

Working together to develop an Epilepsy Deaths Register (EDR)

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Background

An on-line registry of epilepsy deaths (EDR) was set up in the UK in March 2013. The registry is a collaboration between SUDEP Action UK, academic partners and other not for profit organisations and is accessible to reporters in the UK and internationally. Cases may be reported by families, friends and professionals using a layered approach. Reported cases are monitored to identify potential duplication of reporting. The registry currently collects demographic and descriptive data of the circumstances leading up to death.

Objectives

1. Provide a secure platform for the reporting of epilepsy deaths.
2. Develop sections for reporting by families, friends, health professionals and coroners/medical examiners
3. To link with academic partners to establish a research ready resource overseen by an advisory group

Method

SUDEP Action has 20 years' experience of supporting families bereaved through SUDEP and other epilepsy related deaths. The charity worked with health professionals and academic partners to identify the requirements of a family focused registry. This registry is designed to supplement other registries developed from specialists in epilepsy monitoring units. The question frame was developed through literature review & panel meetings with families and professionals. A layered approach was used to capture the range of data. The panel findings and literature review were used to develop the question frame that was then iteratively tested by bereaved families associated and the authors. A web designer worked with the charity to provide a web based register that was secure, easily accessible and allowed coding of the data.

Reporting a death

This register is owned and managed by SUDEP Action, in partnership with Epilepsy Ireland, NFPOs that offer support to bereaved families in the UK and Ireland. Families in contact with the charities are offered the chance to report the death through the EDR and most families are keen to do this to help 'others benefit from our experience'.

There is no restriction on reporting so families, friends or professionals can all enter data onto the register whether the victim is under the care of Epilepsy Monitoring Units (EMU) or non-specialist arms of the health service. In this way, the EDR supplements the excellent work done by the international registry set up by specialists in EMU.

Phased development

The development of the register is dependant on funding. And so an incremental (layered) approach is necessary.

Layer 1 collects a minimum data set of deceased and reporter (most commonly families and friends) to build an epidemiological database to inform health strategists

Layer 2 invites doctors, nurses or coroners/medical examiners to contribute clinical information about a case and Layer 3 (planned 2014) to carry out a psychological autopsy of cases through family and professional interviews

The web based platform enables SUDEP Action to use resources provided by other NFPO to extend the EDR to other countries

Layer three Psychological autopsies	Individual interviews
Layer Two Health professionals	Clinical summaries
Layer One Family/Friends	Location and circumstance

Limitations

In common with all registers, the EDR can only hold data from registered deaths and will not capture all deaths. Information from the register will become more representative as registrations increase.

The register will not hold detailed clinical records of cases because of the difficulties in accessing hospital records and gaining consent from 3rd party health services. Summary data will be collected by coroner summaries and health professional reports in some but not all cases.

The register necessarily collects post hoc information but offers families the opportunity to assist certain research initiatives

Research resource

The registry will provide data from a gradually increasing number of cases. Registries will only capture a percentage of such cases and the data collection will take some years to provide a representative sample of deaths. In the first year, cases from 6 different countries have been registered and the register is actively developing international partnerships.

Conclusion

This NFPO based register offers a reporting facility that can be accessed by friends, family and professionals for all people who fall victim to SUDEP. The data provided by the register is a valuable supplement to the registers of people monitored in EMU therefore gives a wider range of risk groups.

Project Management Group

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