Public Health England

Protecting and improving the nation's health

Deaths associated with neurological conditions in England 2001 to 2014

Data analysis report

National Neurology Intelligence Network
National End of Life Care Intelligence Network

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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Published January 2018
PHE publications
gateway number: 2017688

PHE supports the UN
Sustainable Development Goals

About the National Neurology Intelligence Network

The National Neurology Intelligence Network (NIN) is part of Public Health England's (PHE) National Mental Health, Dementia and Neurology Intelligence Network (NMHDNIN).

The purpose of the NMHDNIN is to:

- develop relevant, timely and authoritative intelligence tools and resources
- take a strategic lead across the system on the innovative development of information for improvement, embedding our intelligence tools and products in local systems
- develop strong partnerships with key stakeholders and the academic, commercial and voluntary sectors – with the aim of continually driving up standards in intelligence products aimed at improving population health and reducing health inequalities

The intelligence resources and tools produced by the NIN can be found on the network's website.

About the National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services. For more information about the Network and its partners see www.endoflifecare-intelligence.org.uk.

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Summary

Health intelligence can play a vital role in effective planning health services. While there is a paucity of detailed data on the needs of those with neurological conditions, mortality statistics are an available source that can begin to address this gap. The purpose of this report is to use mortality data to help provide insight about people with neurological conditions.

This report is about people who have died with a neurological condition recorded on their death certificate in England during the period of 2001 to 2014. It investigates:

- the numbers and rates of deaths associated with neurological conditions and their recent trends
- the demographic characteristics of people dying with neurological conditions
- the underlying cause of death and association with the broad disease groups
- the place of death

The data source for this analysis is the Office for National Statistics: Public Health England Annual Mortality Extract. The report is based on deaths of people who were usually resident in England, aged 20 and over and died with an adult neurological condition recorded on their death certificate. Detailed analysis has been provided for the 7 condition groups below (previously defined by the NIN[(1)]):

- Epilepsy
- Motor neurone disease and spinal muscular atrophy
- Multiple sclerosis and inflammatory disorders
- Neuromuscular diseases
- Parkinsonism and other extrapyramidal disorders/tic disorders,
- Traumatic brain and spine injury
- Tumours of the nervous system

How have deaths associated with neurological conditions changed over recent years?

There were 366,728 deaths of people aged 20 and over with a mention of neurological conditions in England over the time period of 2001 to 2014. The number of deaths relating to neurological conditions has been steadily increasing year on year, from 23,051 in 2001 to 31,925 in 2014, an overall increase of 39% over the period.

During this time an increase in the number of deaths was noted for most of the neurology conditions groups with the exception of Motor neurone disease and spinal muscular atrophy where a slight drop was recorded in 2014. Over this time period:

- 31% of deaths in the cohort had a mention of Parkinsonism and other extrapyramidal disorders/tic disorder
- 20% deaths had a mention of tumours of the nervous system
- 9% with a mention of epilepsy
- 8% with a mention of traumatic brain and spine injury
- 7% with a mention of motor neurone disease and spinal muscular atrophy
- 6% with a mention of multiple sclerosis and inflammatory disorders
- 3% with a mention of neuromuscular diseases
- 3% with a mention of diseases of central nervous system
- 1% with a mention of development disorders
- 15% with a mention of rare and other neurological conditions

The directly age-standardised mortality rate (ASMR) of any mention of neurological condition had significantly increased from 71 per 100,000 population in 2003-05 to 80 per 100,000 population in 2012 -14, a rise of 12%. In contrast the directly ASMR for all-cause deaths continued on a downward trend, from 1,471 deaths per 100,000 population in 2003-05 to 1,213 per 100,000 population in 2012-14, a decrease of 17%.

What are the demographic characteristics of the people that have died with a neurological condition?

56% of deaths aged 20 years and over with any mention of neurological conditions were male; whereas men account for only 48% of all-cause deaths.

The age distribution by gender of neurological deaths is similar to all-cause deaths. The age group with the largest number of deaths with a mention of neurological condition were people aged 80 to 84 years, accounting for 18% of male neurological deaths and 17% of female neurological deaths in this period of time.

There were a higher proportion of deaths with a mention of neurological conditions in younger age groups, accounting for over 17% of all deaths between 20 and 24 years. By contrast, less than 3% of deaths aged 90+ had neurology mentions recorded.

From 2001 to 2014, the average age of death recorded for people with a mention of neurological condition rose from 70 to 73 years, a larger increase than the all-cause deaths average age which rose by 2 years from 76 to 78 over the same period. In 2014, the average age of death associated with a neurological condition was 5 years lower than deaths in the general population; however some conditions show notable variation to this. Between 2012 and 2014 the mean age of death with a mention of Parkinsonism

and other extrapyramidal disorders/tic disorder was 82 years, higher than the mean age of death from all causes (78 years) and those who died with a mention of neurological conditions (74 years). Deaths associated with epilepsy were generally younger, with a mean age at death of 70.

A greater proportion of epilepsy related deaths occur in areas of higher levels of deprivation. In fact when standardised by age, the rate of deaths associated with epilepsy in the most deprived areas in England is nearly three-times larger than in the least deprived areas, 13 deaths per 100,000 population verses 5 deaths per 100,000.

What do people with neurological conditions die of?

In the period 2012 to 2014, half of the deaths associated with a neurological condition had a neurological condition recorded as the underlying cause. Within this group, Parkinson's disease was the most common individual condition recorded (28%) followed by brain cancers (22%), spinal muscular atrophy (12%), multiple sclerosis (8%), epilepsy (6%) and other degenerative diseases of nervous system not elsewhere classified (8%).

For the remainder of deaths associated with a neurological condition that had a non-neurological underlying causes of death recorded there was a wide range of conditions identified. This group included falls (12%), malignant neoplasm of bronchus and lung (8%), pneumonia - organism unspecified (6%) and stroke - not specified as haemorrhage or infarction (6%).

Around 38% of all deaths associated with a neurological condition also had a comorbidity related to respiratory diseases, 33% related to circulatory diseases, 25% related to malignant cancers and 25% related to falls.

Where do people with neurological conditions die?

There were differences between the places of death for people with a mention of neurological conditions compared to all-cause deaths and cancer related deaths. A higher proportion of deaths with a mention of neurological conditions were recorded in hospitals (49%) and care homes (26%) than for all-cause deaths.

The place of death varied with each neurological condition. Higher proportions of deaths with a mention of neuromuscular diseases and traumatic brain and spine injury occurred in hospitals (acute or community, not psychiatric), with 77% and 81% respectively.

The largest proportion of deaths with a mention of Parkinsonism and other extrapyramidal disorders/tic disorder occurred in care homes (nursing or residential) 43% followed by 41% in hospital (acute or community, not psychiatric).

Introduction

Health intelligence can play a vital role in effective planning health services. While there is a paucity of detailed data on the needs of those with neurological conditions, mortality statistics are an available source that can begin to address this gap. The purpose of this report is to use mortality data to help provide insight about people with neurological conditions.

The cohort analysed in this study consists of people whose deaths had a neurological condition recorded on the death certificate as either the underlying or a contributory cause of death. This approach uses a broad analysis of the deaths associated with neurological conditions. Other research based on the same dataset such as the ONS deaths registered in England and Wales[(2)] used only the underlying cause of death in the analysis. However, some literature suggests that studies based solely on underlying cause of death, underestimate the true 'burden' of disease[(3)]. Concerns to consider typically, in chronic diseases such as neurological conditions are that several co-existing conditions may contribute to death. When more than one disease contributes to death, statistics confined to only one cause for each death may lack precision[(3)].

This report produced by the National Neurology Intelligence Network and supported by the National End of Life Care Intelligence Network, draws on the Office for National Statistics: Public Health England Annual Mortality Extract National dataset to illustrate key facts related to deaths with a mention of neurological conditions over the period 2001 to 2014. It is aimed at stakeholders with the responsibility for the provision of care and the commissioning of services for people with neurological conditions in England.

The findings of the analysis are presented in this report by an aggregation of the collection of ICD-10 codes used to define adult neurological conditions and by the major condition groups.[(1)] These groups are:

- Epilepsy
- Motor neurone disease and spinal muscular atrophy (MNDSMA)
- Multiple sclerosis and inflammatory disorders (MSID)
- Neuromuscular diseases
- Parkinsonism and other extrapyramidal disorders/tic disorders (POED/TD)
- Traumatic brain and spine injury (TBSI)
- Tumours of the nervous system.

Dementia and stroke have been excluded because they are covered by other intelligence networks.

This report provides insight into four themes within the dataset:

- the numbers and rates of deaths associated with neurological conditions and their recent trends
- the demographic characteristics of people dying with neurological conditions
- the underlying cause of death and association with the broad disease groups
- the place of death

The findings section of this report contains the analysis of the mortality dataset for England, for all neurological conditions (aggregated) and for the major neurological condition groups (summarised). Additional charts for each of the condition groups are included in the appendices and are referenced in the relevant sections.

Also provided as part of this suite of intelligence products are the following:

- Deaths associated with neurological conditions in England – data briefing
- Deaths associated with neurological conditions in England – data workbook

All documents are available via GOV.UK
https://www.gov.uk/guidance/neurology-data-and-analysis-a-guide-for-health-professionals

Definitions and methodology

This report is based on deaths of people who were usually resident in England, aged 20 and over and died with a neurological condition recorded on their death certificate. Time trend analysis is based on the years 2001 to 2014, while age standardised analysis is based on 3-year time band and uses periods 2003 to 2005 to 2012 to 2014. The remaining analysis is based on deaths registered over the most recent period 2012 to 2014.

When the term 'neurological condition' is used in this study, this relates to deaths where there was a recording of at least one of the 473 ICD-10 codes used to define adult neurological conditions[(1)]. Analysis has also been provided for 7 specific neurological condition groups listed in table 1. Analysis for the remaining ten condition groups has been excluded from this study due to small numbers of associated deaths but they are included in the aggregated 'neurology' data items.

Table 1: ICD-10 Codes used for analysis

Conditions	ICD-10 Code
Epilepsy	G400, G401, G402, G403, G404, G405, G406, G407, G408, G409, G410, G411, G412, G418, G419, R568
Motor neurone disease and spinal muscular atrophy	G120, G121, G122, G128, G129
Multiple sclerosis and inflammatory disorders	G35X, G360, G361, G368, G369, G370, G371, G372, G373, G374, G375, G378, G379
Neuromuscular diseases	G700, G701, G702, G708, G709, G710, G711, G712, G713, G718, G719, G720, G721, G722, G723, G724, G728, G729, G730, G731, G732, G733, G734, G735, G736, G737, M600, M601, M602, M608, M609, M620, M621, M622, M623, M624, M625, M626, M628, M629
Parkinsonism and other Extrapyramidal disorders/Tic disorder	R251 F950, F951, F952, F958, F959, G903, G10X, G20X, G210, G211, G212, G213, G214, G218, G219, G22X, G230, G231, G232, G238, G239, G240, G241, G242, G243, G244, G245, G248, G249, G250, G251, G252, G253, G254, G255, G256, G258, G259
Traumatic brain and spine injury	S04, S060, S061, S062, S063, S064, S065, S066, S067, S068, S069, S141, S142, S143, S144, S240, S241, S242, S341, S342, S343, S344, T060, T061, T093, T094
Tumours of the nervous system	C700, C701, C709, C710, C711, C712, C713, C714, C715, C716, C717, C718, C719, C793, C720, C721, C722, C723, C724, C725, C728, C729, D320, D321, D322, D330, D331, D332, D333, D334, D337, D339

Definitions of the neurological conditions cohort

Epilepsy
Is a common serious neurological condition where there is a tendency to have seizures that start in the brain[4]. Overall prevalence in England[5] is at 0.8%, but it varies widely throughout the country. Some people have epilepsy as a primary condition, in others it can be a consequence of other conditions such as head injury or stroke etc. In adults the prevalence of the condition increases with age.

Motor neurone disease and spinal muscular atrophy (MNDSMA)
Rare neurodegenerative diseases characterised by progressive weakness of the bulbar, limb, thoracic and abdominal muscles. These are a group of conditions in which the motor nerve cell dies. Motor neurone disease is often severe, disabling and generally fatal within 3 years of onset but the rate of progression of the illness varies widely. Spinal muscular atrophy is grouped with motor neurone disease as they are similar, however it is usually genetic in origin and has a much slower rate of progression[6].

Multiple sclerosis and inflammatory disorders (MSID)
This category includes inflammatory conditions of the nervous system, of which the most common is multiple sclerosis. Multiple sclerosis is a condition which can affect the brain and/or spinal cord, causing a wide range of potential symptoms, including problems with vision, arm or leg movement, sensation or balance[7]. It is estimated that the number of people with multiple sclerosis in England is around 165 per 100,000. The number of people with multiple sclerosis in the UK is estimated to be increasing at a rate of 2.4% per year, due to people with multiple sclerosis living longer[8].

Neuromuscular diseases
A group of conditions affecting the peripheral nervous system that gradually causes the muscular dystrophies (MD) that lead to an increasing level of disability[9]. This is a grouping of many illnesses, rare and common, that affect the muscle, such as myositis (an inflammation of the muscle), the neuromuscular junction (such as myasthenia gravis) or sometimes both. They can be genetic, such as the muscular dystrophies, or acquired during life, such as myositis.

Parkinsonism and other extrapyramidal disorders/tic disorder (POED/TD)
This is a grouping of movement disorders which damage some of the nerve cells in the brain, causing deterioration and gradual loss of function. This can affect movement, cognition (perception, awareness, thinking, judgement) and behaviour[10]. There are many causes, including genetic and degenerative illnesses. The most common illness in this group is Parkinson’s disease, a neurodegenerative condition that increases in prevalence with age and is currently estimated to affect 100–180 people per 100,000 of the population[10]. The highest estimated Parkinson’s disease prevalence is in 75-79 and 80-84 age groups[11].

Traumatic brain and spine injury (TBSI)
This grouping contains those with significant traumatic injuries to brain and spine.

Tumours of the nervous system
A tumour is a growth of cells in the brain or surrounding coverings that multiply in an abnormal, uncontrollable way. It is not always cancerous[12]. There are many types of tumours on the brain and spinal cord and they range massively in age of onset and severity. In general, the chance of brain or spine injury increases with advancing age.

Definitions of main terms

Underlying cause of death
i) The disease or injury that initiated the train of events directly linked to death; or
ii) The circumstances of the accident or violence that produced the fatal injury.
There is one position in the data set for the underlying cause of death per record; this is the recorded primary cause of death.

Contributory cause of death
Part of the causal sequence of events leading to death, or contributing to the death; the contributory cause of death is the subsequent 15 positions in the data set, so a death record can have a maximum of 15 contributory causes.

Mention (deaths associated with)
A death which has a condition listed as either the underlying cause of death or as a contributory cause of death. Throughout this document the phrase ‘mention of’ and ‘association with’ are used interchangeably and mean the same.

Caveats

The deaths analysed in this study are those where a neurological condition was recorded on the death certificate. The data may not represent a true count of people who have a neurological condition or have lived with a neurological condition prior to death. In some cases reference to a neurological condition may have been omitted from the death certificate, such as in a road traffic accident scenario, where the death may have been perceived as being completely unrelated to the individual's condition. Also in other scenarios the neurological condition may have been diagnosed immediately prior to death, in such cases as a traumatic brain injury resulting from a fall. However the numbers do give an account of the people where neurological conditions are a direct or important factor in the death[13].

This report uses year of registration, not date of occurrence of death, this is consistent with most ONS mortality statistics.

ONS mortality dataset

The data source for this analysis is the Office for National Statistics: Public Health England Annual Mortality Extract. This dataset encompasses information for the cause of death from civil registration records. It lists the underlying cause of death and other conditions that the patient had at the time of death. Deaths are coded in line with the International Statistical Classification of Diseases and Related Health Problems (ICD).

Statistical methods

Age standardised mortality rates (ASMR) are calculated to provide the number of deaths per 100,000 population that occurred in an area if it had the same age structure as the standard population and the age-specific rates of the area applied. ASMR is calculated by dividing the number of deaths by the actual local population in a particular age group multiplied by the 2013 European standard population (ESP) for that particular age group and summing across the relevant age groups[14]. Statistical significance was assessed throughout the report by calculating whether the 95% confidence intervals for data points overlap.

ONS coding changes

During the period of this study, the Office for National Statistics (ONS) changed the way it coded deaths from previous ICD-10 versions to the most recent ICD-10 v2013 in January 2014. This change was carried out so that a common automated cause of death coding system could be used to code in any language to improve the comparability of mortality statistics across Europe and internationally[15]. This report is primarily focussed on deaths associated with (mentions) neurological conditions and this change in coding system should not have impacted on the findings.

Overview of mortality trends for neurological conditions

1.1. Deaths associated with neurological conditions

There were 366,728 deaths in people aged 20 and over with a mention of neurological conditions in England over the time period of 2001 to 2014. The number of deaths steadily increased year on year, from 23,051 in 2001 to 31,925 in 2014, an overall increase of 39%. The trend in deaths related to neurological conditions is counter to the trend for all-cause deaths, which have fallen by 6%. Neurological deaths in 2014 accounted for 7% of overall deaths in England.

Figure 1: Recorded deaths, persons aged 20 and over, England, 2001 to 2014

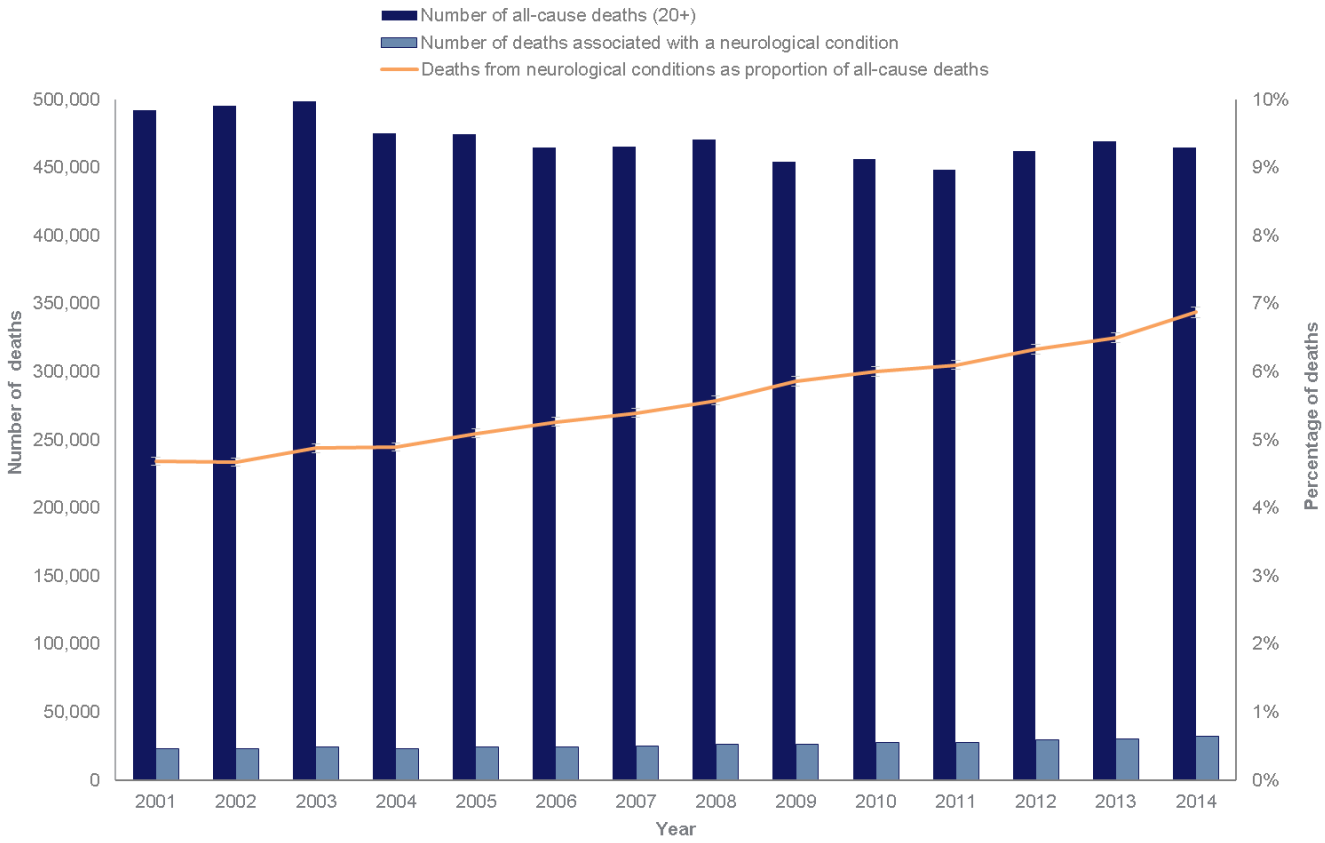
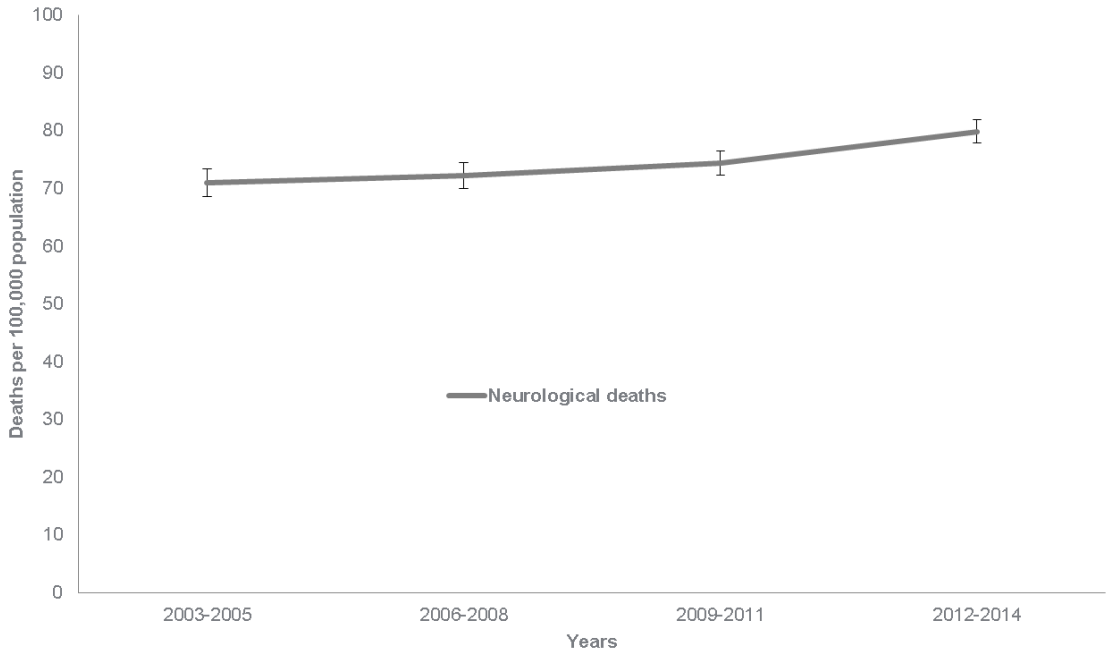


Figure **2** illustrates that the directly age-standardised mortality rate (ASMRs) of any mention of neurological condition had significantly increased from 71 per 100,000 population in 2003[a] to 2005 to 80 per 100,000 population in 2012 to 2014. This represents an ASMR increase of 12% in that period. In contrast the ASMR for all-cause deaths has continued on a downward trend, from 1,471 deaths per 100,000 population in 2003 to 2005 to 1,213 per 100,000 population in 2012 to 2014. Since 2003, all-cause deaths age-standardised mortality rates have decreased by 17%.

Box 1: Directly age standardised rates are calculated to enable comparison by removing variation in crude rates due to age structure. DASRs calculated use the 2013 European Standard Population (ESP).

Figure 2: Directly age-standardised mortality rates for all deaths associated with neurological conditions per 100,000 population, England, 2003-2005 to 2012-2014, persons aged 20 and over



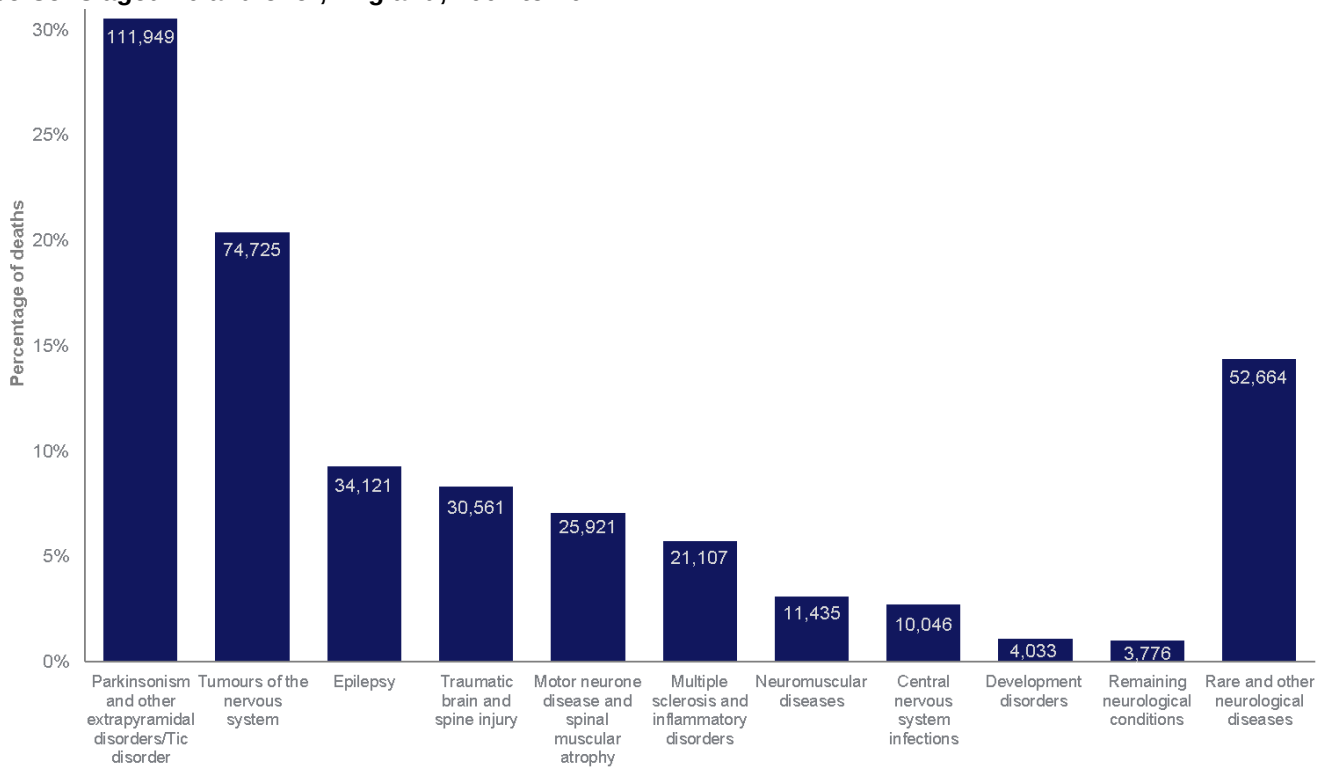
[a] The age standardised mortality rate are 3 years combined statistics and thus to utilise the latest data, the 2001 and 2002 data was omitted from the calculations.

1.2. Deaths with neurological conditions by specific condition group

Figure 3 illustrates that over the time period of 2001 to 2014 nearly 31% of deaths related to neurological conditions had a mention of POED/TD[b]. A further 20% were deaths with a mention of tumours of the nervous system, epilepsy deaths accounted for 9%, TBSI for 8%, MNDSMA for 7%, MSID for 6% and 3% for neuromuscular diseases.

In addition to the 7 core groups being analysed in this study, 3% of deaths were associated with diseases of the central nervous system and 1% for development disorders. 15% of deaths were associated with the rare and other neurological disease conditions groups.

Figure 3: Proportion and number of all deaths associated with a neurological conditions groups, persons aged 20 and over, England, 2001 to 2014



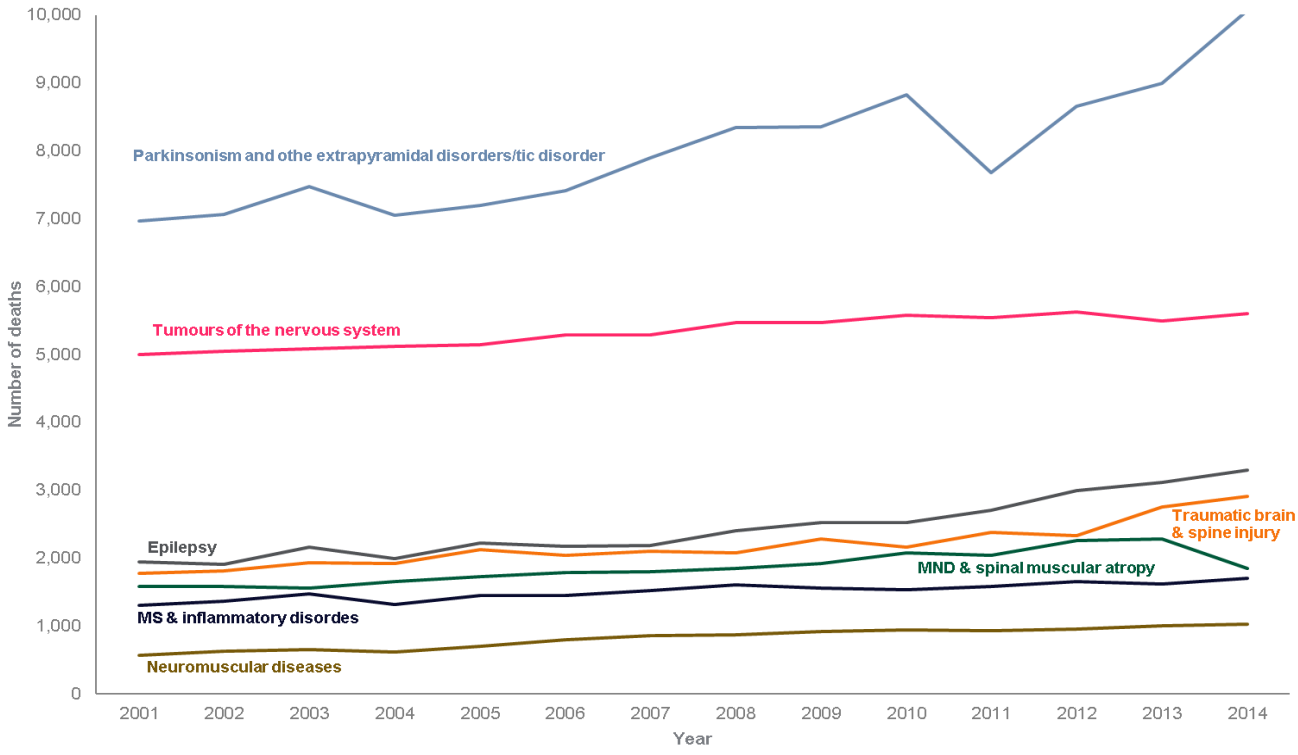
Note: Some people can have more than one neurological condition mentioned; they will therefore be counted in more than one of the presented groups

[b] Motor Neurone disease and spinal muscular atrophy (MNDSMA)
Parkinsonism and other extrapyramidal disorders/tic disorder (POED/TD)
Traumatic brain and spine injury (TBSI)

An increase in the number of deaths were noted for all seven major neurology condition groups between 2001 and 2014, with the exception of MNDSMA which noted a slight drop in 2014 (Figure 4).

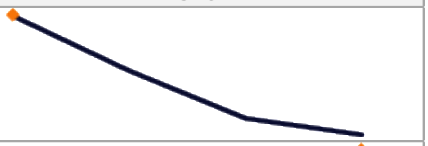
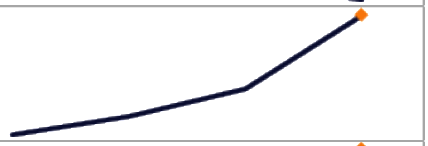
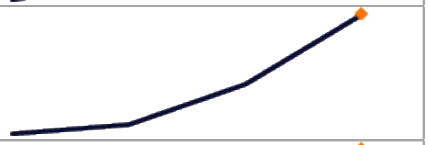
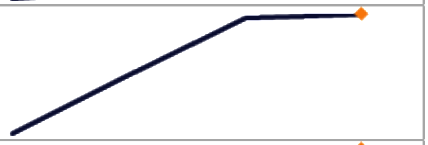
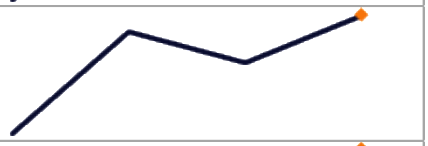
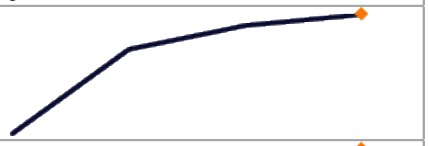
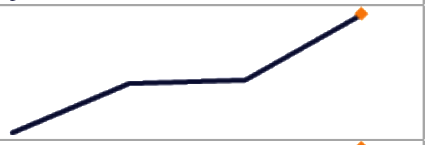
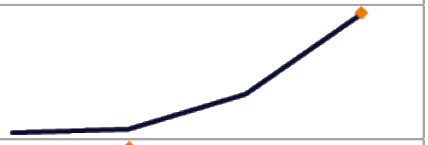
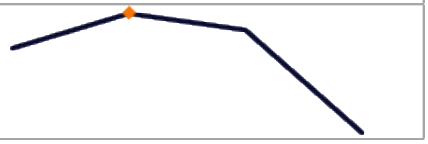
The numbers of deaths associated with POED/TD and tumours of the nervous system are the highest throughout this period of time, with the latter group remaining fairly constant throughout the period. However deaths associated with POED/TD have been steadily increasing throughout the time period, to approximately 10,000 deaths in 2014. Epilepsy and TBSI also noted steady increases more recently while the remaining condition groups continued on a more levelled trend. More detailed time trend charts of the individual conditions mentioned above can be found in Appendix 1.

Figure 4: Time trend of number of deaths associated with neurological conditions, persons aged 20 and over, England, 2001 to 2014



The increasing trend for the standardised rates seen for deaths with a mention of neurological conditions was also seen for most of the individual conditions as shown in Table 2. However, the standardisation has removed the visible drop in 2014 for MNDSMA and reversed the trend for tumours of the nervous system to a decreasing trend which indicates stronger links to ageing.

Table 2: Directly age standardised mortality rate per 100,000 population, England 2003 to 2005 to 2012 to 2014, aged 20+

Conditions	2003-2005	2006-2008	2009-2011	2012-2014	Trend
All deaths	1470.6	1351.3	1247.3	1213.4	
Neurological conditions	71.0	72.2	74.4	79.8	
Epilepsy	6.1	6.2	6.9	8.1	
Motor neurone disease & spinal muscular disorders (MNDSMA)	4.9	5.3	5.6	5.7	
Multiple sclerosis & inflammatory disorders (MSID)	4.1	4.3	4.2	4.3	
Neuromuscular diseases	1.9	2.4	2.5	2.6	
Parkinsonism & other extrapyramidal disorders/tic disorder (POED/TD)	22.1	23.0	23.1	24.3	
Traumatic brain & spine injury (TBSI)	5.8	5.8	6.1	6.9	
Tumours of the nervous system	15.1	15.3	15.2	14.6	

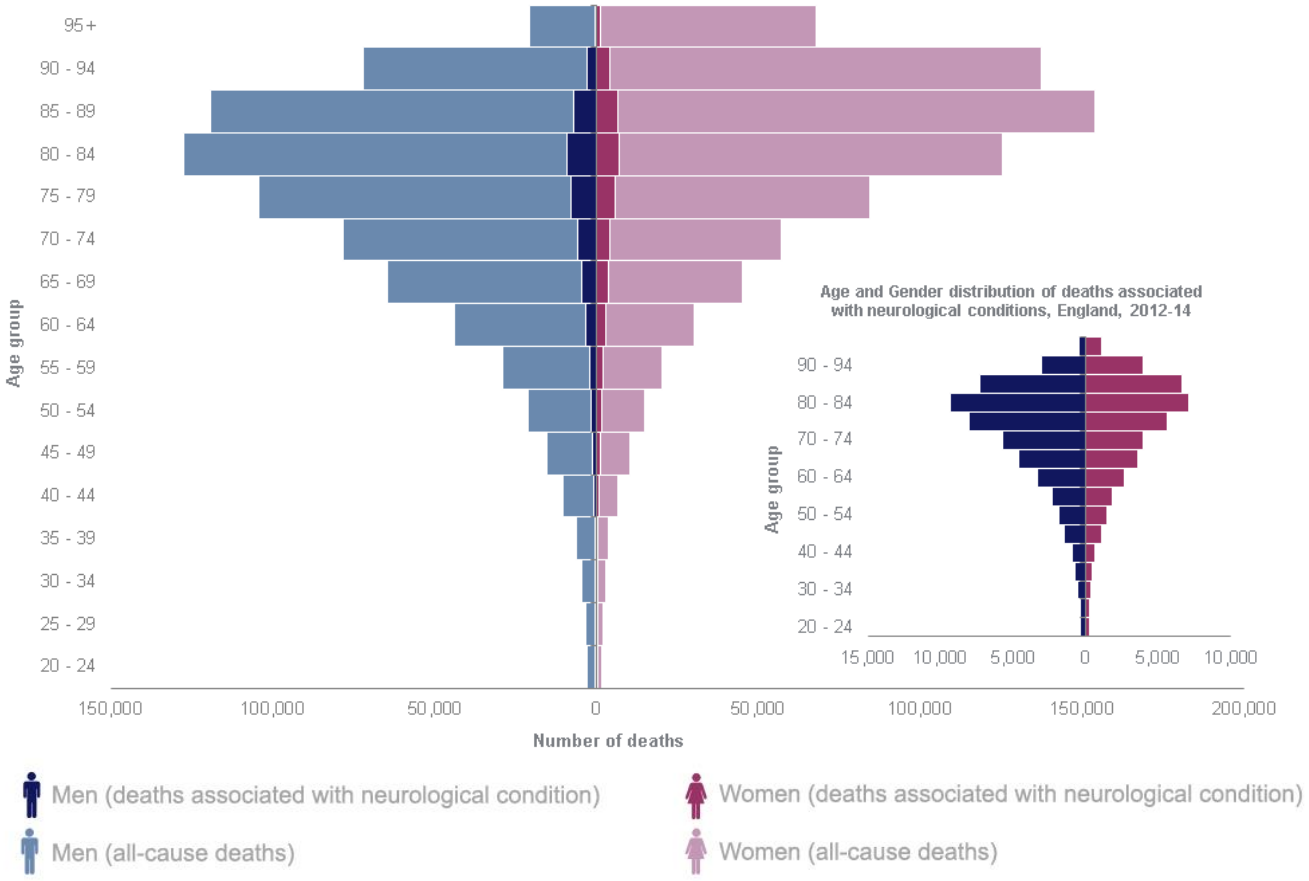
Note: every chart in Table 2 is based on its own vertical axis so the charts are not directly comparable but are indicative of the direction of change and the highest value is marked as an orange diamond. The values are provided in the table on the left hand side of the charts.

1.3. Age and gender at death

There were 91,685[c] deaths (51,023 men and 40,662 women) with a mention of neurological conditions in the period 2012 to 2014 in England, accounting for 7% of all-cause deaths. The majority of deaths with any mention of neurological conditions were amongst men (56%), whereas men account for only 48% of all-cause deaths in 20 years and over age group.

The majority of deaths of people with neurological conditions occur in 60 years and above age groups, with the largest number of deaths occurring in people aged 80-84 years with 9,381 deaths in men and 7,089 women. This age group accounted for 18% of male deaths with a mention of a neurological condition in this period of time, and 17% of female deaths. The age distribution for each gender had a similar shape as for all-cause deaths, however deaths in women aged 85-89 years seemed more pronounced for all-cause deaths, than the with deaths with a mention of neurological conditions.

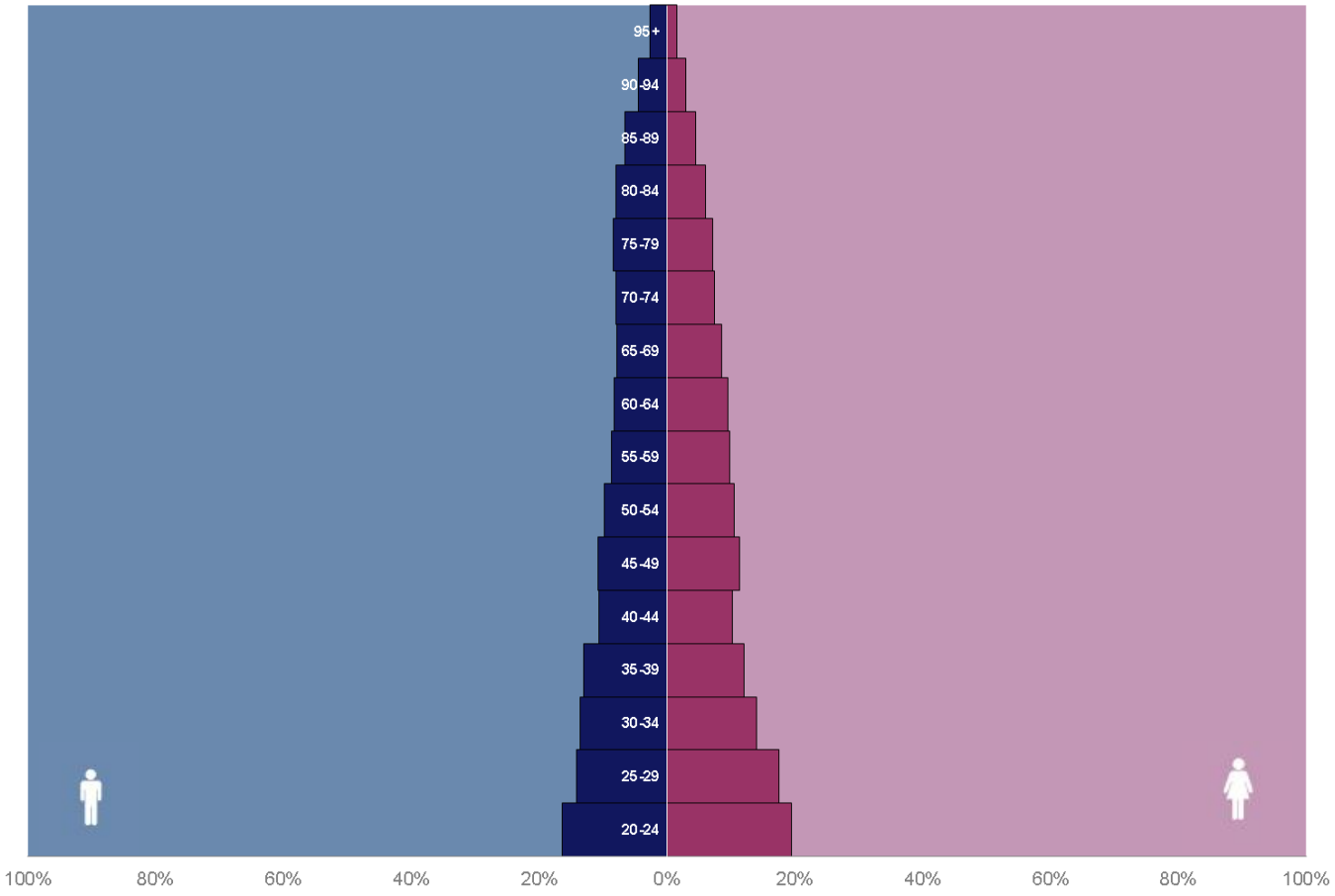
Figure 5: Age and gender distribution of all-cause deaths and deaths associated with neurological conditions, persons aged 20 and over, England, 2012-2014



[c] Number of neurological deaths in 2012 (29,248) , 2013 (30,512), 2014 (31,925)

Further analysis by proportion of all-cause deaths (Figure 6) shows that there were a higher proportion of deaths with a mention of neurological conditions in the younger age groups. Over 17% of all-cause deaths between 20 and 24 years of age had a mention of a neurological condition, with epilepsy and traumatic brain and spinal injuries accounting for 4% each and tumours of the nervous system and neuromuscular diseases accounting for 2% each of all deaths in the age group. By contrast, less than 3% of deaths for those aged 90+ had such mention recorded.

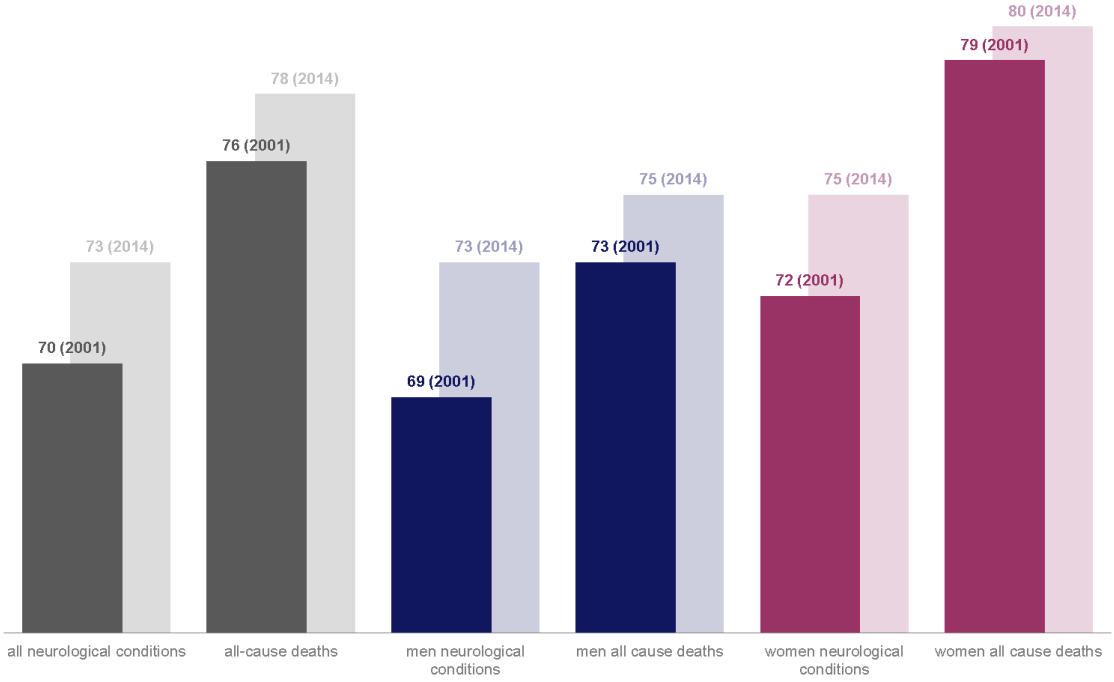
Figure 6: Age and gender distribution of deaths associated with neurological conditions as proportion of all-cause deaths, persons aged 20 and over, England, 2012-2014



During the period of 2001 to 2014, the average age at death recorded for people with a mention of neurological condition increased by 3 years, from 70 to 73 years, compared with the all-cause deaths average age in England which increased by 2 years from 76 to 78 years (Figure 7). In 2014 the average age at death associated with a neurological condition was 5 years lower than deaths in the general population.

Between 2001 and 2014, the average age of death with a neurology mention had increased by 4 years for males and 3 years for females, a larger increase than for all-cause deaths. In 2014 the average age at death associated with a neurological condition was 2 years lower for males and 5 years lower for females when compared with the gender equivalent of all-cause deaths in the population.

Figure 7: Average age at death for 2001 and 2014, persons aged 20 and over, Englandd



There were 34% more male deaths with a mention of POED/TD than females. The age group with the largest number of deaths with a mention of POED/TD occurred in people aged 80-84 years with 2,897 (26%) female deaths and 4,800 (29%) male deaths being recorded (Appendix 2e).

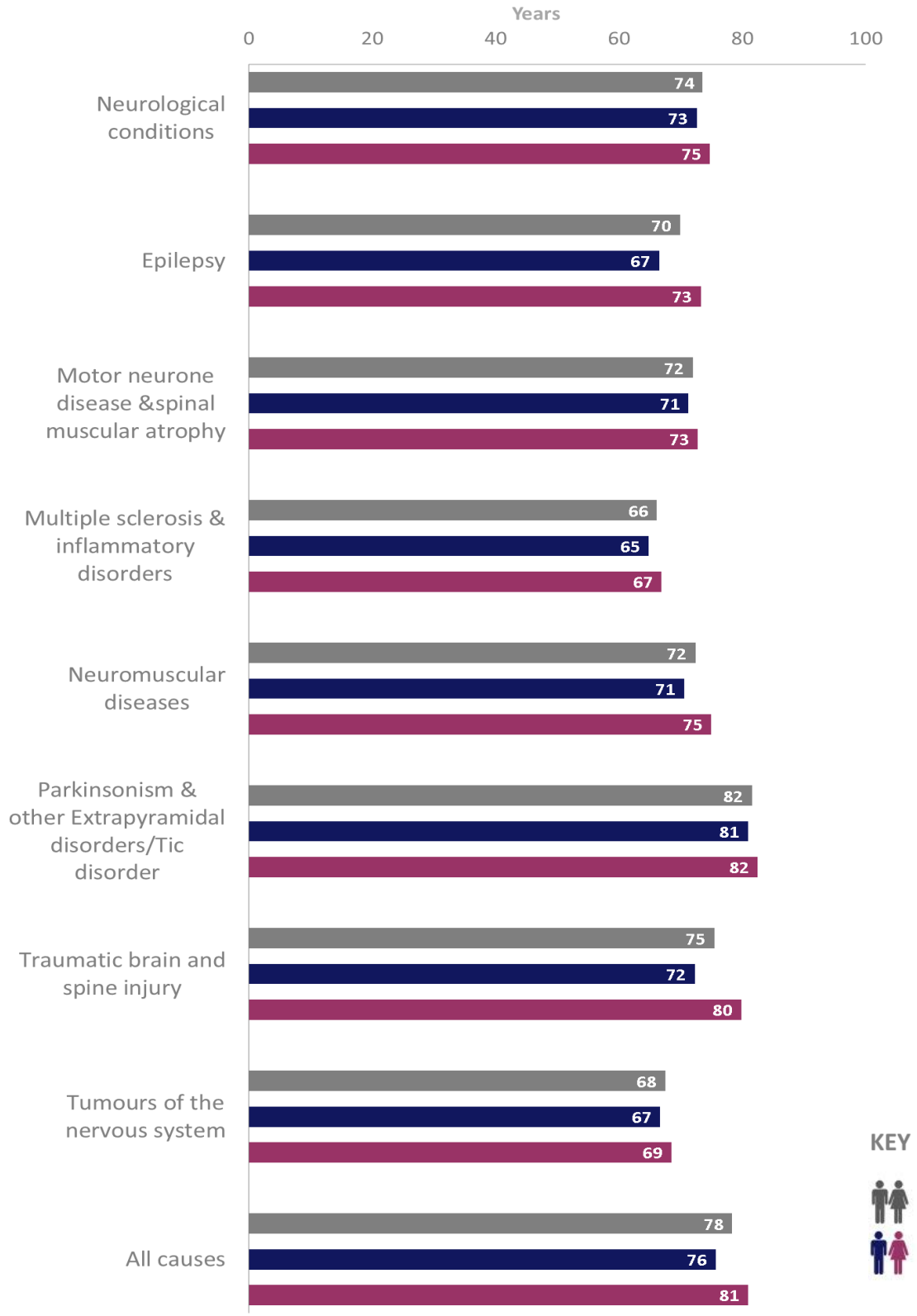
In contrast 29% more women died with a mention of MSID than men. The age group with the largest number of deaths with a mention of MSID occurred in people aged 65-69 years with 512 (16%) female deaths and 290 (16%) male deaths. More details can be found in Appendix 2.

Further analysis by mean age of death (Figure 8) showed that between 2012 and 2014 the mean age of death with a mention of POED/TD (82 years) was higher than the mean age of death of all causes (78 years) and the mean age of death of where a neurological condition was mentioned (74 years). MSID had the lowest mean age of death compared to the other condition groups, 66 years.

The mean age of death associated with Epilepsy and TBSI saw the largest differences by gender, with males dying with epilepsy on average 6 years earlier and males with TBSI dying on average 8 years earlier than females with the same conditions.

[d] As the age structure of the population in each of the cause groups may be quite different, care should be taken in comparing the average age at death between groups. An increase in the average age at death between 2001 and 2014 may not necessarily mean that people are living longer with a neurological condition.

Figure 8: Mean age of death associated with neurological conditions in England, 2012-14[e]



[e] As the age structure of the population in each of the sex-specific cause groups may be quite different, care should be taken in comparing the average age at death between cause groups and between the sexes.

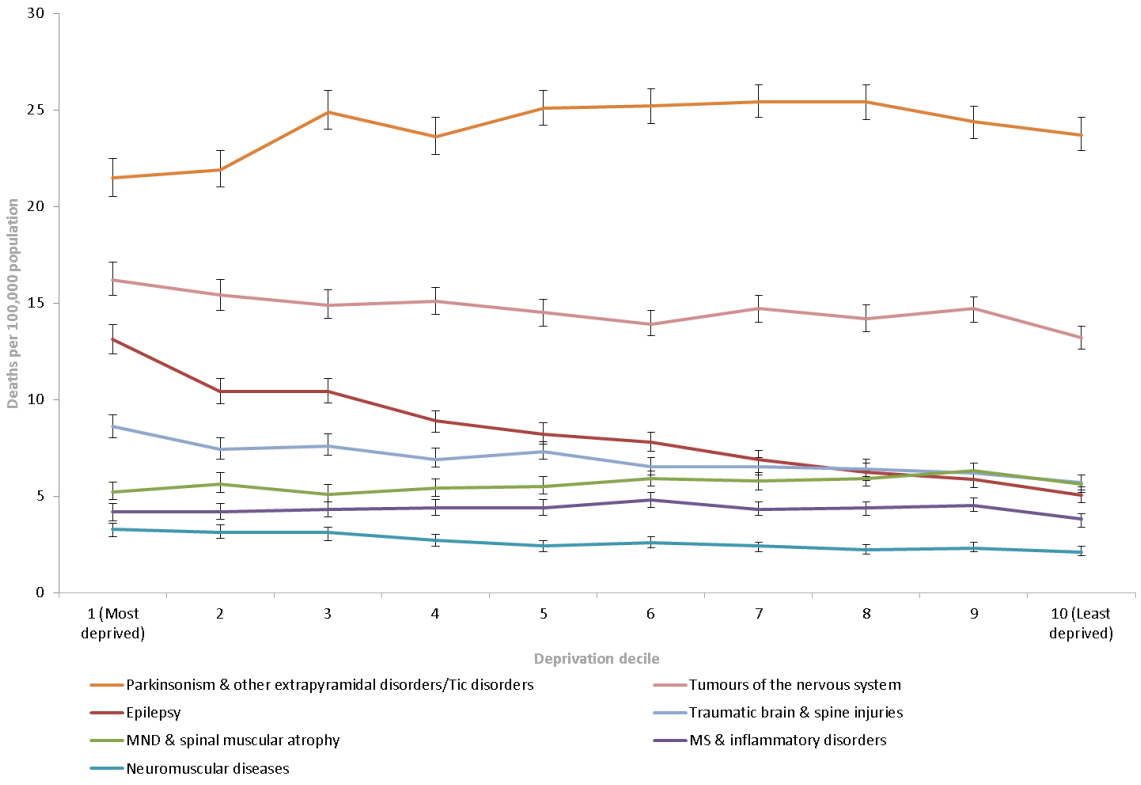
1.4. Socio-economic status – index of deprivation

Generally it is understood that there is no significant pattern in the relationship between the level of deprivation and the overall rate of neurological deaths in the population. However it is acknowledged that there is a significant difference in rates of deaths between the most deprived and least deprived areas in England.

Box 2: A socioeconomic condition such as poverty is one of the determinants of health. The analysis in this section is based on the Index of Multiple Deprivation (IMD) 2010 and investigates the relationship between neurological conditions and deprivation, and how it differs between conditions.

Figure 9 illustrates the age standardised mortality rates for deaths associated with individual condition groups. For all condition groups except epilepsy, there is no significant pattern in the relationship with deprivation. However for deaths associated with epilepsy there is a significant pattern in the relationship, with the rate of deaths in the most deprived areas being nearly three-times larger than in the least deprived areas in England, 13 deaths per 100,000 population verses 5 deaths per 100,000. Furthermore the mortality rates in the three most deprived areas are significantly higher than those with lesser deprivation.

Figure 9: Age standardised rates for neurological conditions by deciles of deprivation, persons aged 20 and over, England, 2012-2014



1.5. What are people with neurological conditions dying of?

1.5.1. Underlying cause of death

In the period 2012 to 2014 there were 91,685[f] deaths associated with a neurological condition. In 50% of these deaths the underlying cause was recorded as one of the 473 ICD-10 codes used in the study as the definition of adult neurological conditions.

Box 3: Underlying cause of death (UCOD) defined as:
i) The disease or injury that initiated the train of events directly linked to death; or
ii) The circumstances of the accident or violence that produced the fatal injury.

Parkinson's disease was the most common individual condition recorded on the death certificates as the underlying cause of death accounting for 14% of all deaths associated with neurological conditions. Brain cancers accounted 11% of deaths, spinal muscular atrophy 6% of deaths, multiple sclerosis 4%, epilepsy 3% and other degenerative diseases of nervous system not elsewhere classified accounted for 4% of all deaths associated with neurological conditions. Illustrated in Figure 10.

The largest non-neurological underlying causes of death recorded for the cohort includes falls (6%), malignant neoplasm of bronchus and lung (4%), pneumonia - organism unspecified (3%) and stroke - not specified as haemorrhage or infarction (3%). Further detail is included in Figure 100.

The underlying cause of death associated with all neurological conditions varied considerably from those of all-cause deaths as illustrated in Figure 10. In addition to more neurological condition related deaths, there were also smaller proportions related to chronic ischaemic heart disease including acute myocardial infarction (4% versus 13%), Alzheimer's disease and the dementias (3% versus 8%), other COPD[g] (1% versus 5%), malignant neoplasm of bronchus and lung (4% versus 6%) and pneumonia (3% versus 5%). However, a similar proportion of deaths were reported in both groups for strokes (3%).

[f] Number of neurological deaths in 2012 (29,248), 2013 (30,512), 2014 (31,925).
[g] COPD - Chronic obstructive pulmonary disease

Figure 10: Individual conditions recorded as the underlying cause of death (top 30 causes) – proportions with association with neurological condition, persons aged 20 and over, England, 2012-2014

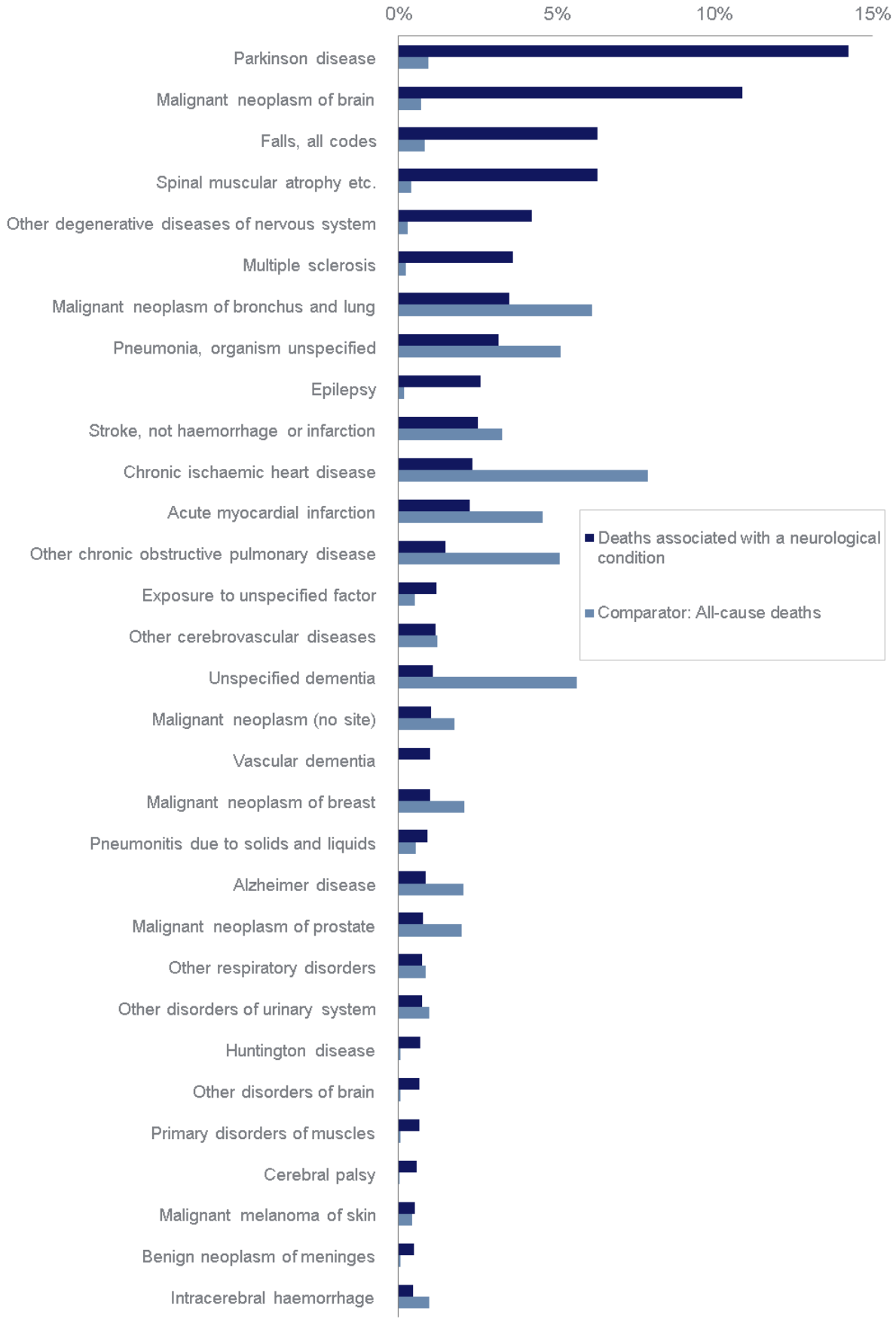


Figure 11 is a bubble chart illustrating the relative proportion of underlying cause of death for each neurological condition group by chapters of the International Classification Disease (ICD-10) for the deaths of people aged 20 and over between 2012 and 2014, with comparators of all neurological conditions and all-cause deaths. The size of the bubble represents the relative proportion of deaths for each chapter by condition group.

For all-causes of death the most common UCOD was recorded as cancer in 29% of cases, followed by CHD[h], Stroke and other (28%) and respiratory diseases (14%). Diseases of the nervous system[i] category was the 6th most common UCOD with 3% of deaths.

However, for deaths associated with neurological conditions, the top UCOD groups were diseases of the nervous system with 37% of deaths, followed by cancer (22%- of which 13 percentage points were tumours of the nervous system) , CHD, stroke and other diseases of the circulatory system (12%) and respiratory diseases (7%).

Differences can be noted for different neurological condition groups as illustrated in Figure 11. Most neurological conditions show diseases of the nervous system as the most common UCOD (for example 91% of deaths associated with MNDSMA[j]). However cancers (94%) are the predominant UCOD among deaths associated with tumours of the nervous system and falls were commonly associated with traumatic brain and spine injuries (69% of TBSI deaths).

Deaths associated with epilepsy had the highest recorded UCOD of CHD, stroke and other diseases of the circulatory system (26%) and dementia and Alzheimer's (13%). These were higher percentages in comparison to deaths associated with all neurological conditions.

Musculoskeletal system and connective tissue was the second most common UCOD in deaths associated with neuromuscular diseases (16%), followed by CHD, stroke and other diseases of the circulatory system (14%) and respiratory diseases (10%). Deaths associated with POED/TD had a similar level of respiratory diseases recorded as an UCOD in comparison to all-cause deaths (14%).

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[h] CHD **–** Coronary heart disease

[i] ICD-10 Chapter 6 – Diseases of the nervous system (G00 – G99) broadly represents the neurological conditions defined in this report excluding tumours of the nervous system (C70, C71, C72, C79.3, D32 , D33)

[j] Motor Neurone disease and spinal muscular atrophy (MNDSMA)
Parkinsonism and other extrapyramidal disorders/tic disorder (POED/TD)
Traumatic brain and spine injury (TBSI)

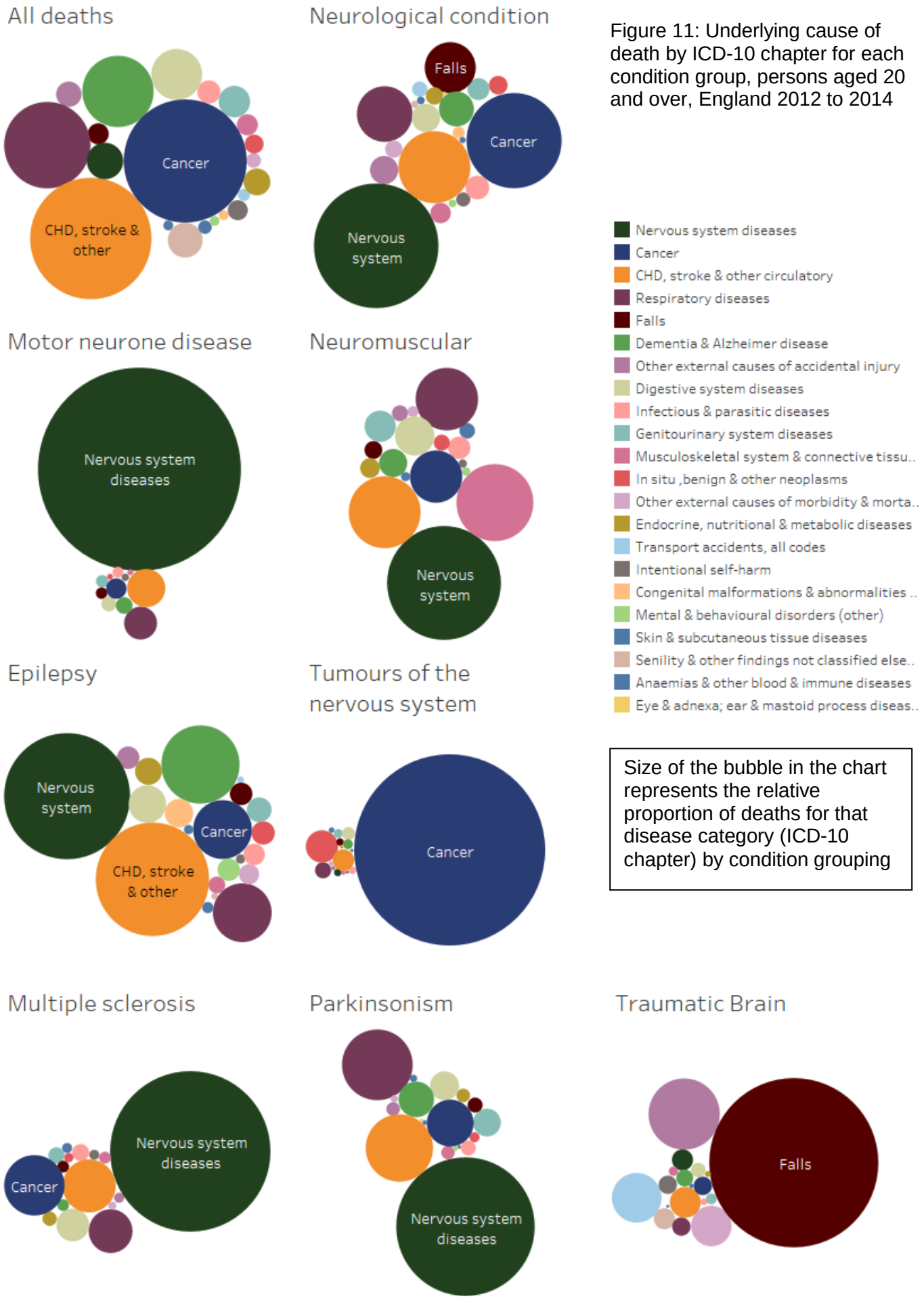


Figure 11: Underlying cause of death by ICD-10 chapter for each condition group, persons aged 20 and over, England 2012 to 2014

1.5.2. Deaths associated with the broad disease groups and falls

This section of analysis investigates the wider condition codes recorded on the death certificate along with the neurological condition[k]. The aim is to provide insight into the level of comorbidity and complexity of needs[l] that exists for individuals with a neurological condition and are illustrated in Figure 12.

Box 4a: Up to fifteen contributory cause of death codes can be recorded along with the underlying cause on a death certificate.

The broad disease groups considered were respiratory diseases, circulatory diseases and malignant cancers. These groups account for 35%, 47% and 32% of all-cause deaths respectively aged 20+ in England during the period 2012 to 2014[m]. A death where there was a mention of a fall has been included because it was one of the highest ranked causes of death for people with a mention of neurological conditions.

1.5.2.1. Respiratory diseases

Between 2012 and 2014, 34,846 people aged 20 and over died with a mention of both neurological condition and a respiratory disease. This represented 38% of people aged 20 and over who died with a mention of neurological conditions.

Box 4b: Respiratory diseases occupy codes J00 to J99 in the ICD-10 coding system. Major causes of death within this broad category include influenza (J10–J11), pneumonia (J12–J18) and chronic lower respiratory diseases (J40–J47).

The age and gender profile for those dying with neurological conditions and respiratory disease was similar to that observed for neurological conditions overall. A higher proportion of males had a mention of both neurological conditions and respiratory disease (41%) compared to 35% of females. For all deaths of people aged 20 and over with a mention of respiratory disease 7% also had a mention of neurological conditions.

1.5.2.2. Circulatory diseases

30,138 people aged 20 and over who died with a dual mention of a neurological condition and a circulatory disease. This accounted for 33% of people aged 20 and over who died with a mention of neurological conditions.

Box 4c: Circulatory diseases occupy codes I00 to I99 in the ICD-10 coding system, and include some of the most common causes of death, including ischaemic heart diseases (I20–I25) and cerebrovascular diseases (I60–I69).

[k] A mention of a neurological condition and a mention of the three broad disease groups and falls.
[l] The broad groups are not mutually exclusive, i.e. one person could have more than one of these conditions alongside their neurological condition(s).
[m] Sum of the disease group proportions will exceed 100% due to one or more of the broad conditions being recorded on the death certificate.

There are age and gender profile similarities between those people who died with a recorded neurological condition and circulatory diseases and for neurological conditions overall. A higher proportion of males had a mention of both neurological conditions and a circulatory disease 34% compared to 32% of females. For all deaths of people aged 20 and over with a mention of circulatory diseases, 5% also had a mention of neurological conditions.

Figure 12: Broad diseases group deaths – proportions with an association with neurological condition; persons aged 20 and over, England, 2012 to 2014

1.5.2.3. Malignant cancers

There were 22,987 deaths in the period where a dual mention of neurological condition and malignant cancer was recorded. This accounted for 25% of all people aged 20 and over who died with a mention of neurological conditions.

Box 4d: Malignant cancers occupy codes C00 to C97 in the ICD-10 coding system. Major causes of death within this broad category include lung cancer (C33–C34), colorectal cancer (C18–C21), breast cancer (C50) and prostate cancer (C61).

The age and gender profile similarities between those dying with neurological conditions and malignant cancer and those dying with neurological conditions overall were also observed here. A higher proportion of men had a mention of both neurological conditions and malignant cancer (26%) compared to 24% of women. For all-cause deaths of people aged 20 and over with a mention of malignant cancer 5% also had a mention of neurological conditions.

1.5.2.4. Falls

Between 2012 and 2014, 6,222 people aged 20 and over died with a mention of a neurological condition and a mention of a fall. Accounting for 7% of all people aged 20 and over who died with a mention of neurological conditions.

Box 4e: Falls occupy codes W00 to W19 in the ICD-10 coding system.

The age and gender profile for those dying with neurological conditions and falls were similar to one another (Figure 12). 7% of males and 7% of females had a mention of both neurological conditions and falls. For the 14,326 all-cause deaths of people aged 20 and over with a mention of falls, 43% also had a mention of neurological conditions.

Charts for the individual neurological conditions and broad disease groups can be found in Appendix 3. The condition with the largest association with falls is that of TBSI[n] where between 2012 and 2014, 5,793 people aged 20 years and over died with a mention of these two groups of conditions. This represents 93% of all neurological condition deaths with a fall in the age group and 73% of those with a mention of TBSI. The age and gender profile for those dying with TBSI and falls was similar to that observed for TBSI overall (Appendix 3f). A higher proportion of men had a mention of both TBSI and falls (54%) compared to 46% of women. For all neurological conditions deaths of people aged 20 and over with a mention of falls 6% also had a mention of TBSI.

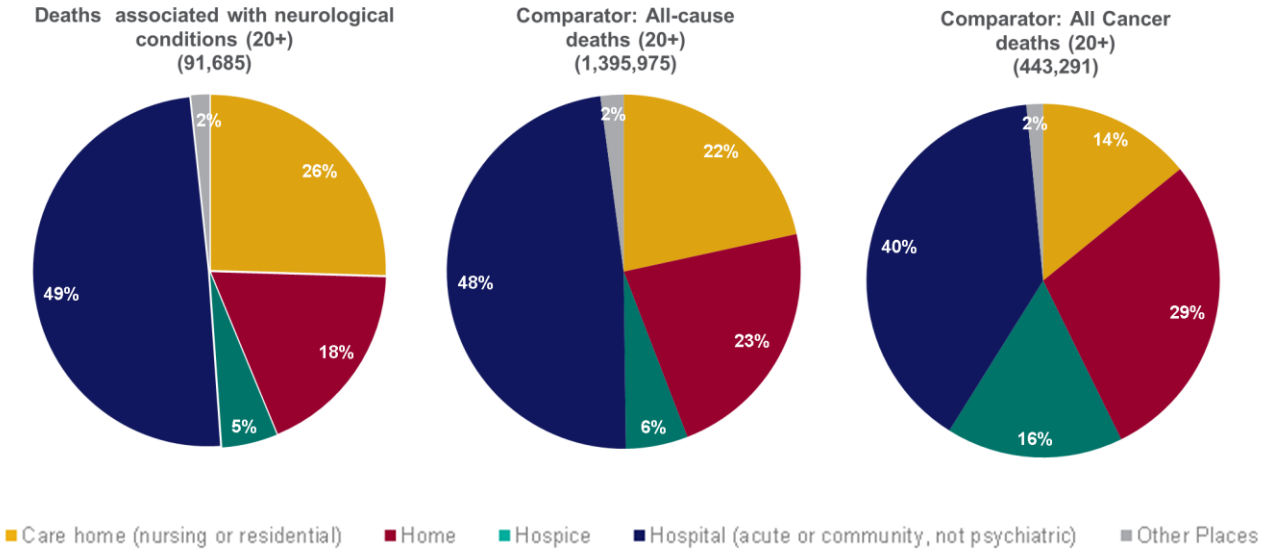
[n] Traumatic brain and spine injury (TBSI)

1.6. Where do people with neurological conditions die?

This section examines the location of death of those people with a mention of a neurological condition on their death certificate. The locations are categorised as – at home, in a hospice, in hospital, in a nursing/residential care home or in another place.

The largest proportion of deaths with a mention of a neurological condition occurred in a hospital environment (acute or community, not psychiatric) where 49% of the cohort deaths occurred. Around 26% of deaths occurred in a care home (nursing or residential), 18% occurred at home, 5% in a hospice and 2% in another place. This is illustrated in Figure 13 along with the proportions for all-cause deaths and cancer deaths (including tumours of the nervous system).

Figure 13: Place of death – proportions with an association with neurological condition, cancer and all-cause deaths; persons aged 20 and over, England, 2012 to 2014



In comparison to the location of all-cause deaths, similar proportions of neurological related deaths occurred in hospital (49% verses 48%), hospices (5% verses 6%) and other locations (2% verses 2%), although a larger proportion died in care homes (26% verses 22%) and a smaller proportion died at home (18% verses 23%). The larger proportion of neurological deaths occurring in care homes may reflect the residential status of older people with such conditions as Parkinsonism, where the care home may be their permanent place of residence.

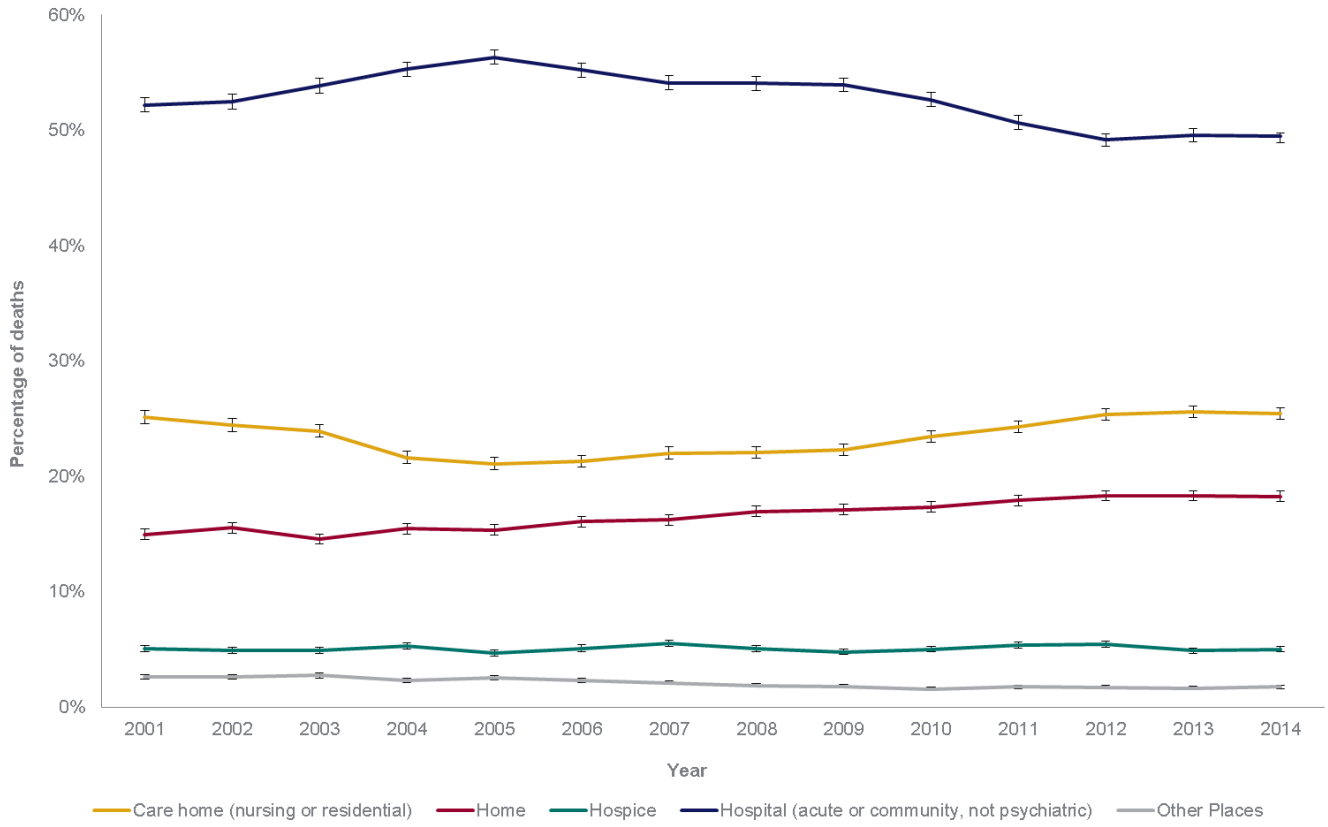
The common perception that people with terminal cancer are able to access palliative care appears to be reflected in the location that cancer deaths occur. In comparison to cancer related deaths, only one-third of neurological condition related deaths occurred in hospices (5% versus 16%) and two-thirds at home (18% versus 29%). A greater proportion of neurological condition related deaths occurred in hospital (49% versus 40%) and care homes (26% versus 22%).

The proportion of deaths for people with a neurological condition occurring in hospital in 2014 was significantly lower than in 2001, a reduction from 52% to 49% (Figure 14). The proportion peaked in 2005 at 56% and has steadily declined to 49% in 2012 and since remained stable.

The proportion of care homes deaths for people with a mention of neurological conditions varied somewhat over the period between 2001 and 2014, with the smallest proportion occurring in 2009 (22%). However, by 2014, the proportion of deaths occurring in care homes was the same as in 2001 (25%).

By 2014, a greater proportion of deaths associated with neurological condition were recorded as deaths at home. The trend in the proportion of these deaths has been increasing since 2001, with the proportion in 2014 being statistically higher than in 2009.

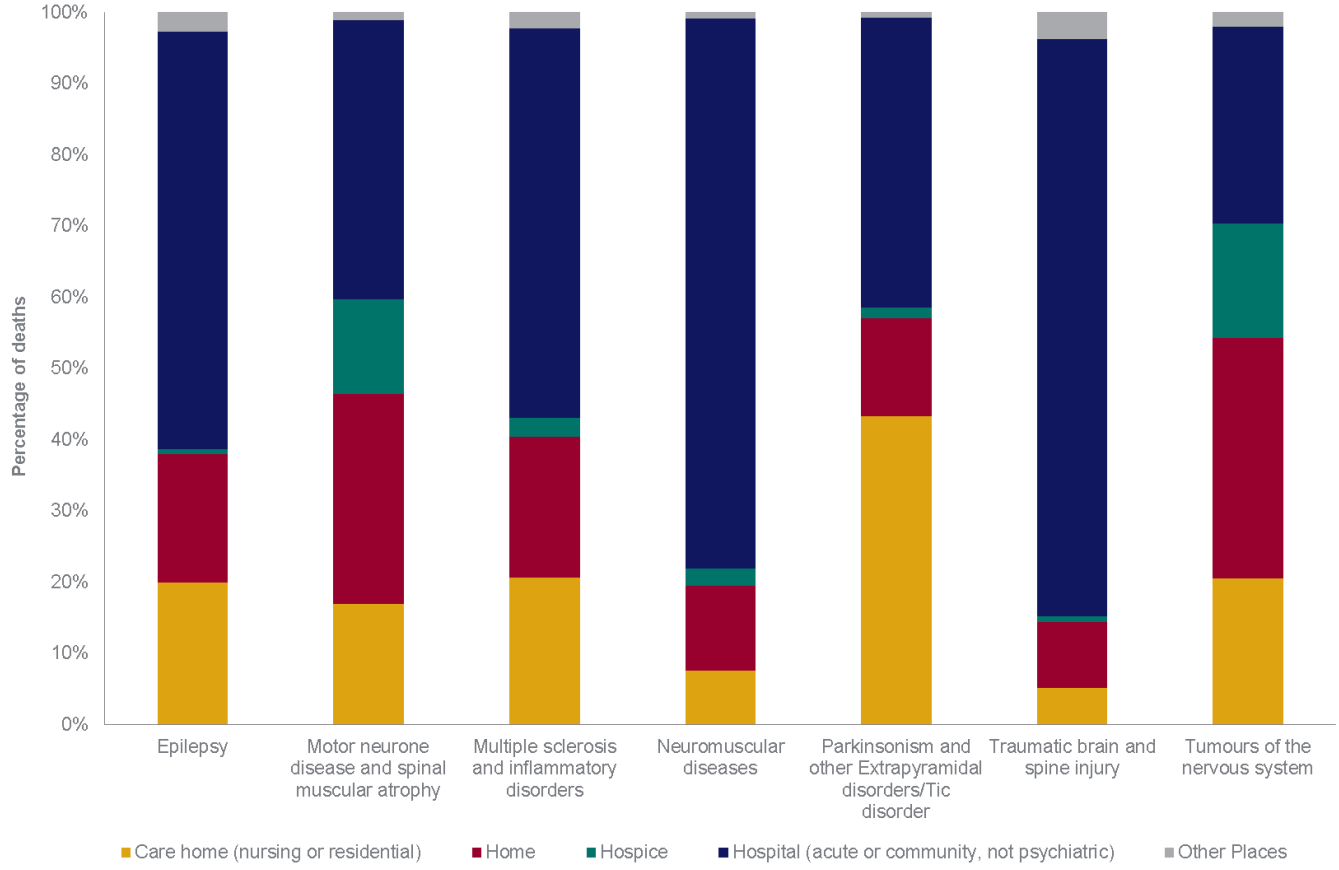
Figure 14: Place of death – deaths associated with neurological condition; persons aged 20 and over, England, 2001 to 2014



The distribution of the place of death varies between different neurological conditions groups as illustrated in Figure 15. Higher proportions of deaths with a mention of neuromuscular diseases and TBSI[o] occurred in hospitals (acute or community, not psychiatric), with 77% and 81% respectively.

The majority of deaths with a mention of POED/TD occurred in care homes (nursing or residential) 43% followed by 41% in hospital (acute or community, not psychiatric).

Figure 15: Place of death – deaths associated with specific neurological conditions; persons aged 20 and over, England, 2012-2014



[o] Parkinsonism and other extrapyramidal disorders/tic disorder (POED/TD)
Traumatic brain and spine injury (TBSI)

Appendices

List of appendices:

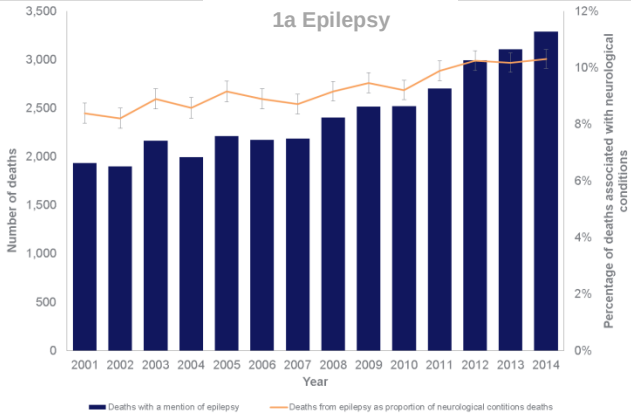
Appendix 1: Deaths by specific neurological conditions, England 2001-14, 20+

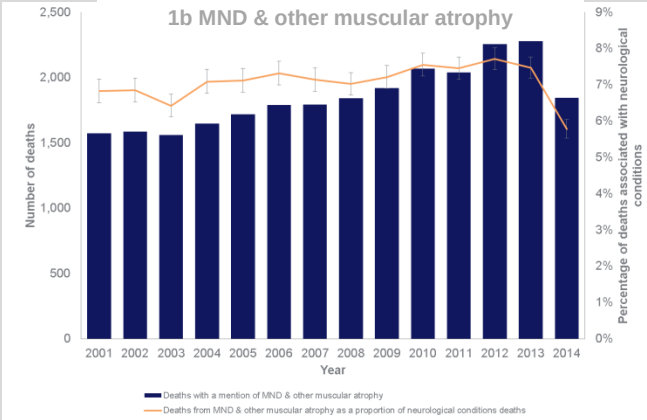
Time trends of both mortality rates and number of deaths by neurological condition groups relevant to section 1.2

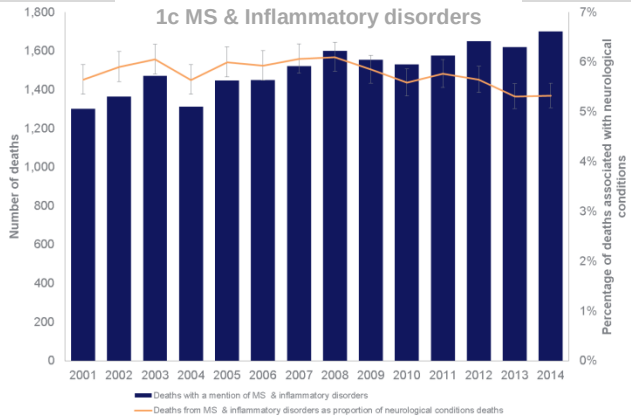
Legend:

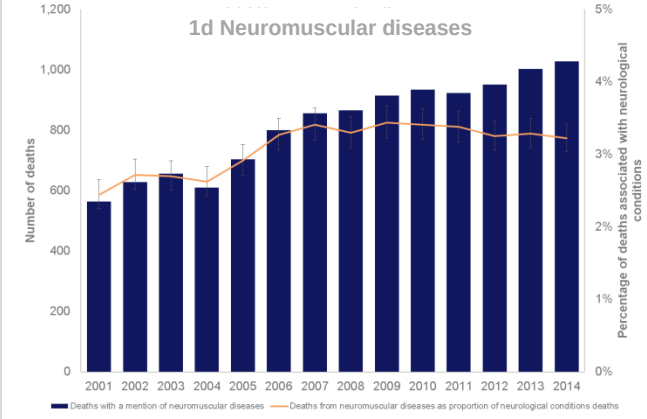
Deaths associated with a neurological condition

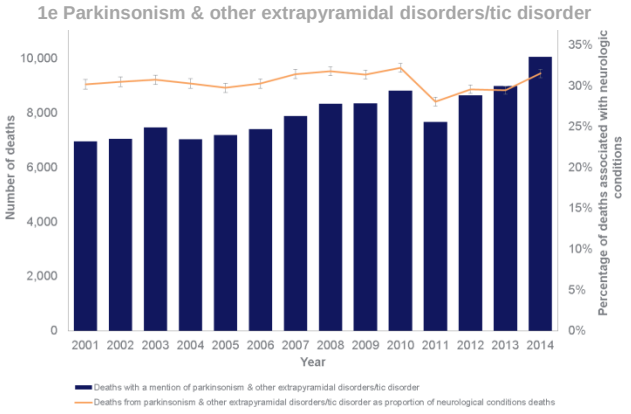
Proportion of all neurological conditions

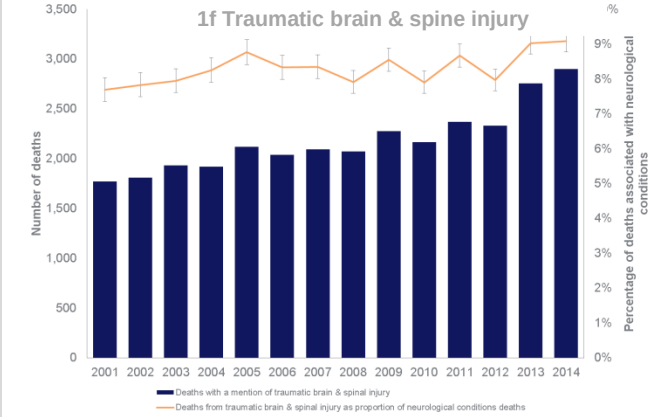


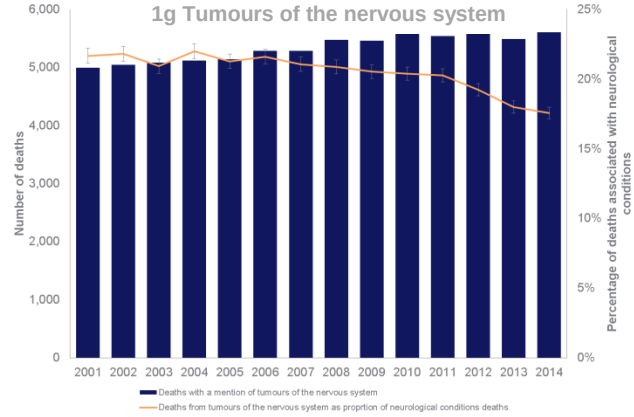












Appendix 2: Age and gender by condition groups

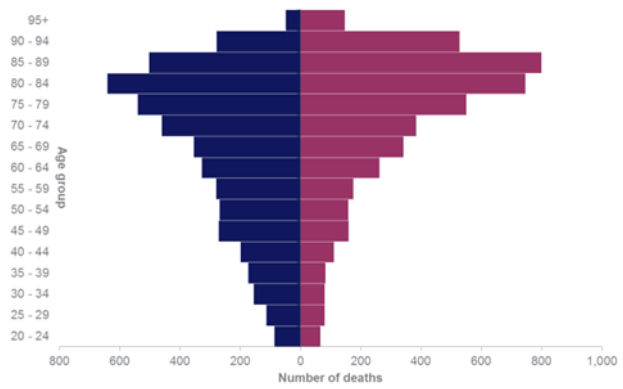
Age and gender breakdown charts for individual neurological condition groups, in reference to section 1.3.

Legend:

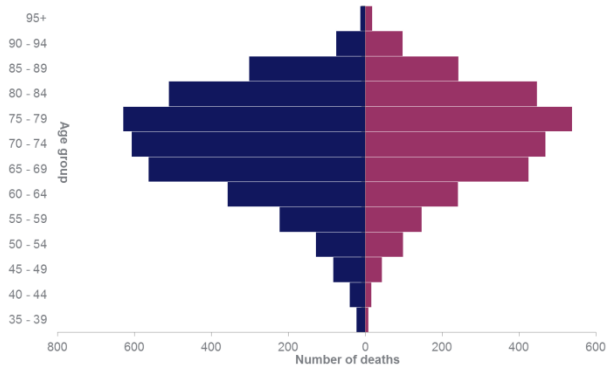
Men (deaths associated with all neurological conditions)

Women (deaths associated with all neurological conditions)

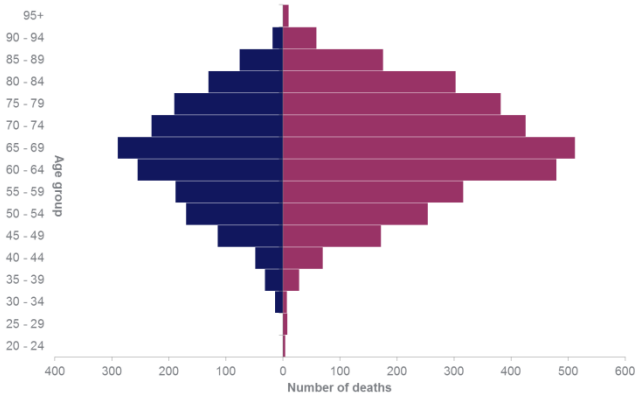
2a Epilepsy



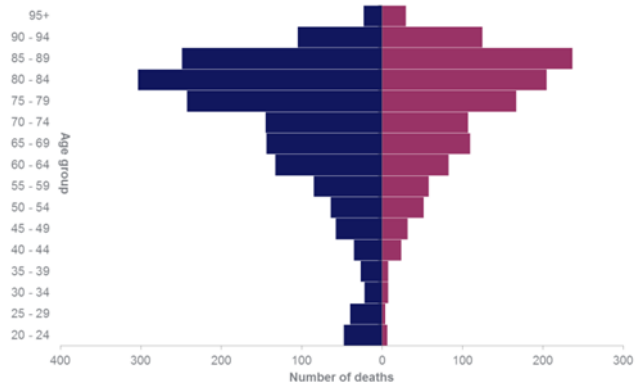
2b MND & other muscular atrophy



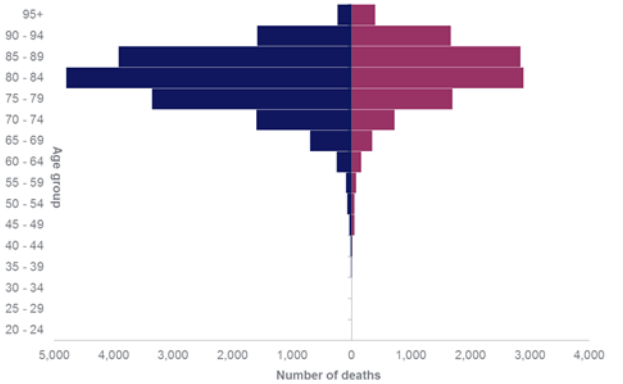
2c MS & Inflammatory disorders



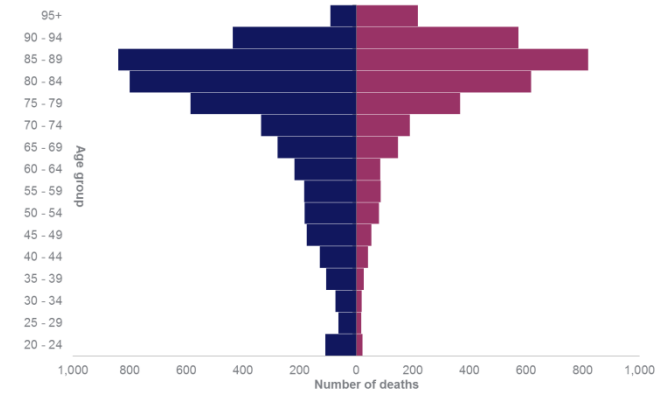
2d Neuromuscular diseases



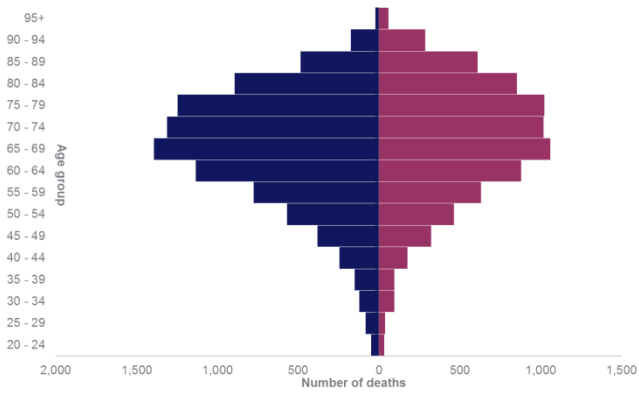
2e Parkinsonism & other extrapyramidal disorders/tic disorder



2f Traumatic brain & spine injury



2g Tumours of the nervous system



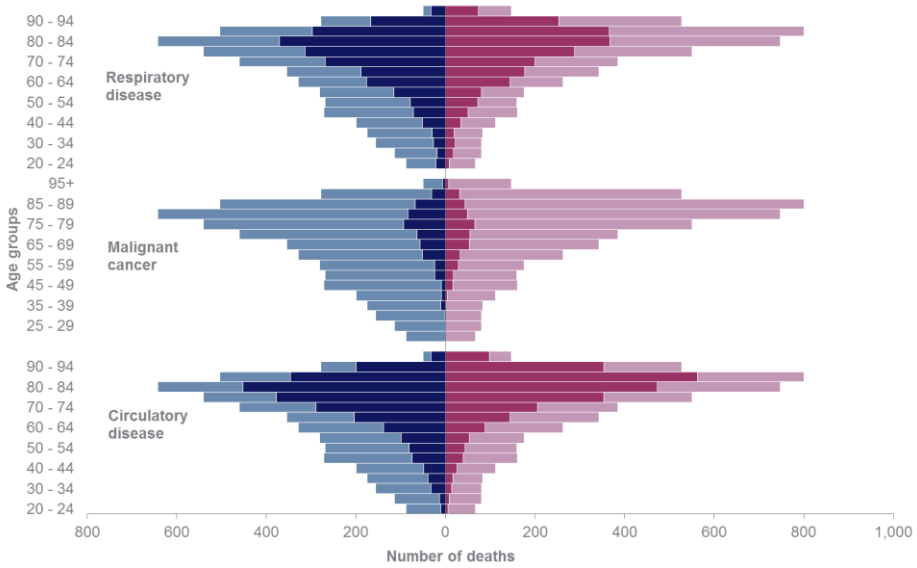
Appendix 3: Proportion of deaths associated with broad disease groups

Broad diseases group deaths – proportions od deaths associated with neurological condition; persons aged 20 and over, England, 2012-2014

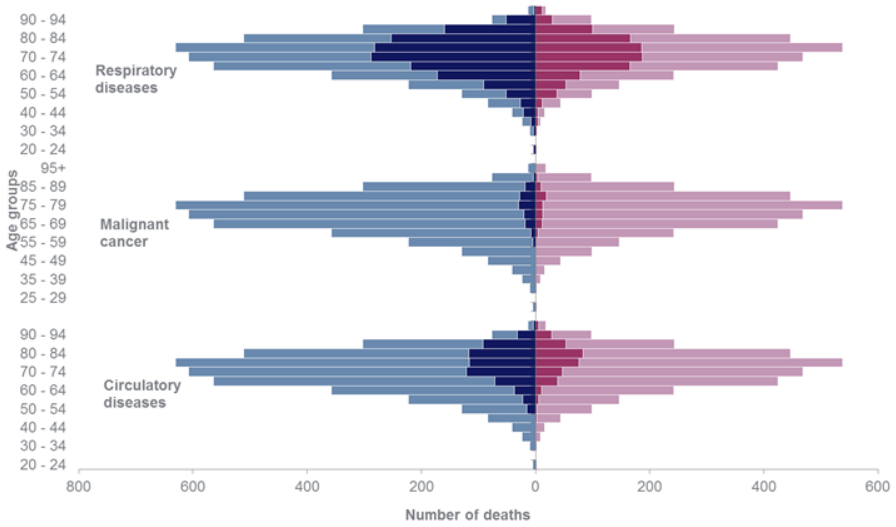
Legend:

- Men (deaths associated with neurological conditions and other condition)
- Men (deaths associated with all neurological conditions)
- Women (deaths associated with neurological conditions and other condition)
- Women (deaths associated with all neurological conditions)

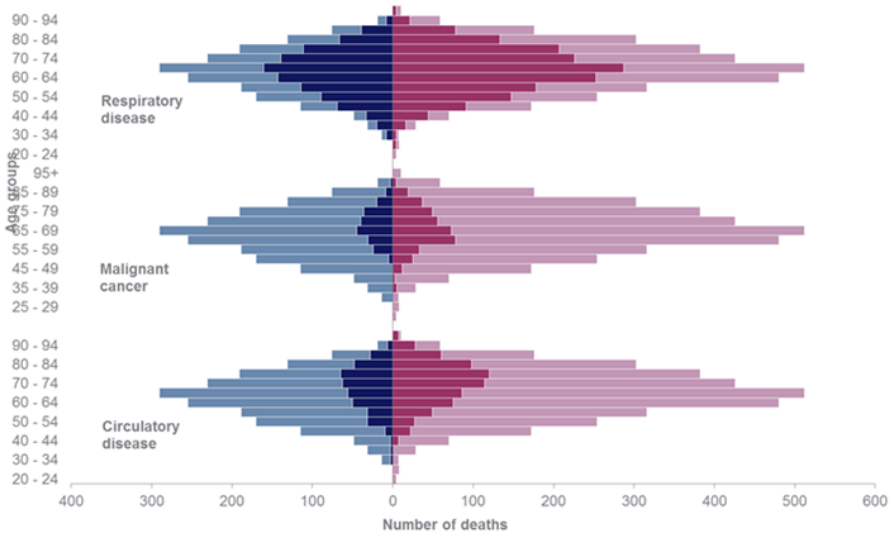
3a Epilepsy and another condition



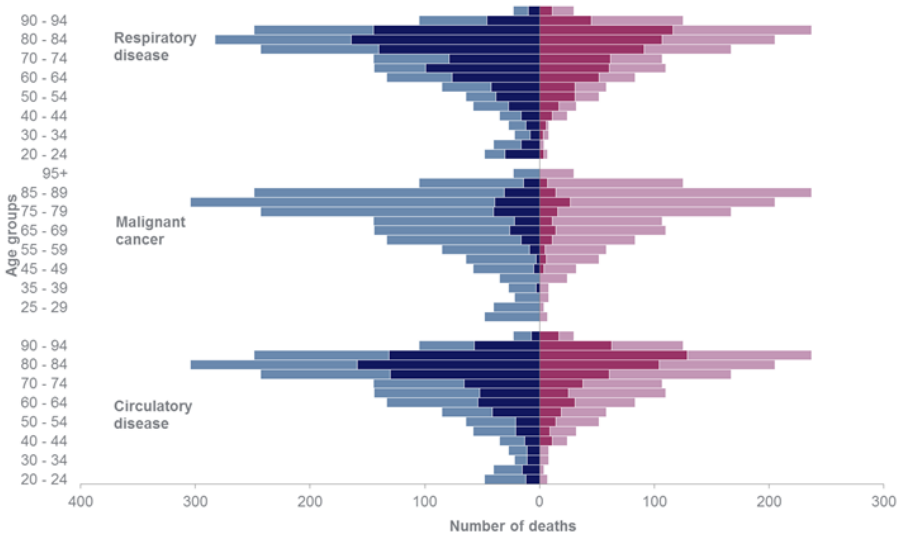
3b MND & spinal muscular atrophy and another condition



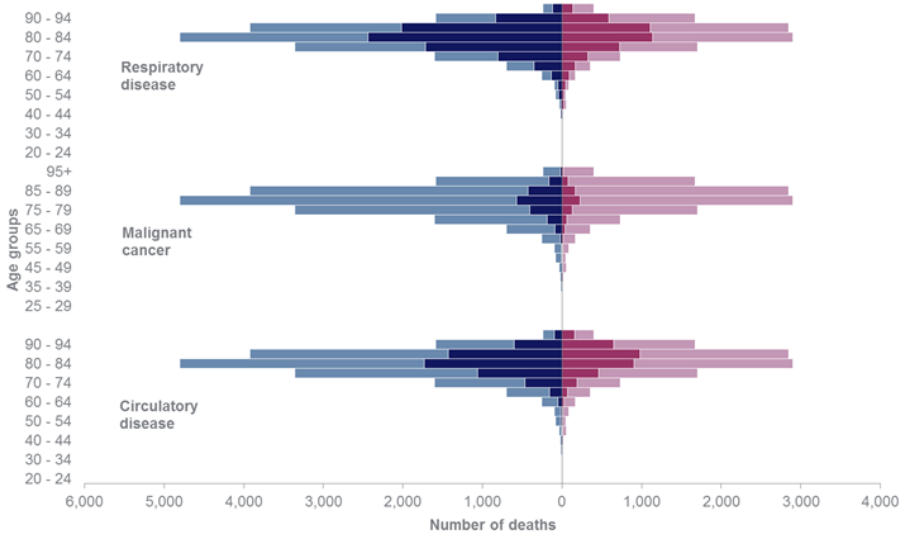
3c MS & inflammatory disorders and another condition



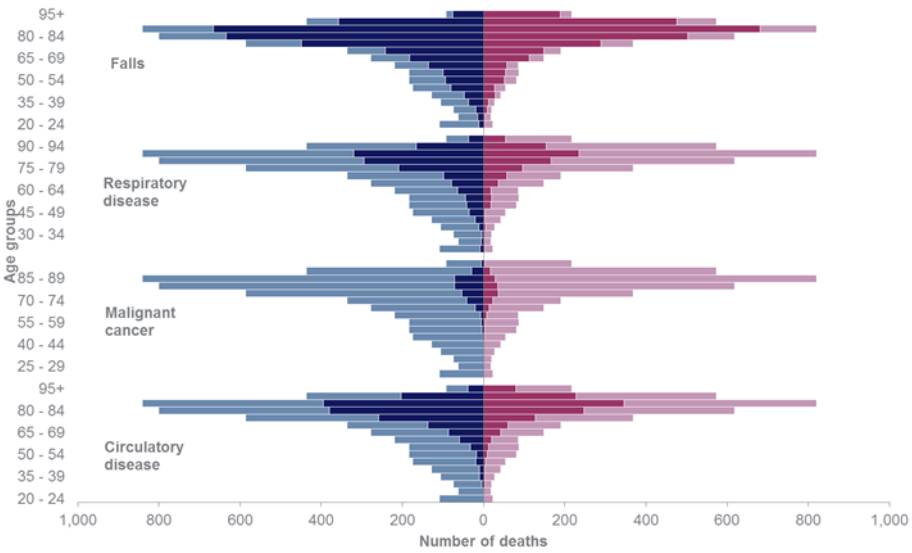
3d Neuromuscular diseases & another condition



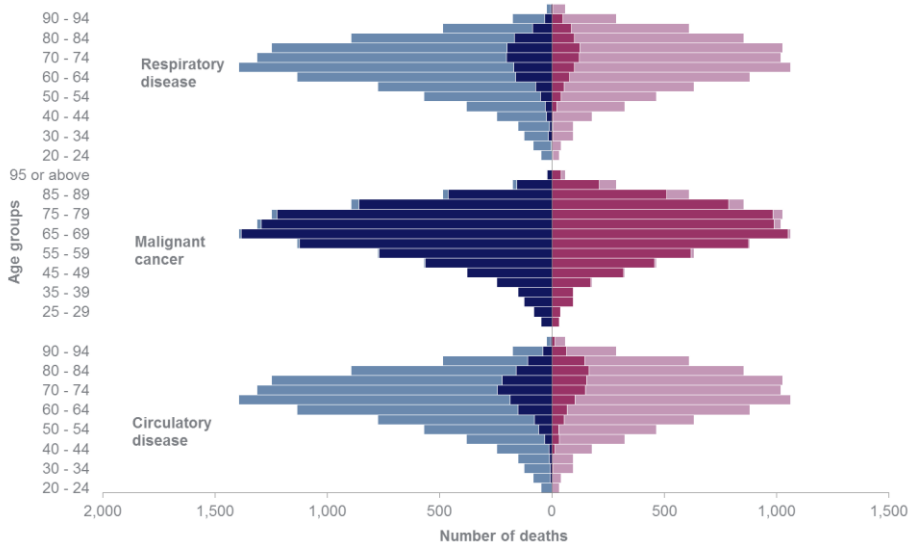
3e Parkinsonism & other extrapyramidal disorders/tic disorder and another condition



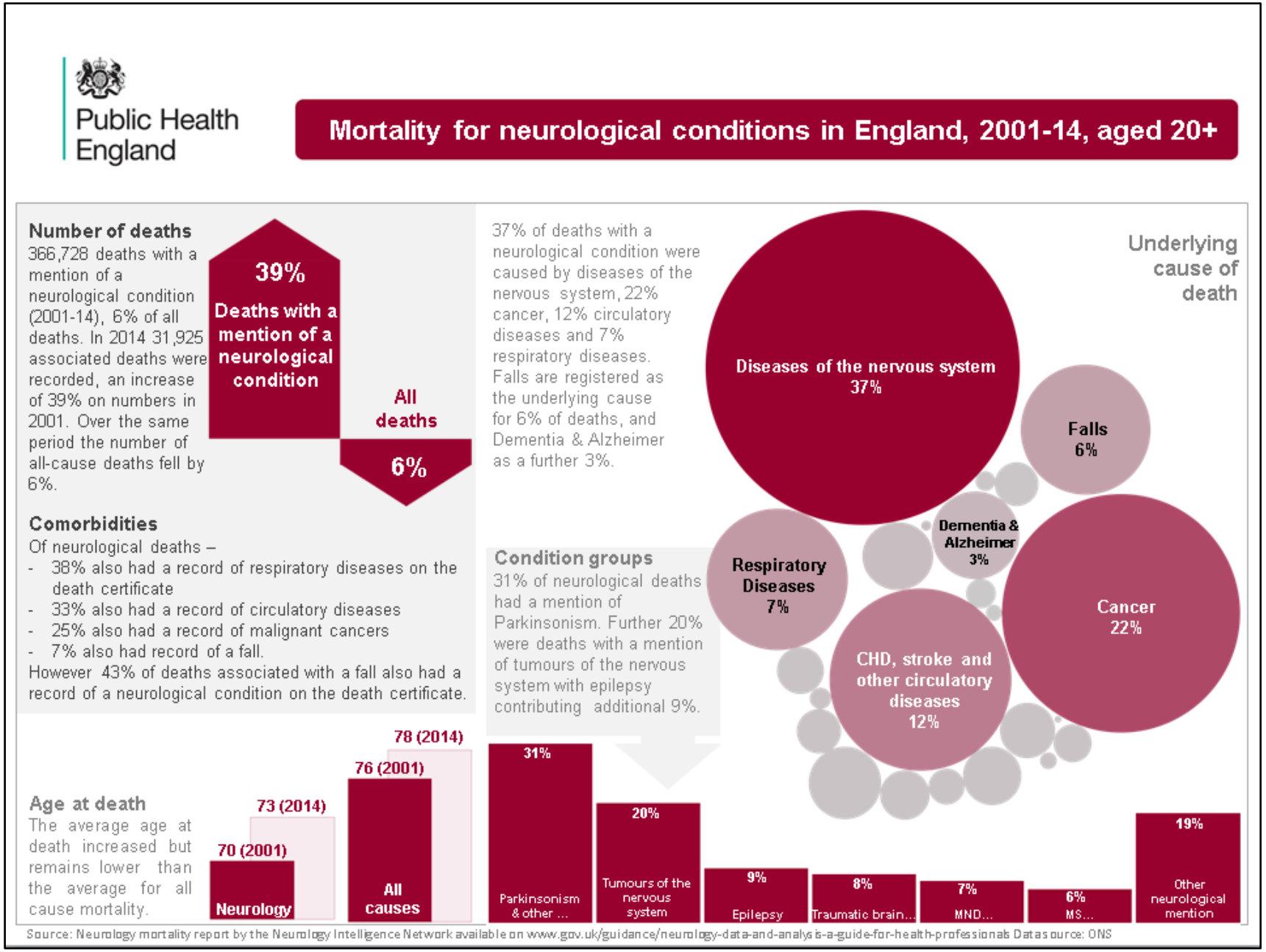
3f Traumatic brain & spine injury and another condition



3g Tumours of the nervous system and another condition



Appendix 4: Visual summary of key facts



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