

The influence of research on professional practice and public policy

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Epilepsy Action
United Kingdom

IBE member organisations want to enhance the quality of life of people affected by epilepsy.

To do this we must improve professional practice and change public policy.

- Improvements need to be evidence based.
- Evidence comes from research.
- So if you want to improve professional practice or change public policy then research is the key.

Can it be
done?



How do you do it?

- Identify the problem
- Do the research
- Get the evidence
- Communicate the evidence
- Make the change
- Measure the improvement

UK in 2002:

59% of deaths in children were considered by the expert panel to have been potentially or probably avoidable

National Clinical Audit of Epilepsy-related Death

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A Prospective Study of the Requirement for and the Provision of Epilepsy Surgery in the United Kingdom

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Conclusions: Based on a prevalence of 5/1,000 persons with epilepsy, $\leq 4,500$ patients in the U.K. require epilepsy surgery. Every year, 450 patients with newly diagnosed epilepsy who may eventually require surgery are added to this “surgical pool.” At the current annual rate of operations, a large number of refractory patients remain untreated. This is probably partly because many patients are not referred for specialist care and therefore remain underinvestigated. **Key Words:** Epilepsy surgery—Treatment gap—Prospective.

BRIEF COMMUNICATION

A survey of adult and pediatric epilepsy surgery in the United Kingdom

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SUMMARY

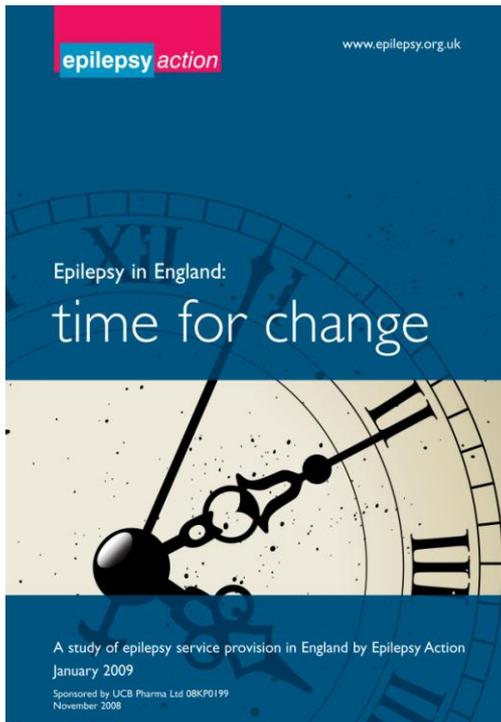
All consultant epilepsy neurosurgeons were asked to prospectively record all epilepsy surgery procedures carried out at their center between April 2010 and March 2011. Figures were compared to a previous survey completed in 2000. Of a total of 710 procedures, temporal lobe surgery was the most common resective surgery. Although extra-temporal lesional surgery was less common, vagus nerve

stimulator (VNS) implantation accounted for almost half the procedures. The numbers for all surgical procedures, with the exception of VNS implantations, had decreased. This decrease may represent a global rather than a regional phenomenon. Further longitudinal multinational data on epilepsy surgery is required to confirm or refute this theory.

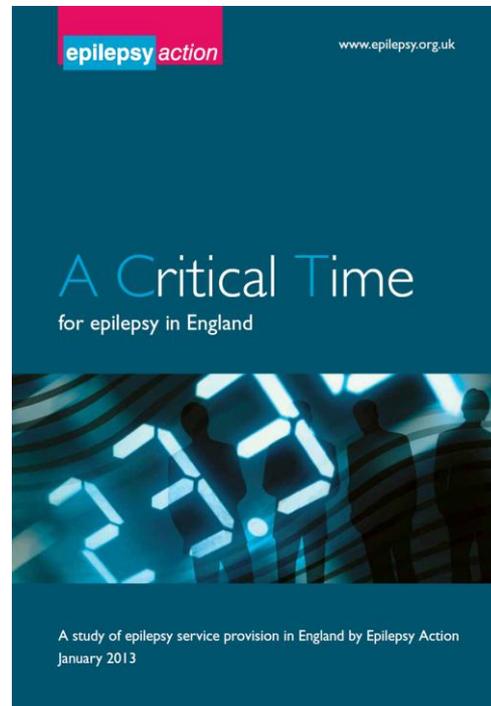
KEY WORDS: Epilepsy surgery, Adult, Pediatric, Refractory epilepsy.

Research evidence tells us...

- 40% of children are not being referred to a tertiary service when they should be.
- Not enough children are getting the brain surgery they need.
- Children with epilepsy are dying unnecessarily.



Communicate the evidence with a campaign



Recommendation

The NHS Commissioning Board should adequately plan and provide tertiary epilepsy services, including guaranteeing fair and ample access to non-drug interventions.





epilepsy action

Epilepsy Action believes that all people with epilepsy should have access to specialist healthcare and treatment for their condition.

The NHS structure is **changing** and **not enough is being done** to plan good epilepsy services for the future.

27%	17%	34%
of local authorities provided the services needed to meet our needs	of local commissioning groups have agreed actions to meet our needs	of local commissioning groups have agreed to meet our needs for epilepsy

"We know that there are historic weaknesses in the commissioning of services, which the epilepsy charities and stakeholders have drawn attention to in recent reports, correspondence and parliamentary questions... the urgency for change is all the greater because these failures carry huge costs, as well as having a massive impact on the lives of people with epilepsy."

The Right Honourable David Cameron MP, Prime Minister, May 2011.



A guide for
Paediatricians:
Children's Epilepsy
Surgery Service
(CESS)

Guidelines for
children's epilepsy
brain surgery
referrals in England



Children's Epilepsy Surgery Service (CESS) set up in November 2012.

Guidelines published May 2013.

Currently only 110 children a year get brain surgery for epilepsy.

CESS aims to see 1,050 referrals a year with 350 children proceeding to surgery.

This will increase epilepsy brain surgery for children by

200 per cent

Identify the problem

RESEARCH

EVIDENCE

CAMPAIGN

CHANGE

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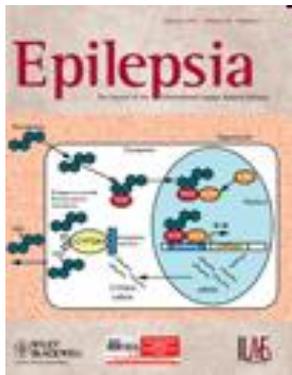
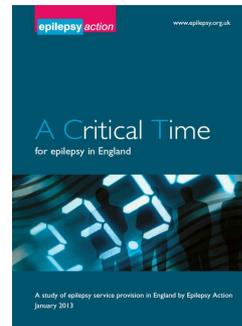


Table 2. Pediatric epilepsy surgery in the United Kingdom 2010-2011

Type of surgical procedure	No. (number of procedures per million inhabitants) ^a
Temporal lobe resection	13 (5.5%)
Mesial temporal sclerosis	(1.15 per 10 ⁶)



the adult population of epileptic colonies

**Report on a patient-census
carried out in the eleven Homes
and Colonies for epileptic patients
in Great Britain based on the
population as at 13th June, 1962**

**KATHLEEN JONES
AILEEN TILLOTSON**

This is IBE's first ever piece of published research.

It's the Jones & Tillotson study published in 1965. It helped to end the old epileptic colonies in the UK.

It found that the colonies were not meeting the needs of their residents well enough.

It proposed a more community based care approach with special centres for epilepsy.

The UK Government's Reid Report of 1969 endorsed this view.

The old colonies either closed or converted into new epilepsy centres.

IBE member organisations can make a unique contribution to research into epilepsy

- This is because they reflect the authentic voice and interest of people with the condition.
- That's why IBE members should be:
 - Seeking to influence the research agenda
 - Ensuring research is about real life
 - Communicating the results of research
 - Using research as a catalyst for change