RESEARCHING THE IMPACT OF EPILEPSY WITH LIMITED RESOURCES

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IBE RESEARCH TASK FORCE WORKSHOP
30TH INTERNATIONAL EPILEPSY CONGRESS IN MONTREAL

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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.

Ireland: Methodology

"studies using <u>multiple sources</u> 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.

CSO Central Statistics Office

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.

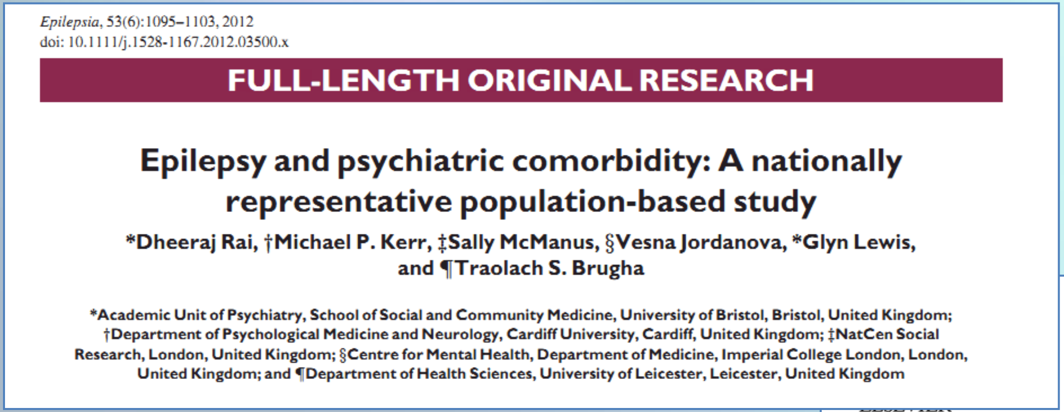
Using population-based surveys

- **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.**

Data may already exist…

BELGIUM	
Health Interview Survey	**1997**
Health Interview Survey	**2001**
Health Interview Survey	**2004**
CYPRUS	
Health Survey 2003	**2003**
GERMANY	
German National Health Examination & Interview survey	**1998**
NORWAY	
Survey on Living Conditions and Health Care & Social Relations	**2002**
IRELAND	
Disability Module Q2 (QNHS)	**2002**
Disability Module Update Q1 (QNHS)	**2004**
LUXEMBOURG	
LFS ad hoc module employment & disability (over 25 European countries)	**2002**
POLAND	
Health Population Status in Poland in 1996	**1996**
Health Population Status in Poland in 2004	**2004**
PORTUGAL	
National Health Survey	**1995**
National Health Survey	**2004**

Using population-based surveys



Epilepsia, 53(6):1095–1103, 2012
doi: 10.1111/j.1528-1167.2012.03500.x

FULL-LENGTH ORIGINAL RESEARCH

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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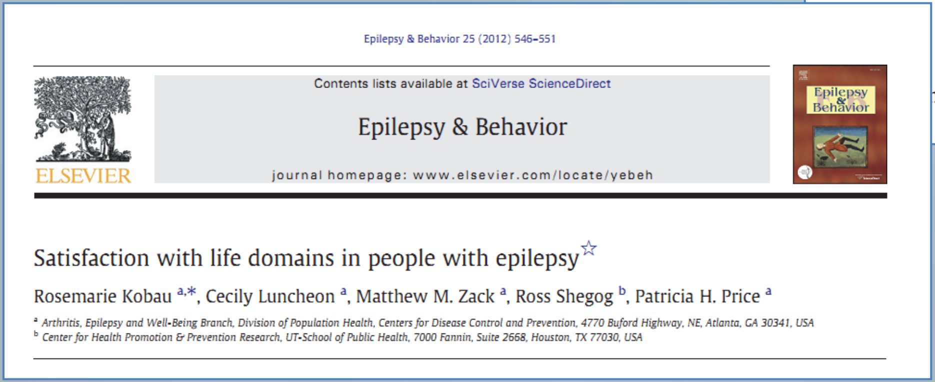
www.elsevier.com/locate/yebeh

Prevalence of epilepsy and health status of adults with epilepsy in Georgia and Tennessee: Behavioral Risk Factor Surveillance System, 2002

marie Kobau,[a,*] Colleen A. DiIorio,[b] Patricia H. Price,[a] David J. Thurman,[a] Linda M. Martin,[c] David L. Ridings,[d] and Thomas R. Henry[e]



Epilepsy & Behavior 25 (2012) 546–551

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ELSEVIER

Satisfaction with life domains in people with epilepsy☆

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(3) Data from Secondary Data Analysis

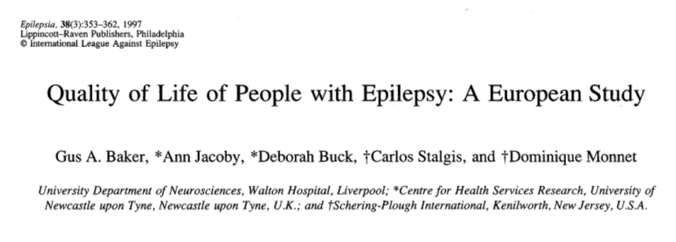
- What is already available in your country that you can tap into?
- Drug prescription databases can provide useful information on the numbers and profile of people with a diagnosis of epilepsy who are prescribed AEDs.
- Also useful to provide information on the cost of treatment.
- Caution - Statistical analysis can be very complex!

Data from Secondary Data Analysis

- 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



Epilepsia, **38**(3):353–362, 1997
Lippincott–Raven Publishers, Philadelphia
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Quality of Life of People with Epilepsy: A European Study

Gus A. Baker, *Ann Jacoby, *Deborah Buck, †Carlos Stalgis, and †Dominique Monnet

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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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