

The Epilepsy Deaths Register Bereaved families driving research

What have we learned?

Karen Osland Dip. Couns
May 2019

THE
EPILEPSY DEATHS REGISTER

Making every epilepsy death count





The Epilepsy Deaths Register (EDR)

~ More than a keeper of stories – a catalyst for change ~

- Launched 2013
- Conceived, developed and funded by SUDEP Action
- Supported by experts in the field and UK government

~ A landmark - the first of its kind ~



Developing the register

- Web-based platform
- Underpinned by research and experience of working with the bereaved
- A framework for a safe and sustainable register

~ Helps to shape future research ~



Administration, Governance & Management

SUDEP Action EDR Management Committee

Jane / Mike / Karen / Tracy

EDR Steering Committee

Jane / Mike / Rhys / Karen

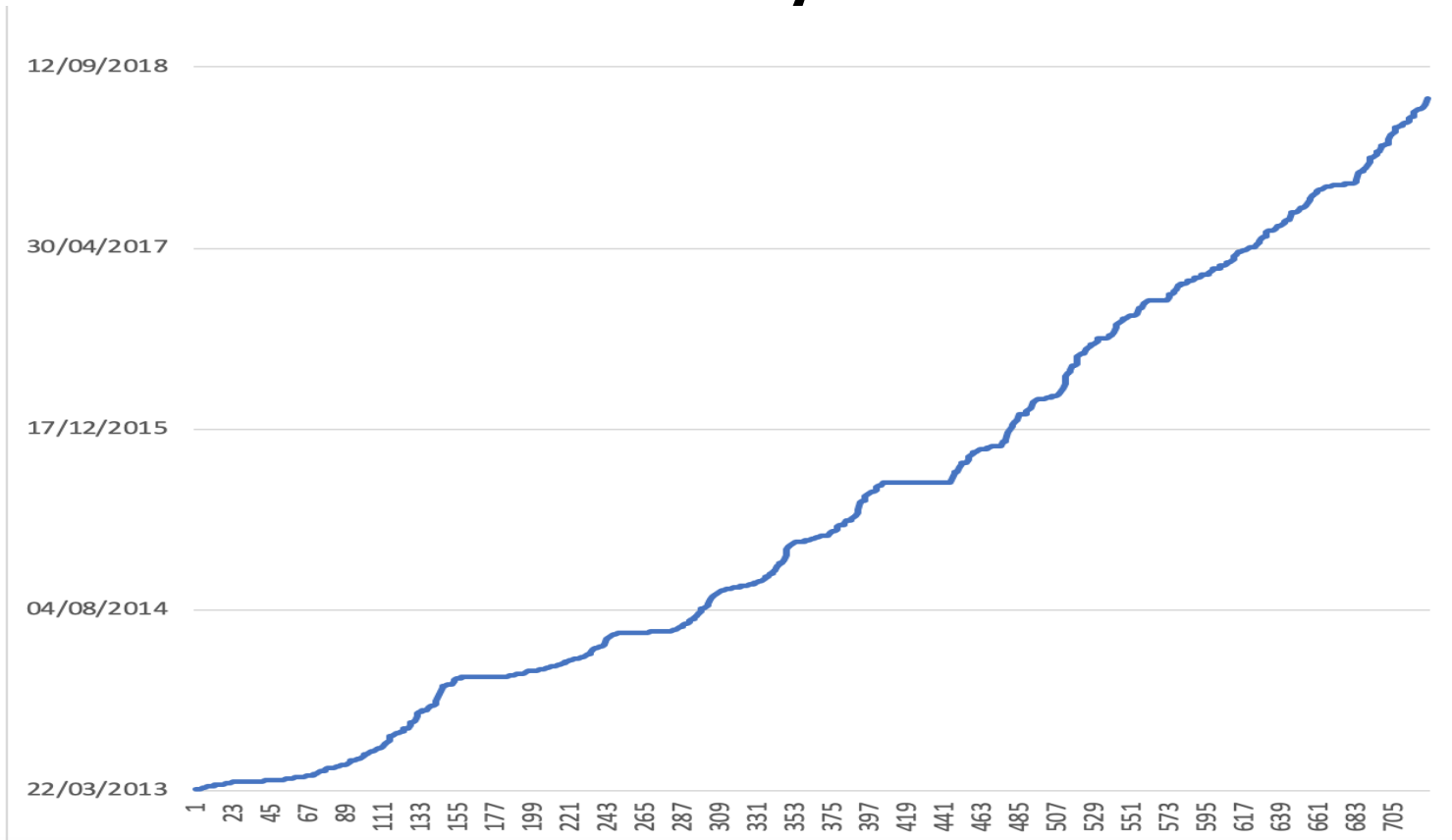
SUDEP Action EDR team

Jane / Karen / Tracy

~Confidentiality is part of our day to day working practice~



Sustainability





Reporting to the register

	Registered within a year of death
2013	24%
2014	27%
2015	43%
2016	46%
2017	63%
2018	70%



Annual reports

- 9% no diagnosis (52% were under care of epilepsy service)
- 79% under specialist care at time of death
- 52% did not know epilepsy could lead to premature death
- 58% circumstances of death not explained
- 69% not invited to discuss death with doctor



Contact with professionals after a death

“no one has explained anything about his death to me..and no one has asked me what happened those 3 nights leading up to his death...only police asked me briefly while at my home that night”

~

“I found my answers by searching the internet”

~

“I stumbled across the SUDEP Action website after he died, the pain was so devastating, I realised I needed to at least know more facts. So I could come to some peace and reconciliation with my sons death”

~

~ **Bereaved family experiences** ~



Death certification

In 26% of cases the family did not know the cause of death, or that the post-mortem and coroner's process was still ongoing

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

~ Inconsistencies can hamper research ~



The people not known to specialists

25 (8.5%) cases reported that the deceased had not yet received an epilepsy diagnosis – despite 52% of those being under the care of a specialist

In total 78% of registrations were under the care of an epilepsy specialist at the time of death

~ Information needs to cascade out ~



Collaborating with others

Using the EDR as a key component in learning from epilepsy deaths

- Work with other research teams
- Maximise learning from research data
- Avoid re-trauma for the bereaved
- Best use of funding



The Future

Educational papers and posters

- Social and Lifestyle factors
- Minority groups
- Extremes of age
- SUDEP deaths in 'low risk'
- Non-SUDEP deaths



The Future

The EDR will continue to develop and evolve

- Collection of death certificates
- Updating questionnaires
- Permission to inform medical professionals
- Collaborations

~The EDR -acknowledged as a rich resource~



*~ More than a keeper of stories - A springboard for
action & change ~*





THANK YOU

**The Epilepsy Deaths Register
Bereaved families driving research**

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