RESEARCHING THE IMPACT OF EPILEPSY WITH LIMITED RESOURCES

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Overview of presentation

• An example from Ireland

• Experiences with the following data sources:
  – (1) primary and specialist services
  – (2) national statistics office
  – (3) secondary data analysis
  – (4) epilepsy support groups

• Conclusions
‘Limited Resources’

- Financial – more funds, more options.
- Expertise – epilepsy, research design, statistics.
- Data – new and existing.
Ireland: Research Questions

• How many people have epilepsy in Ireland?
• What is the impact of epilepsy on those who have a diagnosis and family members who provide support?
• ‘Highlight figures’ for policy makers.
• Determine equitable resource allocation.
“studies using multiple sources for identification will identify the vast majority of persons with epilepsy and can be considered to be population-based (or community-based) and thus representative of the general epilepsy population”

Forsgren et al., (2005)
Ireland: Sources of Data

(i) Primary Care Data – survey of GPs
(ii) Specialist Care Data – survey of Neurologists
(iii) Self-Report Data – survey of general public
(iv) Anti-Epileptic Drug Prescription Data
(v) HIPE Data – survey of hospital inpatient data

Some more readily available than others...
(1) Data from primary and specialist services

- Getting data from neurologists, epileptologists, family physicians can be difficult!
- Many competing demands on their time.
- No sentinel practices in Ireland which gather data for research purposes.
- Low complement of neurologists.
A finding in itself...

- A useful statistic may be to identify the number of specialists per 100,000 population in your country.

- *Irish Consultant Neurologists Association, Neurological Alliance of Ireland, Association of British Neurologists:* recommend a ratio of one Consultant per 100,000 population.

- Desk research revealed:
  - 24 posts in Ireland, needed 42.
(2) Data from Ireland’s National Statistics Office

- Statutory national statistics office may be able to source population-based epilepsy data.
- Quarterly National Household Survey (QNHS) covers 39,000 households (pop 4.2 million).
- Meets requirements of quarterly labour force surveys in EU member states.
- Includes Health Module on ad hoc basis.
Using an omnibus survey

Simple Question:
Has your doctor ever diagnosed you with any of the following conditions? (lifetime prevalence)

The Answer:
Prevalence of self-reported lifetime epilepsy in Ireland is approximately 10 per 1,000 for those aged over 18 years = 31,000 people in Ireland.
Using population-based surveys

• If you are a member state, you are likely to host a similar survey to submit labour force statistics to the EU.

• Health surveys for general population used in epilepsy research to gather self-report data:
  • Prevalence
  • Quality of life, co-morbidities

• Caution - Need to be mindful of self-report biases and to read the question in context.
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<tr>
<th>Country</th>
<th>Survey Description</th>
<th>Year</th>
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<td>BELGIUM</td>
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<td>NORWAY</td>
<td>Survey on Living Conditions and Health Care &amp; Social Relations</td>
<td>2002</td>
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<td>IRELAND</td>
<td>Disability Module Q2 (QNHS)</td>
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<td>Disability Module Update Q1 (QNHS)</td>
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<td>LUXEMBOURG</td>
<td>LFS ad hoc module employment &amp; disability (over 25 European countries)</td>
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<td>POLAND</td>
<td>Health Population Status in Poland in 1996</td>
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Using population-based surveys

Epilepsy and psychiatric comorbidity: A nationally representative population-based study

*Dheeraj Rai, †Michael P. Kerr, ‡Sally McManus, §Vesna Jordanova, *Glyn Lewis, and †Traolach S. Brugha

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Satisfaction with life domains in people with epilepsy

Rosemarie Kobau, Cecily Luncheon, Matthew M. Zack, Ross Shegog, Patricia H. Price

4 Atlanta, Epilepsy and Well-Being Branch, Division of Population Health, Centers for Disease Control and Prevention, 4770 Buford Highway, NE, Atlanta, GA 30341, USA
5 Center for Health Promotion & Prevention Research, Uni-School of Public Health, 7000 Fannin, Suite 2008, Houston, TX 77030, USA
(3) Data from Secondary Data Analysis

• What is already available in your country that you can tap into?

• Drug prescription databases can provide useful information on the numbers and profile of people with a diagnosis of epilepsy who are prescribed AEDs.

• Also useful to provide information on the cost of treatment.

• Caution - Statistical analysis can be very complex!
• Approached national statistics office - keen to explore secondary analysis of existing state data.
• Assisted with analysis under direction of researchers.
• For Ireland, overall standardised prevalence estimates for treated epilepsy ranged 7.1 to 10.5 per 1,000.
(4) Data from epilepsy support groups

• Survey of members of epilepsy associations.

• Unrepresentative group as more likely to have more severe epilepsy but provide valuable information:
  – May be impossible to include those who do not engage with services
  – Sample selection previously used (Baker et al., 1997)
  – By definition represent those who require and seek support
Findings from Ireland

• Key findings illustrating the ‘burden of epilepsy’ in Ireland for people and families.

• Physical: Identified side effects of medication as an issue.

• Limiting: Almost half reported that seizures prevented them from engaging in activities.

• Stigma: More than half said they felt others were uncomfortable in their presence.
Conclusions

• Variety of ways in which useful information can be sourced using limited resources.

• Consider accessing:
  – National population-based surveys
  – Analysis of existing data
  – Surveying members

• Above all, ask for assistance!
  • National statistics offices
  • Universities – always looking for projects.
Thank you!

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Mr Gerry Brady
Prof. Patricia Noonan Walsh
Prof. Cecily Kelleher
Prof. Teresa Burke
Prof. Norman Delanty

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