

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

Parkinson's prevalence in the United Kingdom (2009)

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Summary

Knowing the prevalence of Parkinson's cases is essential for planning health-care and ensuring that there is an adequate service for people with the condition. A small number of prevalence studies have previously been carried out in various United Kingdom (UK) regions over the last two decades.¹⁻⁵ Their results on prevalence range from 105 to 178 persons with Parkinson's per 100,000 population when adjusted for age.^{1,3} This suggested that the number of people with the condition in the UK could range from 51,000 to 120,000. These wide-ranging findings made it very difficult to estimate how many people with Parkinson's there were in the UK. That encouraged us to evaluate Parkinson's prevalence in the United Kingdom using the world's largest computerised database of anonymised longitudinal medical records – General Practice Research Database (GPRD). We used data from 2009 - the last year for which data is currently publicly available.

We identified all patients whose records were contained within the GPRD in 2009 with a definite diagnosis of Parkinson's in their medical record using specific inclusion criteria and diagnosis codes. The prevalence of the condition was calculated as the proportion of total GPRD population who had a Parkinson's diagnosis which was then stratified by age, gender and geographical location. Annual rates were scaled up to the UK population to estimate the overall prevalence of Parkinson's within the UK.

The Parkinson's prevalence rate in 2009 was calculated as 27.4/10,000 which is equivalent to 126,893 cases when scaled up to the total UK population. The Parkinson's prevalence rate was 30.9/10,000 among males and 24.1/10,000 among females. This equates to 69,850 males and 57,043 females. The highest prevalence rate of Parkinson's was among those aged 80-84 and 85+ years. Within the individual home countries, there were 107,835 people with Parkinson's in England, 10,019 in Scotland, 5,890 in Wales and 3,147 in Northern Ireland.

Using the population data from the National Statistics Office, the number of people with Parkinson's was extrapolated to 2020 according to a mathematical modelling of future population trends. This resulted in a predicted increase to 161,000 in 2020 which represents a 26.7% increase on the 2009 figure although the accuracy of this figure can't be guaranteed.

Parkinson's prevalence in the United Kingdom in 2009

Background

Parkinson's is the second most common chronic neurodegenerative condition in older people especially beyond the age of sixty.^{6,7} It occurs as a result of the progressive loss of dopamine-producing nerve cells in a region of the brain called the substantia nigra. The condition is characterised by symptoms of tremor, rigidity and bradykinesia, and therefore affects many activities of daily life. People with Parkinson's also experience non-motor symptoms including problems with mood, sleep and memory.

A number of previous studies have estimated Parkinson's prevalence in various countries. Their findings of prevalence were extremely varied.⁸ Only a small number of studies have been carried out within the United Kingdom over the last two decades.¹⁻⁵ Because they were performed in specific regions including London, a Scottish city and a rural area in North-East of England, the results were biased by the particular characteristics of the populations, access to and quality of health care services in the region, and the accuracy of diagnosis at a local level. This meant that when their results were extrapolated to the whole country the prevalence estimates ranged from 105 to 178 persons with Parkinson's per 100,000 population when adjusted for age (confidence intervals range from 85 to 201).^{1,3} And meant that the estimated number of people with Parkinson's in UK could range from 51,000 to 120,000. These wide-ranging results and the lack of studies with a representative population for the UK encouraged us to calculate a more accurate estimate of the true prevalence of Parkinson's using the world's largest computerised database of anonymised longitudinal medical records, which covers approximately 7.2% of the UK population.

Methods

This is a descriptive epidemiological study based on retrospective data from Primary Health Care records.

Parkinson's cases were identified and calculated using the appropriate Read codes in General Practice Research Database (GPRD) for 2009 - the last year for which complete data is available. The GPRD consists of 7.2% or 3,396,510 people in 2009 and is considered as being representative of the UK population. Absolute numbers of people with Parkinson's were computed in sixteen age groups (from 20 upwards in five year intervals) using the appropriate diagnosis codes (F12, F120 and F12x). All these measures were stratified by age, gender and geographical region (England, Northern Ireland, Scotland and Wales). The total number of Parkinson's cases in the total GPRD population was used to calculate the prevalence rates per 10,000 of the population over 20 years of age. This was recommended because of the small number of cases of Parkinson's in the under 20 year group which would skew the figures if extrapolated for this segment of the total population. These rates then were scaled up to the relevant UK population, using data from the Office of National Statistics.⁶

Study population

A prevalence case of Parkinson's was defined as:

- a. A diagnosis code indicating definite Parkinson's within their clinical or referral record;
- b. Diagnosed previously or during the time of study and previously or during registration period;
- c. Registered with the practice at the time of the study.

Definite Parkinson's was diagnosed according to the UK Parkinson's Disease Society Brain Bank criteria⁹ and was coded with codes of F12, F120 and F12x). This excluded patients with Parkinsonian tremor, Parkinson posture and/or Parkinson gait.

Parkinson's and some Parkinsonisms share similar symptoms, and as a consequence are sometimes misdiagnosed, more often at the primary care level. However, these conditions strongly differ in their aetiology and characteristics as well as ways of treatment. Therefore, patients diagnosed with Parkinsonism (Drug induced Parkinsonism, Malignant Neuroleptic syndrome, Postencephalytic Parkinsonism, Vascular and Syphilitic Parkinsonisms as well as secondary Parkinsonism due to other reasons) after the record of definite Parkinson's were excluded from the study.

Data analysis

The data was managed and analysed in Stata software version 10.1 and provided as aggregated tables in Excel format by GPRD. Prevalence rates were computed with 95 percent confidence intervals (95% CI) by applying normal approximation and computing it by adding/deducting two standard errors. GPRD is representative of the UK population and there were no standardisation methods applied. For more accurate estimates prevalence rates were scaled up by age intervals stratified by gender and geographical region using equally broken down UK population figures.

Results

Total Parkinson's prevalence

The Parkinson's prevalence rate in 2009 was calculated as 27.4/10,000 (95% confidence interval (CI) 26.9-28.0) which is equivalent to 126,893 cases when scaled up to the total UK population.

Parkinson's prevalence among males and females

The Parkinson's prevalence rate was 30.9/10,000 (95% CI 30.1- 31.8) for males and 24.1/10,000 (95% CI 23.3- 24.8) for females. This equates to 69,850 males and 57,043 females with the condition.

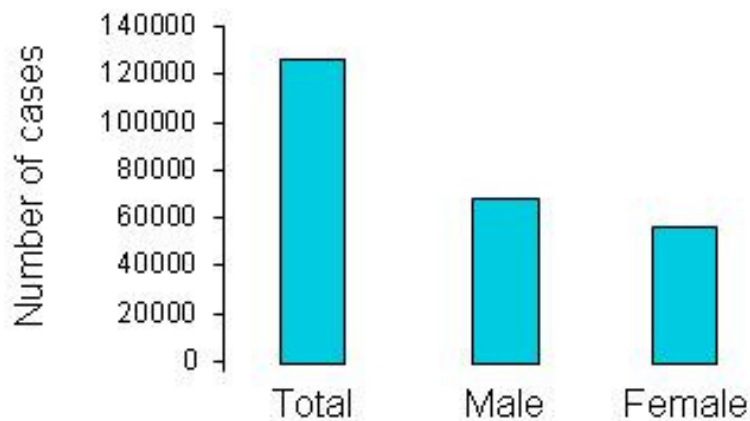


Figure 1 Total and gender-specific Parkinson's prevalence figures

Parkinson's prevalence by age groups

The highest prevalence rate of Parkinson's was among those aged over 75 years (Figure 2). When scaled up to relevant UK population the highest estimated Parkinson's prevalence was in 75-79 and 80-84 age groups (Figure 3).

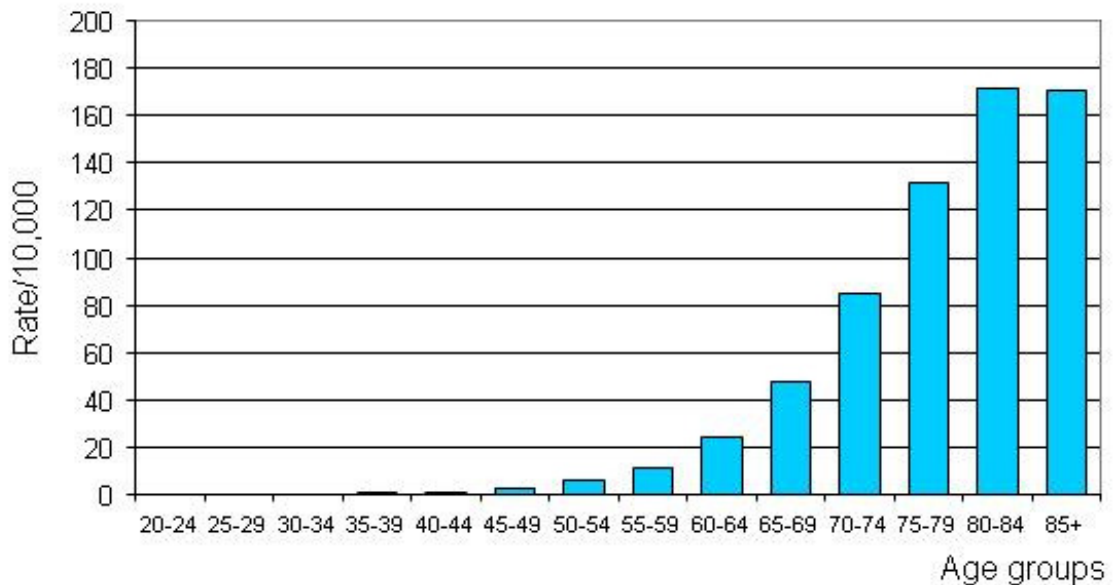


Figure 2. Parkinson's prevalence rate per 10,000 members of the population divided into 14 age groups in the UK in 2009

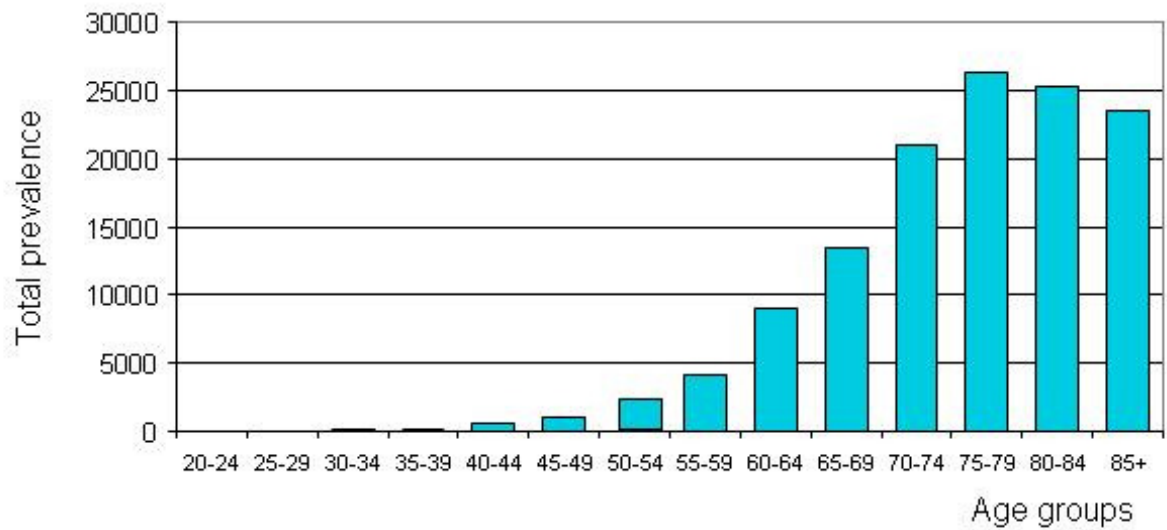


Figure 3. Estimated total cases of Parkinson's divided into 14 age groups in the UK in 2009

Geographical variation

Some geographical variation was seen, with highest prevalence rate in 2009 in England (28.0/10,000, 95% CI 27.4-28.6) and lowest in Scotland (23.9/10,000, 95% CI 22.2-25.6, Figure 7). This approximates/equates to 107,835 people with Parkinson's in England, 10,019 in Scotland, 5,890 in Wales and 3,147 in Northern Ireland.

Prevalence future trends

The UK population over 20 years of age was broken down into four age groups and we applied polynomial regression (Poly) to estimate future trends up to 2020. This is expected to particularly increase the number of people aged 60-79 years old ($R^2 \geq 0.98$, Figure 18).

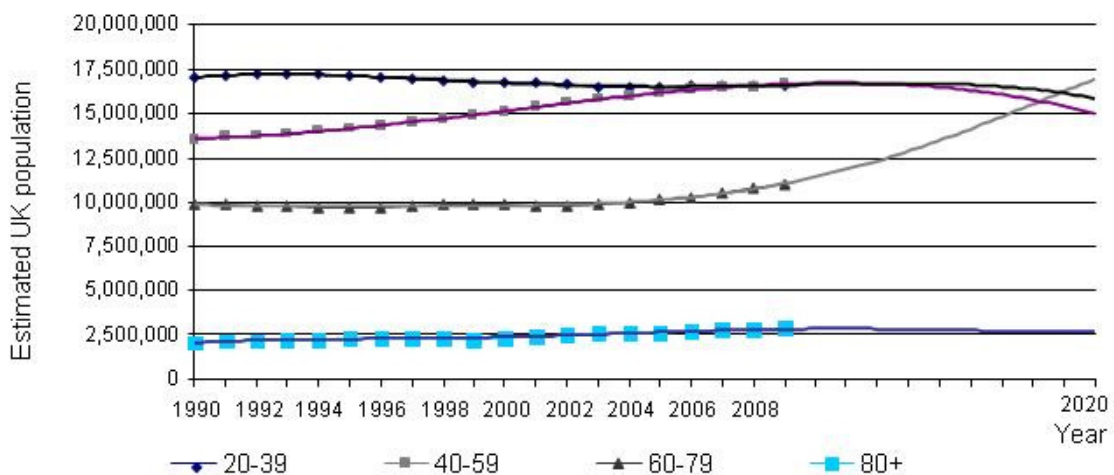


Figure 4. UK population over 20 years of age for years 1990-2009 divided into four age groups and foreseen to year 2020

After applying 2009 prevalence figures to the future population trends in the four age groups we could expect additional 37,582 Parkinson's cases in people aged 60-79 years in 2019. This would contribute to an overall increase of Parkinson's prevalence and there could be 162,165 cases of Parkinson's in the UK in 2020 which is an increase of 26.7% over the 2009 figures (Table 1). However, it must be emphasised that this is only an estimate based on population trends and does not take other factors into account such as changes in incidence rates over this time period.

Table 1. Predicted Parkinson's prevalence for year 2019 based on 2009 estimated Parkinson's prevalence and populations trends in the UK

Age group	2009		2020	
	Population	Estimated Parkinson's prevalence	Population	Predicted Parkinson's prevalence
20-39	16,567,286	402	15,820,000	384
40-59	16,639,732	7,978	15,000,000	7,192
60-79	10,987,129	69,833	16,900,000	107,415
80+	2,837,809	48,678	2,750,000	47,172
Total (over 20)	47031956	126,893	50,470,000	162,165

Discussion

Our study is based on the use of existing medical records, and as a result, it may underestimate the prevalence of the condition compared to rates obtained by questionnaire-based screening or door-to-door studies.^{8,13} This is because it doesn't include patients who have not sought medical attention for their condition or whose records have not been retrieved.^{5,7,12} This means there could be additional 25 percent of Parkinson's cases undiagnosed in the community, which is the average figure for undiagnosed Parkinson's within Europe.⁷ The number of younger people (under the age of 40) is considerably lower than previously reported in smaller studies and this may be associated with a misdiagnosis or incorrect reporting of the condition. Many previous studies have drawn attention to the difficulties in diagnosing Parkinson's and distinguishing it from other Parkinsonian syndromes.¹⁴ In addition, a small number of cases in a particular group makes it difficult to extrapolate accurately. However, because of amount of data for older people, the estimates for Parkinson's in the older age groups are considered to be robust.

The health care system in the United Kingdom is organised locally and the population of a general practice is representative of the surrounding area.¹⁵ However, we are aware that some of the Parkinson's patients under the care of district hospital or consultant neurologist may be not recorded in the GPs database and this may explain the underreporting of younger cases.⁵ However, the study included many regions with different access to medical services, therefore we believe that it won't affect the total result significantly.

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