The influence of research on professional practice and public policy

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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.
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, ≤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 extratemporal 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.
Recommendation

The NHS Commissioning Board should adequately plan and provide tertiary epilepsy services, including guaranteeing fair and ample access to non-drug interventions.
Children’s Epilepsy Surgery Service (CESS) set up in November 2012.


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
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