



# **Epilepsy prevalence, incidence and other statistics**

## **Joint Epilepsy Council of the UK and Ireland**

The Joint Epilepsy Council is the umbrella charity providing the representative voice working for the benefit of people affected by epilepsy.

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## Introduction

The Joint Epilepsy Council (JEC) first produced nationally recognised incidence and prevalence figures in 2005. These figures have been reviewed and updated and show a large rise in the number of people with a diagnosis of epilepsy and a prescription for anti-epileptic drugs. It is suggested that this rise is due to a combination of four reasons:

- Greater attention to recording and monitoring people with epilepsy due to initiatives such as the GP Quality and Outcomes Framework.
- The introduction and implementation of the NICE and SIGN clinical guidelines.
- The ageing population and the higher incidence of epilepsy in later life.
- The general population increase.

It is acknowledged that an exact figure for the number of people with epilepsy is difficult to produce due to complicating factors such as misdiagnosis rates, inconsistent reporting, variations in the definition for active epilepsy and anti-epileptic drugs (AEDs) being prescribed for other conditions.

A variety of sources were reviewed in the production of these data including, in particular, the General Practice Research Database (GPRD) Data sets, Quality and Outcomes Framework prevalence data and NHS Information Centre for Health and Social Care and the IMS Health Disease Analyzer.

The prevalence and incidence figures used in this report are based on an analysis of GPRD data commissioned by the Joint Epilepsy Council applied to the Office of National Statistics (ONS) mid-year population estimates 2010<sup>1</sup> (see methodology).

The prevalence figures are based on patients with a diagnosis of epilepsy along with a current prescription of AEDs. Incidence figures are based on a new diagnosis of epilepsy and a new prescription for AEDs.

The numbers do not therefore include patients with epilepsy who are not receiving AED treatment, for whatever reason. In addition, although we recognise the high rate of misdiagnosing of other conditions as epilepsy, these data have not been validated for the accuracy of the diagnosis. The data may therefore include a significant number of people (20-30%) who have been given a diagnosis of epilepsy and a prescription for AEDs but do not in fact have epilepsy.

Nevertheless these data are important and useful despite these limitations; health services social services and education organisations have to design and provide support services for people with epilepsy based on the population with that diagnosis undergoing treatment.

The Joint Epilepsy Council believes that the figure of approximately 600,000 people in the UK with a diagnosis of epilepsy and receiving AED treatment is the best and most accurate estimate currently available.

These data are intended to provide an open and consistent approach to epilepsy statistics and members are encouraged to use the information within their own work.

## The epilepsies

Epilepsy is a tendency to have recurrent seizures. It can affect anyone, at any age, from any walk of life. It is one of the most common serious neurological conditions.

Epilepsy is not a single condition. There are over 40 different types of epilepsy consisting of at least 29 syndromes and a further 12 or so clinically distinct groups defined by the specific cause or underlying cause.<sup>2</sup>

There are at least 40 different seizure types and perhaps as many as 50 and individuals may have one or several different seizure types.<sup>3</sup>

Approximately 60% of people have tonic clonic seizures, 20% complex partial, 12% mixed tonic clonic and partial, 3% simple partial and less than 5% absence seizures, myoclonic seizures and other types.<sup>4</sup>

Around 3% of people with epilepsy are photosensitive and have seizures induced by photic stimuli.<sup>5</sup>

## Prevalence

Prevalence is a measure that allows us to determine a person's likelihood of having a disease or condition. Therefore, the number of prevalent cases is the total number of cases of disease or condition existing in a population at any given time.

A prevalence rate is the total number of cases of a disease existing in a population divided by the total population.

**Approximately 600,000 people in the UK have a diagnosis of epilepsy and take anti-epileptic drugs.**

This is equivalent to approximately 1 in 103 people.

The prevalence rate of epilepsy in the UK is approximately 9.7 per 1,000 or 0.97%.

Based on 2010 population estimates the prevalence in each country is as follows (to the nearest 1,000):

Country	Population, 2010 census estimate	Number of people with epilepsy	Prevalence rate, %	Prevalence rate
England	52,234,000	496,000	0.95%	1 in 105
Wales	3,006,000	32,000	1.06%	1 in 94
Scotland	5,222,000	54,000	1.03%	1 in 97
Northern Ireland	1,800,000	20,000	1.11%	1 in 90
United Kingdom	62,262,000	602,000	0.97%	1 in 103

(Note due to rounding slight apparent inconsistencies may result).

## **Prevalence by different sections of the community in the UK**

See Appendix I for a chart of prevalence by age group.

**Children aged 4 years and under with epilepsy**, the total number of is approximately 7,600 or 1 in 509.

**Children aged 16 years and under with epilepsy**, the total number of is approximately 51,500 or 1 in 240

**Children and young people aged 18 years and under with epilepsy**, the total number is approximately 63,400 or 1 in 220.

**People 25 years of age and under with epilepsy**, the total is approximately 112,700 or 1 in 177.

**People aged 65 and over** with epilepsy, the total is approximately 154,000 or 1 in 67.

**Women of childbearing age** (12 – 50) with epilepsy, the total is approximately 139,000. As a proportion of the total population of people with epilepsy this equals 23 per cent.

**People with learning or intellectual disability:** More than one in five people with epilepsy have learning or intellectual disabilities.<sup>6</sup>

### **Social deprivation**

Epilepsy prevalence is 25 per cent higher in the most socially deprived areas compared to the least socially deprived areas.<sup>7</sup>

### **World wide**

Epilepsy affects around 50 million people worldwide; 80 per cent of them are in developing countries. In these countries, although most cases can be treated, around 75% of people with epilepsy are not receiving appropriate treatment.<sup>8</sup>

## **Incidence**

Incidence is a measure of disease or condition that allows us to determine a person's probability of being diagnosed with a disease during a given period of time.

Therefore, incidence is the rate of newly diagnosed cases of a condition.

An incidence rate is the number of new cases of a disease divided by the number of persons at risk of the disease in a set time period.

The following have been calculated based on figures from the GPRD applied to the 2010 population estimates.

In the UK the incidence is approximately:

51 per 100,000 per year

or

0.51 cases per 1,000 of population per year.

Equivalent to approximately 32,000 new cases diagnosed per year (based on 2010 population estimates).

Equivalent to approximately 87 new cases each day of the year.

### **Incidence by age**

The incidence of epilepsy varies significantly by age. See appendix 2 for a graph of incidence by age.

## Misdiagnosis

Misdiagnosis rates in the United Kingdom, where a diagnosis of epilepsy is incorrectly made, are between 20 – 31 percent.<sup>9</sup>

Using an assumed rate of 23 per cent this equates to 138,000 people with a diagnosis of epilepsy and receiving AEDs who do not have the condition.

Up to 40% of children referred to a tertiary clinic do not have epilepsy.<sup>10</sup>

This does not include those with epilepsy who have been misdiagnosed as having a different condition for which figures are unavailable.

## Cost of misdiagnosis

These figures are based on those in the Clinical Guidelines and Evidence Review for the Epilepsies: the evidence base for the NICE Epilepsy Clinical Guideline.<sup>11</sup> The medical costs have been updated for hospital and community health service (HCHS) inflation.<sup>12</sup> The non-medical costs have been increased by RPI.<sup>13</sup>

Country	Population - 2010	People with epilepsy	Misdiagnosed, 23%	Medical Cost, £334	Non-medical, £1,602	Total
England	52,234,000	496,000	114,100	£ 38,109,000	£182,788,200	£ 220,897,200
Wales	3,006,000	32,000	7,400	£ 2,472,000	£ 11,854,800	£ 14,326,800
Scotland	5,222,000	54,000	12,400	£ 4,142,000	£ 19,864,800	£ 24,006,800
Northern Ireland	1,800,000	20,000	4,600	£ 1,536,000	£ 7,369,200	£ 8,905,200
United Kingdom	62,262,000	602,000	138,500	£ 46,259,000	£221,877,000	£ 268,136,000

## **Treatment gap**

- In the UK, 70% of the population with epilepsy could be seizure free with optimal treatment.<sup>6</sup>
- Currently only 52% of the population of people with epilepsy are seizure free.<sup>14</sup>
- This 18% treatment gap equates to 108,000 people with epilepsy having seizures when with optimal treatment they could be seizure free.
- Too few children are offered, or referred early enough for, the surgery which could cure their epilepsy or reduce their seizures. In 2008 only 108 operations were carried out compared to the estimate that 400 were required.<sup>15</sup>
- It is considered that there is a backlog of as many as 2,300 children who could benefit from surgery.<sup>15</sup>
- Too few adults are offered, or referred early enough for, the neurosurgery which could cure their epilepsy or greatly reduce their seizures. It is estimated that no more than 200 - 300 individuals are treated each year in the UK compared to an estimate of at least 1,000 that are required.<sup>16</sup>
- It is considered that there is a backlog of at least 5,000 adults who could benefit from neurosurgery.<sup>16</sup>

## **Epilepsy related deaths**

- In the UK 1,150 people died of epilepsy related causes in 2009<sup>17</sup>, 644 males and 506 females.
- In England and Wales 110 or 11% of those deaths are young adults or children under the age of 25.<sup>18</sup>
- Approximately 42% or 480 of the deaths per year are probably or potentially avoidable.<sup>19</sup>
- Sudden unexpected death in epilepsy (SUDEP) is defined as the sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in patients with epilepsy, with or without evidence for a seizure, with exclusion of documented status epilepticus, and when post-mortem examination does not reveal a structural or toxicological cause for death.<sup>20</sup>
- SUDEP accounts for approximately half of all epilepsy related deaths.

## **Years of life lost**

- In England and Wales between 2007 and 2009, 68,422 years of life were lost due to epilepsy<sup>21</sup> in people aged between one and 74.

- This equates to 22,807 years of life lost each year.
- The average number of years of life lost per person was 30.2.

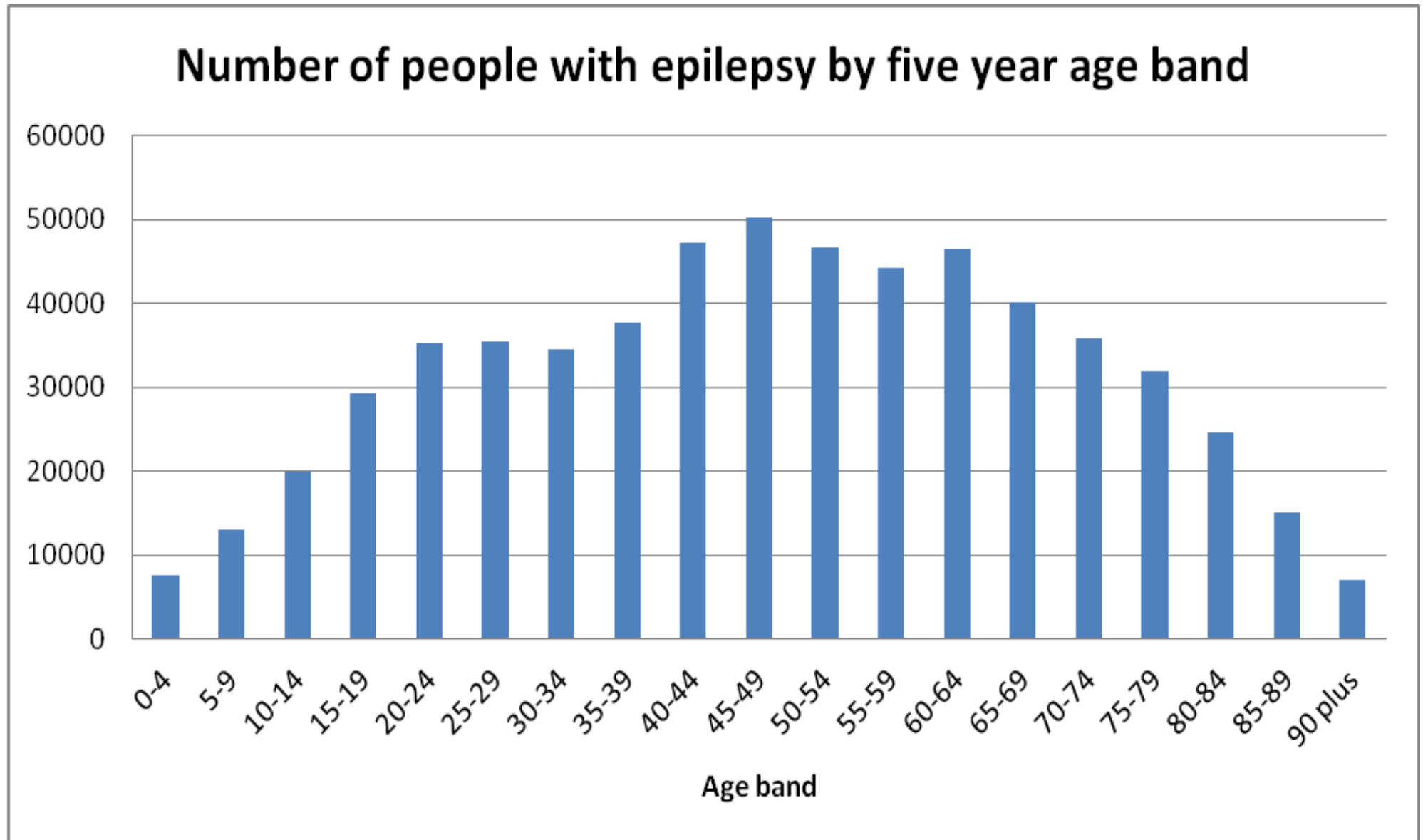
### **Consequences of epilepsy**

- Epilepsy is the largest single source of one day admissions amongst neurological conditions in the North East of England.<sup>22</sup>
- In England, Wales and Scotland 69,700 people with epilepsy were claiming disability living allowance in 2009. This costs £244 million per year.<sup>23</sup>
- “..... although a medical condition, epilepsy often has an impact on the education of children and young people. One third of children with epilepsy have continuing seizures which are likely to affect their concentration, behaviour and/or attendance levels at school. Even for the two thirds of children whose seizures are controlled, the anti-epileptic drugs they are taking can impact upon their concentration and learning.”<sup>24</sup>

### **Funding of epilepsy research**

- Epilepsy research received only 0.6% of new Medical Research Council research funding in 2009/2010.<sup>25</sup>

Appendix I



## Incidence of epilepsy per 100,000



## **Methodology and discussion**

### **Methodology**

In 2009 the JEC commissioned the General Practice Research Database (GPRD) to provide updated prevalence and incidence numbers. The prevalence data search was based on a diagnosis of epilepsy from Read or Pegasus codes and a current prescription for an AED. The incidence data search was based on a new diagnosis for epilepsy and a new prescription of an AED.

The data covers 625 GP practices and over five million patient records. The data were extracted in five year age bands and across a five year period – the age being the age at mid-period (in 2006). Incidence and prevalence data were obtained. The incidence and prevalence results have been applied to the mid-2010 populations of England, Scotland, Wales and Northern Ireland.<sup>1</sup>

### **Other evidence**

Three other recent sources of alternative evidence for the prevalence of epilepsy were considered. In addition various papers on epidemiology were reviewed.

### **Quality and Outcomes Framework data.**

This is available for all four countries as part of the recording of the epilepsy registers of GP practices under the epilepsy quality marker. The following data are from 2009/10.

They give a prevalence of 0.78%, England<sup>26</sup>, 0.73%, Scotland<sup>27</sup>, 0.73% Wales<sup>28</sup> and 0.76% Northern Ireland.<sup>29</sup>

This is considered likely to be an underestimate as:

- These data only record people with epilepsy aged 18 years and above.
- There are some significant variations in England between SHA, PCT and practice level reporting within the GPRD.
  - SHA prevalence<sup>30</sup> variance 0.6% to 0.9%.
  - PCT prevalence<sup>31</sup> variance 0.4% to 1.1%.
  - GP prevalence<sup>32</sup> variance 0.0% to 13%.
- In Scotland<sup>27</sup> NHS Board prevalence varies from 0.61% to 0.81%.
- In Wales<sup>28</sup> Local Health Board prevalence varies from 0.61% to 0.84%.
- In Northern Ireland<sup>29</sup> Local Commissioning Group prevalence varies between 0.71% and 0.85%.

### **National Institute for Health and Clinical Excellence**

In January 2009 NICE published an implementation review of the NICE epilepsies guidelines.<sup>33</sup> As part of this work it commissioned the NHS Information Centre for Health and Social Care to use the IMS Health Disease Analyzer to provide up to date prevalence figures. This identified a prevalence rate of 0.95%. This used the QOF diagnosis codes but did not cross reference for a current prescription of anti-epileptic drugs. The IMS Health Analyzer is based on 130 GP registers covering 1.1 million patients.

### **Prevalence study in the Republic of Ireland**

The most recent study of epilepsy prevalence is that carried out on behalf of Brainwave in Ireland. The headline figure for people age five and over with a diagnosis and receiving treatment for epilepsy is 8.3 – 9 per 1,000.<sup>34</sup>

## United States of America

According to the Epilepsy Foundation approximately 3,000,000 people in the USA have epilepsy<sup>35</sup>. Based on a population (from the US Census Bureau) of 307,000,000<sup>36</sup> this equates to a prevalence rate of 0.98% or 1 in 102 people.

## Other papers

Some existing papers suggest the prevalence to be between 0.7 and 0.8% for the whole population. In particular:

1. *The incidence and prevalence of neurological disorders in a prospective community based study in the United Kingdom. (Brain 2000)*<sup>37</sup>. It is noted that this paper provides a lifetime prevalence estimate for epilepsy. The prevalence figures are based on a review of three GP practice databases from 1996 and validation is only undertaken through a review of the patient's notes.
2. *Epilepsy prevalence and prescribing patterns in England and Wales. (Health Statistics 2002)*<sup>38</sup>. This is the main paper upon which the previous figures were based and used the same data source as being used in this review, the GPRD database. The baseline figures data for this paper was from 1994 – 1998.

## Discussion

The GPRD data upon which these estimates are based gives a prevalence higher than that previously quoted by the JEC. That was also based on the GPRD but on data from between 1994 and 1998 and population data for 2003. The increase cannot be accounted for by population growth alone.

The current data are in line with two more recent studies, the NICE health analyzer study and the Brainwave study in Ireland and the prevalence rate reported in the USA.

For reasons noted above the QOF data are likely to be an underestimate.

It is also likely that better recording due to the GMS contract at GP level of people with a diagnosis of epilepsy, along with the focus of NICE and SIGN clinical guidelines, will have led to better recording and monitoring of people with epilepsy across General Practice. These changes have been introduced subsequent to the 1994-98 data upon which the original statistics were based.

It is recognised that there are limitations in the GPRD data.

The principal limitation is a lack of validation of the diagnosis of epilepsy. This limitation applies to most epilepsy epidemiology studies. It includes all those who have a diagnosis of epilepsy but actually have been mis-diagnosed and have a different condition.

Nevertheless these data are important and useful despite these limitations; health services, social services and education organisations have to design and provide support services for people with epilepsy based on the population with that diagnosis undergoing treatment.

As part of those services, reviewing and getting the diagnosis and treatment correct should be an important priority. Over time this may lead to a reported reduction in those with a diagnosis of epilepsy and receiving AED treatment.

The Joint Epilepsy Council believes that the figure of 600,000 in the UK with a diagnosis of epilepsy and receiving AED treatment is the best and most accurate estimate currently available.

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