- What interventions can support clinical, patient, carer decision-making and risk management
- What is the impact on the family? / How can services for families be improved

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The Epilepsy Deaths Register is owned and operated by SUDEP Action.

The Epilepsy Deaths Register is endorsed by government, but in the UK there are no major bodies that fund registers or their infrastructure.

Results

25 (8.5%) people who died had not received an epilepsy diagnosis despite 52% of these patients being under care of an epilepsy service.

In total 77.8% of those registered were under the care of an epilepsy specialist at the time of their death. 52.6% of reporters did not know that epilepsy could lead to premature death.

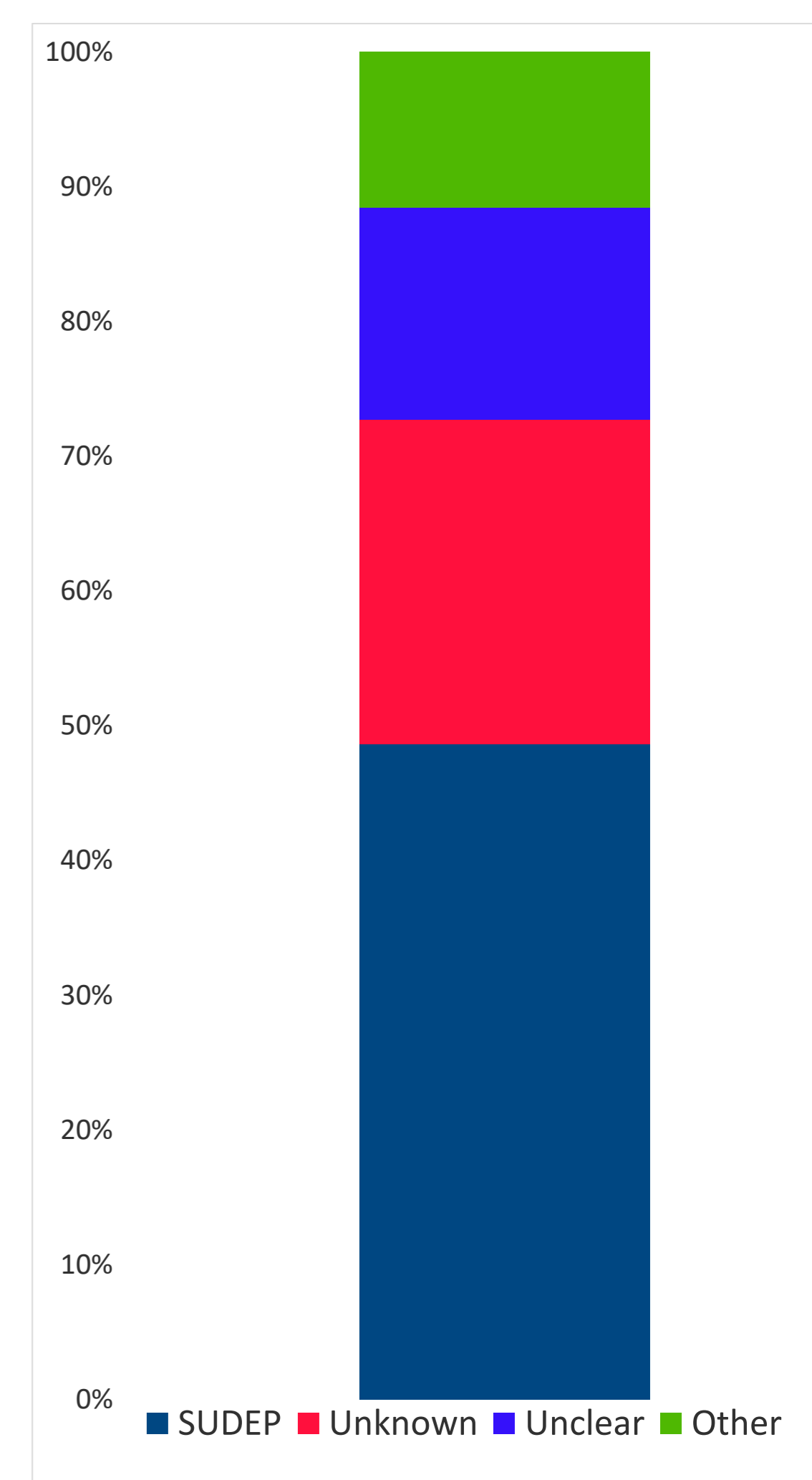
58.1% felt they never had the circumstances of their loved one's death adequately explained. 69.4% were not invited to discuss the death with a doctor or nurse.

Is the cause of death known to the relatives? (right)

In 106 registrations (26.4%) the family did not know the cause of death, or post-mortem and coroner's process was ongoing.

In 69 (15%) of cases the death certificate, or the cause of death told to the family, was vague or insufficient such as 'acute epilepsy'.

11.2% of cases gave a clear cause of death such as suicide or drowning, the remainder, 47.1% (n=214), were identified as SUDEP.



References

1. Chen S et al. Under-reporting of sudden unexpected death in epilepsy Epileptic Disorders 2018
2. Deaths Associated with Neurological Conditions in England Public Health England 2018
3. Thronton J. Data show big rise in deaths of people with neurological disorders BMJ 2018
4. Nashef L, Leach JP. SUDEP, the aftermath: supporting the bereaved Practical Neurology 2017