

How prevalent is epilepsy in Europe?

19 February 2013

Joint Task Force, Epilepsy Advocacy Europe
Workshop on the Cost and Prevalence of Epilepsy
European Parliament, Brussels

Christine Linehan, PhD
Research Fellow, Trinity College Dublin, Ireland
Honorary Senior Lecturer, Tizard Centre, University of Kent, UK



TRINITY
COLLEGE
DUBLIN

OUTLINE OF PRESENTATION

Will outline...

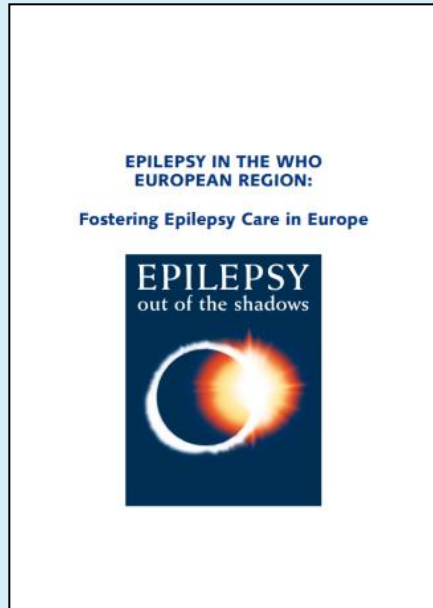
- (1) Determining epilepsy prevalence.
- (2) The number of studies conducted in Europe.
- (3) Where studies have, or have not, been undertaken.
- (4) The range of prevalence estimates.
- (5) Variations in studies.



DETERMINING PREVALENCE

- Typically determine the number of people in a sample (e.g. region/hospital/centre) who have:
 - **Active epilepsy** (experience seizures)
 - **Treated epilepsy** (on AEDs; may be controlled)
 - **Lifetime epilepsy** (have ever had epilepsy)
- Findings are presented as X per 1,000 people.
- Extrapolate estimate to the bigger population = number of people with epilepsy.

PREVIOUS REVIEWS IN EUROPE



- ILAE, IBE and WHO (2010) examined:
- 53 countries covering 850 million people.
- Using a prevalence of 8.2 per 1,000.
- Based on WHO Atlas survey.
- Not just 'active' epilepsy.
= 6 million people with epilepsy

PREVIOUS REVIEWS IN EUROPE

- Study by Gustavsson *et al.*, (2010) on the cost of brain disorders examined:
- 30 countries covering 514 million people.
- Used 34 existing country specific prevalence estimates referenced in publications 2004+.
- Median prevalence = 5.3 (4.0-6.5).
- Not just active epilepsy.
- = 2.6 million people



SEARCHING FOR PREVALENCE STUDIES

- Search of academic databases using the terms **'epilepsy'** AND **'prevalence'**.
- Published in English language.
- From 1982-2012 (three decades).
- One paper per study.
- Excluded subpopulations – older persons, persons with intellectual disabilities, persons in prisons.

Albania	Andorra	Armenia	Austria	Azerbaijan	Belarus	Belgium	Bosnia Herzegovina	Bulgaria	Croatia
									
Cyprus	Czech Republic	Denmark	Estonia	Finland	France	FYR Macedonia	Georgia	Germany	Greece
									
Hungary	Iceland	Ireland	Italy	Latvia	Liechtenstein	Lithuania	Luxembroug	Malta	Moldova
									
Monaco	Montenegro	Netherlands	Norway	Poland	Portugal	Romania	Russia	San Marino	Serbia
									
Slovakia	Slovenia	Spain	Sweden	Switzerland	Turkey	Ukraine	UK	Vatican City	
									

DATABASES SEARCHED

Embase

 embase
BIOMEDICAL ANSWERS

Science Direct



Pubmed



Psycinfo/Abstract (EBSCO host)



Wiley Online



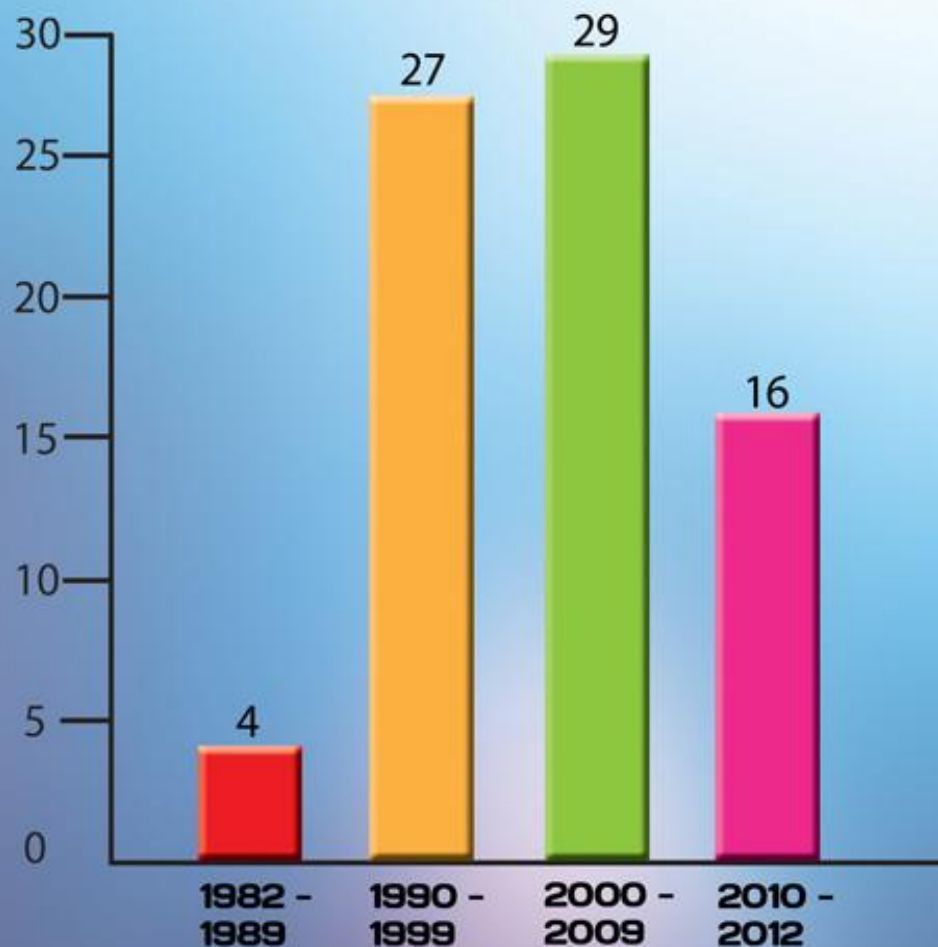
Web of science/web of knowledge



THE NUMBER OF STUDIES CONDUCTED THROUGHOUT EUROPE

- Identified 6,593 papers with terms in the summary.
- Identified 1,335 papers with terms in titles.
- In total **76 eligible studies** were identified published between 1982 and 2012.

Studies on the prevalence of epilepsy across Europe by decade



WHERE STUDIES HAVE, OR HAVE NOT, BEEN UNDERTAKEN

- These studies were undertaken throughout 21 of the 49 countries of Europe (43%).






WHERE STUDIES HAVE, OR HAVE NOT, BEEN UNDERTAKEN







- The 21 countries comprise:
 - 13 of the 27 EU Member States (50%)
 - 2 ‘candidate’ countries
 - 1 ‘acceding’ country
 - 1 ‘potential’ country
 - 4 Non EU States



COUNTRIES WITH > 10 STUDIES

-  UK leads – 16 studies from 1983 to 2012
 -  Turkey -11 studies from 1995 – 2012
 -  Italy – 10 studies from 1983 -2012
- Nearly half of all studies (49%; 37/76) have been conducted in **just three countries.**

COUNTRIES WITH 3-4 STUDIES

-  Denmark – 4 studies from 1986 to 2007
-  Finland – 4 studies from 1989 to 2009
-  NL - 4 studies from 1996 – 2008
-  Norway – 4 studies from 2000 – 2012
-  Spain – 4 studies from 1991 -2012
-  Sweden – 3 studies from 1992 - 2006

COUNTRIES WITH 1-2 STUDIES

Two studies:



Croatia



Estonia



France



Iceland

One study:



Albania



Azerbaijan



Georgia



Germany



Greece



Ireland



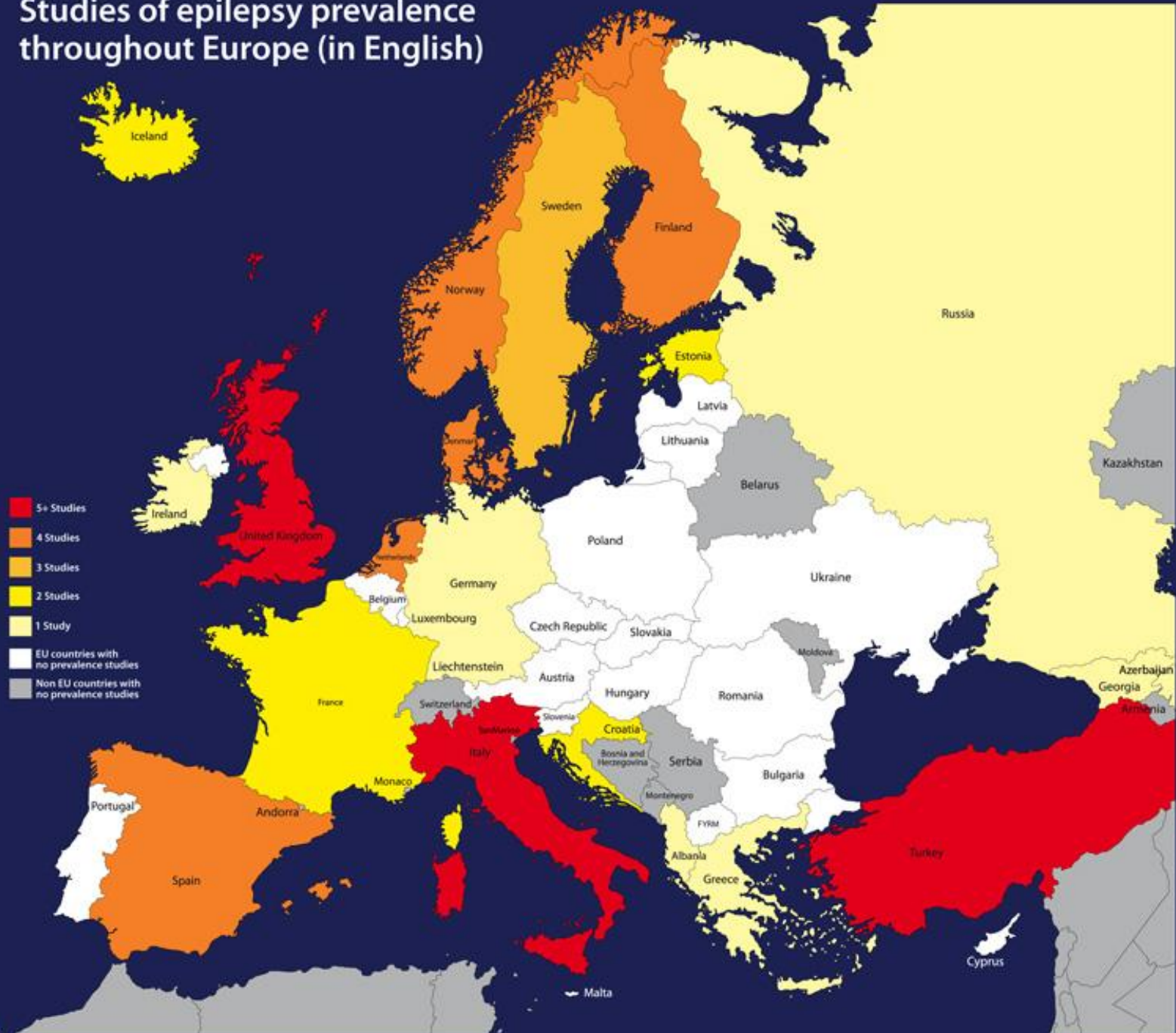
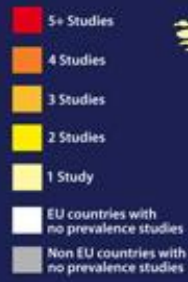
Lithuania



Russia

How Prevalent is Epilepsy in Europe?

Studies of epilepsy prevalence throughout Europe (in English)



AT FIRST GLANCE ...

- Large areas of **Eastern Europe** are unrepresented.
- Most studies are **regional** – national data are rare.
- Might the English language criterion explain the low complement of studies in some countries (e.g. France (2) and Germany (1)?)

VARIATION IN STUDIES

- **Age ranges (difficult to classify)**
 - 42 studies over all age groups (e.g. 0-39 years)
 - 12 adults only (e.g. 55–95 years)
 - 22 children only (e.g. 0-5 years)
- **Size of extrapolated population**
 - 4.9 million in Danish hospital registration study
 - 1,625 in children's study, Eastern Turkey

THE RANGE OF PREVALENCE ESTIMATES

Mindful of comparing apples and oranges..



VARIATION ACROSS STUDIES IN 'ACTIVE'

2.26 – “cases of active epilepsy & epilepsy in remission with treatment” (Greece)

10.9 – cases of active epilepsy (one seizure in past 5 years) (Croatia)

Considerable variation in rates.



INTRA-COUNTRY VARIATION

In Italy:

- active epilepsy 2.7 to 6.63
- treated epilepsy 4.9 to 11.9

In Turkey:

- active epilepsy 3.7 to 10.2

In the UK:

- treated epilepsy 4.5 to 7.4
- lifetime epilepsy 4 to 21

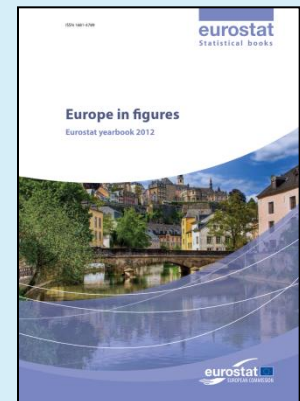


THE TYPES OF METHODOLOGIES THAT HAVE BEEN EMPLOYED

- Most are 'multi-source' ascertainment from medical services – primary care, general hospitals, neurology centres, etc.
- One third (25; 33%) are population-based using door to door methodologies, screenings in schools, communities, etc.
- Prescription databases (11 studies) have also been used with varying algorithms to identify people with epilepsy.

HOW MANY PEOPLE HAVE EPILEPSY?

- If population of Europe is 738 million (as per Eurostat/UN World Population)
- Minimum active rate @ 2.3 = 1,697,000
- Maximum active rate @ 10.9 = 8,044,000
- Difficult to plan / develop policy
- Can we be more accurate?



ILAE EPIDEMIOLOGY COMMISSION REPORT

Standards for epidemiologic studies and surveillance of epilepsy

¹David J. Thurman, ²Ettore Beghi, ³Charles E. Begley, ^{4,5}Anne T. Berg, ⁶Jeffrey R. Buchhalter, ⁷Ding Ding, ⁸Dale C. Hesdorffer, ^{8,9}W. Allen Hauser, ¹⁰Lewis Kazis, ¹¹Rosemarie Kobau, ¹²Barbara Kroner, ¹³David Labiner, ¹⁴Kore Liow, ¹⁵Giancarlo Logroscino, ¹⁶Marco T. Medina, ^{17,18}Charles R. Newton, ¹⁹Karen Parko, ²⁰Angelia Paschal, ²¹Pierre-Marie Preux, ^{22,23}Josemir W. Sander, ²⁴Anbesaw Selassie, ²⁵William Theodore, ²⁶Torbjörn Tomson, and ²⁷Samuel Wiebe for the ILAE Commission on Epidemiology

“The purpose of this document is to promote consistency in definitions and methods in an effort to enhance future population-based epidemiologic studies, facilitate comparison between populations, and encourage the collection of data useful for the promotion of public health” (p.2)

TO CONCLUDE

- Across three decades, 76 studies were completed in 21 countries.
- Nearly half of all studies are undertaken in just three countries.
- Many are regional - national data are rare.
- Large areas of Europe are unrepresented.
- Definitions and estimates vary widely.

THANK YOU

