

# The Prevalence of Epilepsy in Ireland



**Christine Linehan, Patricia Noonan Walsh**  
*Centre for Disability Studies, School of Psychology, University College Dublin*  
**Mike Kerr**  
*School of Medicine, Cardiff*  
**Gerry Brady**  
*Central Statistics Office*  
**Cecily Kelleher**  
*School of Public Health & Population Science, University College Dublin*

# SUMMARY REPORT

May 2009



Brainwave The Irish Epilepsy Association

Brainwave The Irish Epilepsy Association  
249 Crumlin Road, Dublin 12  
Tel: 01 4557500  
Email: [info@epilepsy.ie](mailto:info@epilepsy.ie)  
[www.epilepsy.ie](http://www.epilepsy.ie)

## Background

No epidemiological data on the prevalence of epilepsy currently exists in Ireland. Brainwave The Irish Epilepsy Association commissioned the UCD Centre for Disability Studies, School of Psychology, University College Dublin to determine the prevalence of epilepsy in Ireland. Brainwave requested that the prevalence study be conducted at nationwide level and that the scope of the study include both children and adults.

A Research Advisory Committee was established comprising experts in epilepsy, epidemiology and neurology and an agreed research methodology was ethically approved by two Research Ethics Committees; University College Dublin and the Irish College of General Practitioners. Ethical approval was also obtained from all hospitals, where required, who were invited to participate in this study.

## Defining epilepsy

Epilepsy is one of the most common serious disorders of the brain and is estimated to affect approximately 50 million people worldwide. In 2000 the condition was estimated to account for 0.5% of the whole burden of diseases in the world.

It is the second most commonly seen neurological condition in primary care, and the most commonly seen among Neurologists. Unlike other neurological conditions, epilepsy can be completely controlled in the majority of cases by medication or surgical procedures.

For epidemiological research purposes, the International League Against Epilepsy '*Guidelines for Epidemiologic Studies on Epilepsy*' define epilepsy as "a condition characterized by recurrent (two or more) epileptic seizures, unprovoked by any immediate identified cause". Multiple seizures occurring in a 24-hour period are considered a single event. An episode of status epilepticus is considered a single event. This is the definition of epilepsy used in this study.

## The Importance of Prevalence Data

The prevalence of epilepsy is estimated by calculating the number of people with epilepsy in the population at any one time, divided by the number of people in the same population at the same time. Prevalence is typically expressed as the number of cases per 1,000 people in the population.

Determining the prevalence rate of a given condition is useful on a number of levels:

- Obtaining a reliable estimate of the numbers of people with a given condition
- Assessing whether existing services are appropriate to meet need
- Directing resources to identified populations
- Evaluating the effectiveness of interventions

The International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE) and the World Health Organisation (WHO) state "*correctly identifying people with epilepsy is crucial to establishing the extent of a country's treatment gap and to ensuring that appropriate treatment is offered to those who need it*"

## International Prevalence Data

Studies determining the prevalence of epilepsy in Europe are numerous and have used a variety of methodologies. The majority of these European studies have been conducted in the UK, Nordic, Baltic and western Mediterranean countries. Until now, no study has provided data for an entire country.

In Ireland, where data has not been available until now, estimates have been determined by extrapolating data from other European countries. These extrapolations are commonly based on estimates of between 4-10 active cases per 1,000 population; 'active' being typically defined as the occurrence of one seizure in the previous five years.

Extrapolations to the Irish population (4.2 million) suggests that the total number of people with epilepsy in Ireland falls somewhere between 16,800 and 42,000, a broad range for those charged with addressing the needs of this population.

Recent European studies indicate that the true prevalence of epilepsy in developed countries may be higher than previously thought. For example, recent findings from Norway reported 7 per 1,000 active cases, in a population that excluded high-risks groups such as older persons. Other studies are also now broadening the traditional definition of epilepsy to include those who may be in remission with treatment (i.e. no seizures for more than 5 years and receiving drug treatment at the time of ascertainment).

Studies examining 'lifetime' prevalence (typically defined as those who have ever received a diagnosis of epilepsy) and 'treated' epilepsy (typically defined as those with epilepsy who are currently in receipt of anti-epilepsy medication irrespective of the occurrence of seizures) may also be excluded from the 4-10 per 1,000 population estimate yet their inclusion would provide valuable information on the broader population of those with epilepsy.

## The Prevalence of Epilepsy in Ireland

Multiple sources of data were used to gather information in this study in order to identify the vast majority of persons with epilepsy and therefore be representative of the general epilepsy population

A total of five national data sources were identified:

1. Irish self-report data
2. Irish anti-epilepsy prescription drug data
3. Irish primary care data
4. Irish specialist care data
5. Irish hospital inpatient data.

# 1. Irish Self-Report Data

## Methodology

Irish self-report data were collected through collaboration with the Central Statistics Office (CSO) through their Quarterly National Household Survey (QNHS), a nationwide population-based survey of 39,000 households. In the third quarter of 2007, a Special Health Module was included in the QNHS. This module was asked of all participants aged 18 years and over. Epilepsy was one of a number of health conditions included in a question asking “*Has your doctor ever diagnosed you with any on the following conditions?*” Responses therefore address the prevalence of self-reported lifetime prevalence of epilepsy.

## Results

The findings reveal that nationally, 10 per 1,000 persons over the age of 18 years self-reported that they had received a diagnosis of epilepsy by a doctor. Extrapolating this to the entire Irish population, an estimated 31,000 persons over 18 years have, at some point, been informed by their doctor that they have epilepsy.

Estimates of self-reported epilepsy reported here are similar to those found elsewhere in Europe. It should be noted that self-reported epilepsy may be underestimated due to the stigma and discrimination associated with the condition.

# 2. Irish Anti-Epilepsy Drug Prescription Data

## Methodology

Analysis of Irish anti-epilepsy prescription drug data was conducted with the cooperation of CSO who assisted in the secondary data analysis of the Primary Care Reimbursement Services database (PCRS). The PCRS database provides information on nationwide reimbursement claims for community-based prescriptions. Data in respect of all 15 anti-epilepsy drugs included in the reimbursement scheme was analysed over a four year period (2002 to 2005), by HSE area and by two patient demographics; gender and age to determine the prevalence of treated epilepsy i.e. those with a diagnosis of epilepsy being prescribed anti-epilepsy medication.

Before analysis was undertaken, two adjustments were made to the data. Firstly, de-duplication of individuals appearing more than once in the data was conducted (e.g. persons being reimbursed for prescriptions from more than one reimbursement scheme and persons in receipt of more than one AED).

As AEDs are commonly prescribed for conditions other than epilepsy, a data adjustment was required to eliminate individuals who did not have diagnosis of epilepsy. As Irish information on the reported rates of prescribed AED use by people with and without epilepsy is not available, UK data (from the General Practitioner Research Database, the world's largest computerized database of anonymised longitudinal medical records from primary care) was used. Observed similarities in prescription patterns between Ireland and the UK indicated that in the absence of Irish data on the proportion of persons taking anti-epilepsy medication for non-epilepsy reasons, the use of data from the UK was appropriate. These proportional rates were applied to the PCRS data. For example, a PCRS case being reimbursed for a prescription of levetiracetam, for example, was allocated a 96% probability of having a diagnosis of epilepsy, as per the proportional rates of levetiracetam among people on the GPRD database who were identified as having a diagnosis of epilepsy.

## Results

Following adjustments to the PCRS dataset outlined above, population-based data from the 2002 Census was used to determine prevalence estimates of epilepsy. Data from the 0-4 year age group was omitted from the analysis due to difficulties differentiating reliably between febrile seizures and epilepsy in this age group.

### *Overall*

Nationwide, overall prevalence rates of treated epilepsy, ranged from 8.3 per 1,000 people in 2002 to 9.0 per 1,000 in 2005. Increases were noted each year from 2002 to 2005. Extrapolating to Ireland's total population of those aged over 5 years of age, between 33,000 and 36,000 people over the age of five are being treated for epilepsy.

### *Sex*

The prevalence among females ranged from 7.7 per 1,000 in 2002 to 8.6 in 2005, while the rates for males ranged from 8.9 to 9.5 per 1,000 over the same period.

### *Region*

Crude prevalence data shows that the rate of treated epilepsy for those aged 5 years and above varies considerably by region. The lowest rates were observed in the Eastern Region (from 6.9 per 1,000 in 2002 to 7.9 per 1,000 in 2005) while the Western Region had the highest rates (10.3 per 1,000 in 2002 to 10.8 per 1,000 in 2005).

### *Age*

Data also shows that the prevalence rates of treated epilepsy increases with age as outlined below.

5-11 years	2.9 - 3.3 per 1,000 (2002 – 2005)
12-15 years	4.0 - 4.5 per 1,000
16-24 years	4.6 - 4.7 per 1,000
25-34 years	7.8 - 8.5 per 1,000
35-44 years	8.4 - 9.5 per 1,000
45-54 years	9.6 - 10.5 per 1,000
55-64 years	12.6 - 13.5 per 1,000
65-69 years	13.4 - 14.4 per 1,000
70-74 years	16.0 - 16.6 per 1,000
75 years +	16.5 - 17.3 per 1,000

The secular and regional differences above demand more investigation and may represent true increasing risk factors, lack of protective factors or social factors leading to non-reporting or delayed presentation of epilepsy.

Other UK and European studies also show prevalence estimates increasing annually, higher rates among males, and increased prevalence with age. Note that prevalence estimates of treated epilepsy exclude those patients with epilepsy who remain untreated.

## 3. Irish Primary Care Data

### **Methodology**

Primary care data were gathered from a nationwide postal survey of General Practitioners sourced from the Irish College of General Practitioners (ICGP). A total of 417 GPs were contacted by mail. GPs were asked to supply anonymous information on behalf of each patient with a diagnosis of epilepsy on the practice's active

register, and were either active cases (having had at least one epileptic seizure in the previous 5 years) or cases in remission with treatment. Three waves of the GP survey were undertaken over a 16 month period.

## Results

A total of 92 GPs responded to the survey, a response rate of 22%. A total of 749 patients were identified who met the inclusion criteria, indicating that GP practices had on average, 13 persons with active epilepsy or epilepsy in remission with treatment. As the ICGP estimates a total of 2,760 GPs practising nationwide in Ireland, this indicates an estimate of 35,880 persons with epilepsy attending primary care in Ireland.

These figures are comparable with figures cited in the UK's National Institute for Health and Clinical Excellence Guidelines and by the Clinical Standards Advisory Group (2000) who estimate that a GP with a list of approximately 2,000 patients can expect to provide care for between 10 and 20 people with epilepsy.

It must be noted however that the low response rate from GPs warrants caution in making generalisations based on the findings.

## 4. Irish Specialist Care Data

### Methodology

Specialist Care data was analysed to determine the number of people with active epilepsy or epilepsy in remission with treatment attending specialist care facilities. Data was obtained through a prospective survey of weekly consultations between patients with epilepsy and Consultant Neurologists across the country. A total of 26 Consultant Neurologists, encompassing both paediatric and adult specialists from 16 hospitals were invited to take part. The data gathered anonymously on behalf of each patient with epilepsy was identical to that gathered from Primary Care.

### Results

A total of 18 consultant neurologists, at 13 hospitals provided information on the number of cases presenting at clinics throughout the country on a predefined "prevalence week" (19th – 25th June 2006). A total of 305 patients with active epilepsy and epilepsy in remission with treatment were identified in this week. The average number of consultations undertaken per week was 17. Based on this, an estimated 442 patients with epilepsy may be in receipt of specialist care for epilepsy each week in Ireland.

Note that these figures exclude those with 'suspected epilepsy' a group who are likely to comprise a substantial proportion of those seeking specialist care.

## 5. Irish Hospital Inpatient Data

### Methodology

The Hospital In-Patient Enquiry System (HIPE) is a database of coded discharges recorded at all acute hospitals nationwide. While the data is somewhat limited as a tool for epidemiological research, it does provide valuable information on the number of discharges for persons with epilepsy nationwide. HIPE data from 2000 - 2005 was

requested detailing the number of nationwide discharges from acute hospitals for all persons with a principal or secondary diagnosis of epilepsy. This information was analysed by age and by HSE area.

### Results

HIPE data revealed the total number of discharges during the five year period was 20,889, an average of 3,481 discharges per annum and 67 discharges per week. There was no significant difference noted in the number of discharges for each year examined (2000- 2005).

An examination of regional discharge statistics revealed that the highest proportion of discharges was reported in the Eastern region where the population density is highest. Across all years, one quarter of discharges occurred for those under 14 years, 30% occurred in the 15-34 age category and less than 10% occurred in the 70+ age group.

## Summary & Conclusions

This study is the first nationwide prevalence study of epilepsy anywhere in Europe and provides previously unavailable data on epilepsy in Ireland. Having investigated five different nationwide sources of data, the study provides a comprehensive assessment of prevalence. The level of concurrence across all five sources used strengthens the argument that the true prevalence of epilepsy in Ireland is represented in the figures outlined above.

In summary, the main findings are:

- A national lifetime prevalence of self-reported epilepsy among adults of 10 per 1,000 population.
- A national prevalence of treated epilepsy in Ireland of 8.3 per 1,000 (2002) rising to 9 per 1,000 (2005) for those over the age of 5 years.
- An average of 13 patients with epilepsy presenting to each GP nationwide.
- An average of 17 hospital-based consultations for epilepsy each week per Consultant Neurologist, and therefore approximately 442 consultations nationwide.
- An estimated 67 discharges of persons with epilepsy occurring weekly in acute hospitals in Ireland.

These findings are of critical importance, both in care planning and for those lobbying for care change.

### Acknowledgements

This research was supported by a grant from Brainwave, the Irish Epilepsy Association and was supported by a Research Advisory Committee comprising;

Dr. Teresa Burke, Senior Lecturer Neuropsychology, School of Psychology, University College Dublin; Dr Norman Delanty, Consultant Neurologist, Director, Epilepsy Programme, Beaumont Hospital, and Honorary Senior Lecturer, Royal College of Surgeons in Ireland, Dublin; Dr. Colin Doherty, Consultant Neurologist, Department of Neurology, St. James' Hospital; Mr. Mike Glynn, Chief Executive Officer, *Brainwave*, the Irish Epilepsy Association; Professor Orla Hardiman, Consultant Neurologist, Department of Neurology, Beaumont Hospital & Royal College of Surgeons; Professor Cecily Kelleher, Head of School, School of Public Health & Population Science, University College Dublin; Professor Mike Kerr, Chair in Learning Disabilities and Honorary Consultant in Neuropsychiatry, Cardiff University; Dr Christine Linehan, Senior Researcher, Centre for Disability Studies, University College Dublin; Professor Patricia Noonan Walsh, NDA Professor of Disability Studies, Centre for Disability Studies, University College Dublin.

The authors would also like to acknowledge the contribution of the Primary Care Reimbursement Services.