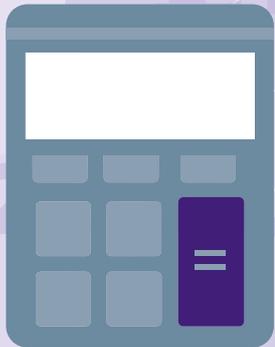




THE
NEUROLOGICAL
ALLIANCE



NEURO NUMBERS 2019

Foreword

Translating data into improved outcomes for people with neurological conditions

The importance of data

Without good data it is difficult to know whether services and treatments are leading to improved outcomes. Or the extent to which the care system is meeting the needs of patients. Over the last ten years we have seen the importance of data and intelligence in supporting rapid advances in cancer and stroke care. Data is also



1 in 6
people have a
neurological condition

important for holding the system to account and incentivising improvement. It is perhaps unsurprising that neurology is barely mentioned in the NHS performance architecture, given there are so few national data sets on which to base national indicators. In policy and campaigning terms, data provides evidence with which to influence change. During the development of the NHS Long Term Plan there was a very clear message from NHS England that if the benefits of a proposal could not be evidenced, it would not be included. It is for all these reasons that The Neurological Alliance has long campaigned for more and better data in neurology, which until recent years, has been virtually non-existent.

Given our interest in neurological data, we have also developed our own datasets, such as the neurology patient experience survey. We regularly publish intelligence highlighting our own and externally produced data findings, and what these findings mean for people with neurological

conditions. Here, in *Neuro Numbers 2019* we publish new data on current neurological prevalence estimates. We reveal there are now an estimated 16.5 million neurological cases, equating to at least 1 in 6 people living with one or more neurological condition(s). We cannot make direct comparisons with 2014 data, the last time we published *Neuro Numbers* (see 'About *Neuro Numbers*' below for more detail). Yet, we know that because of an ageing population, improvements in diagnosis and advances in neo-natal care, neurological prevalence is rising and set to continue to rise. The latest prevalence data is presented here alongside the most recent published national data relating to people with neurological conditions. The national data for people with neurological conditions includes how much money the NHS spends, use of hospital services and data about deaths.

What data is missing?

Most of the care for people with neurological conditions takes place in outpatient neurology clinics or in the community. Yet with existing datasets it is not possible to know what condition an individual attending a neurology appointment has, nor whether the appointment was relating to diagnosis or ongoing management of a condition. There is also no nationally collected dataset about patient outcomes with which to assess the effectiveness of care. Another huge gap is the lack of data about social care for people with neurological conditions. There has also not been any quantification of support from the voluntary sector. This means current estimates of the level of spending on neurological conditions

Foreword (continued)

– £4.4 billion – is only part of the picture. It is also noteworthy that the national spend data included in this publication – the only data publicly available – is several years out of date.

For many of the rarer neurological conditions – which we estimate represent over 150,000 neurological cases – there is little or no data collected at all, meaning this group of patients is virtually invisible to the health system. The other hidden group are people with neurological symptoms, but no confirmed diagnosis.

Without all this additional information, it is hard to understand if £4.4 billion NHS spend (plus an unknown amount of social care spend) represents value for money, or whether it is translating into positive outcomes for the 1 in 6 people living with a neurological condition. Given the rising prevalence, surely it is time neurology was prioritised for improvement in terms of data collection, so the system can make evidence based decisions about care?

While more challenging to determine generic outcome measures than in specialities such as orthopaedics or cancer, it is possible to develop indicators on neurological patient outcomes. We have included in an annex to this publication a set of suggested neurological outcome measures, developed with our membership, and presented against the NHS outcomes framework. The lack of outpatient coding has been discussed by the neurological community for many years, and we are encouraged that the National Neuro Advisory Group has now identified this as a barrier to improvement and is scoping a project to address this. The Office for Statistics Regulation is currently reviewing social care data, which presents an opportunity to learn more about the social care needs of people with neurological conditions.

An improving picture?

Despite the number of needed improvements in neurology data collection, we are tentatively hopeful. Over the last five years we have seen the development of several new data initiatives for neurology. These include, the establishment of the Neurology Intelligence Network and the first national neurological data set, Right Care pathway development, and Getting it Right First Time (GIRFT) neurosurgery and neurology programmes. The Neurological Alliance has further developed the methodology for our own patient experience data collection. The Neurology Intelligence Collaborative, which we helped to set up in 2018, is supporting the coordination

“Surely it is time neurology was prioritised for improvement in terms of data collection, so the system can make evidence based decisions about care?”

of existing data projects and developing new projects to fill gaps in the data. In parallel, the merger of NHS England and NHS Improvement also presents an opportunity for further collaboration between NHS Right Care and GIRFT.

This year is set to be a landmark year for data and neurology as we look forward to the publication of the Neurology GIRFT report, the development of further neurological RightCare pathways, and updates to the RightCare neurology data packs. The Neurology Intelligence Network continues its programme to develop more accurate prevalence estimates

Foreword (continued)

for neurological conditions. The Neurology Intelligence Collaborative is developing plans to improve outpatient coding. We also anticipate our own patient experience survey data being richer than ever before, providing regional and Trust level data about patient experience.

Using data to drive improvement

Just as important however, is what happens after data is published. In 2018 we welcomed a new report by Public Health England about deaths associated with neurological conditions.

‘It is essential that the different parts of the system work together to address the issues being illuminated by the data.’

However, we have yet to see a concerted system-wide effort to tackle some of the stark findings of this report. We have included a few of the findings in this briefing but further work needs to be done to understand the story behind the data. This includes the number of people with neurological conditions whose deaths could have been avoided with better care and support. Given that by the end of 2019 we will have more data than ever before, it is essential that the different parts of the system work together to address the issues being illuminated by the data.

To this end, The Neurological Alliance is calling for data to be translated into real change for people with neurological conditions. This is in addition to our existing calls for more and better data, particularly in relation to rarer neurological conditions. Despite the efforts of RightCare, a recent freedom of information request found that only 37 out of 195 Clinical Commissioning Groups have submitted delivery plans that reference neurological conditions. As it stands, the NHS Long Term Plan is unlikely to do much to raise the profile of neurology among local decision makers, given the lack of pan-neurological priority in the Plan. We want to see national incentives for local and regional decision makers to tackle unwarranted variation in neurological care, based on the opportunities for improvement demonstrated by local-level data.

Over the coming years we look forward to working with our partners in The Neurology Intelligence Collaborative to address some of the shortcomings in the current data and to develop new data sources. We believe this is critical to underpinning improvement in services to deliver better outcomes for people with neurological conditions, as well as better value for money. We also call on both NHS England and regional and local decision makers to take heed of the new data emerging about neurological services, and to act now to give people with neurological conditions the care they need and deserve.

Sarah Vibert
Chief Executive
March 2019

National data



1,654,577

people were admitted with a **neurological mention (including non-emergency)** in 2016/17²

There has been a

24%

INCREASE

in admissions over the 5 years 2016/17²

The NHS spends over



£4.4bn

on **people with neurological conditions**¹



1,009,021

people were admitted as **emergencies with a neurological mention** in 2016/17³

There has been a

21%

INCREASE

in emergency admissions over the 5 years 2016/17³

¹ Department of Health, Programme budgeting data 2012/13, February 2014.

² Extract from inpatient data compendium, dementia and stroke are additional extracts from HES. Neurology Intelligence Network, Public Health England.

³ As above.

National data



12,736,365

bed days were recorded for patients with a neurological mention in 2016/17⁵

There has been an

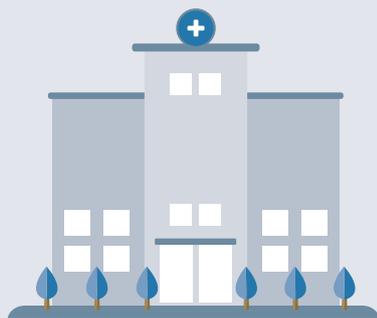


INCREASE

in bed days over the 5 years to 2016/17⁵



**9.78
DAYS**



was the **average length of stay** for people with neurological mention in 2016/17⁴

This compares to an average length of **stay of 7 days** for all patients⁶

There has been a



in **neurological deaths** during 2001–2014⁷

This compares to a



DECREASE in all cause deaths over the same period⁷

Deaths associated with a neurological condition were



more likely to be premature during 2001–2014⁷

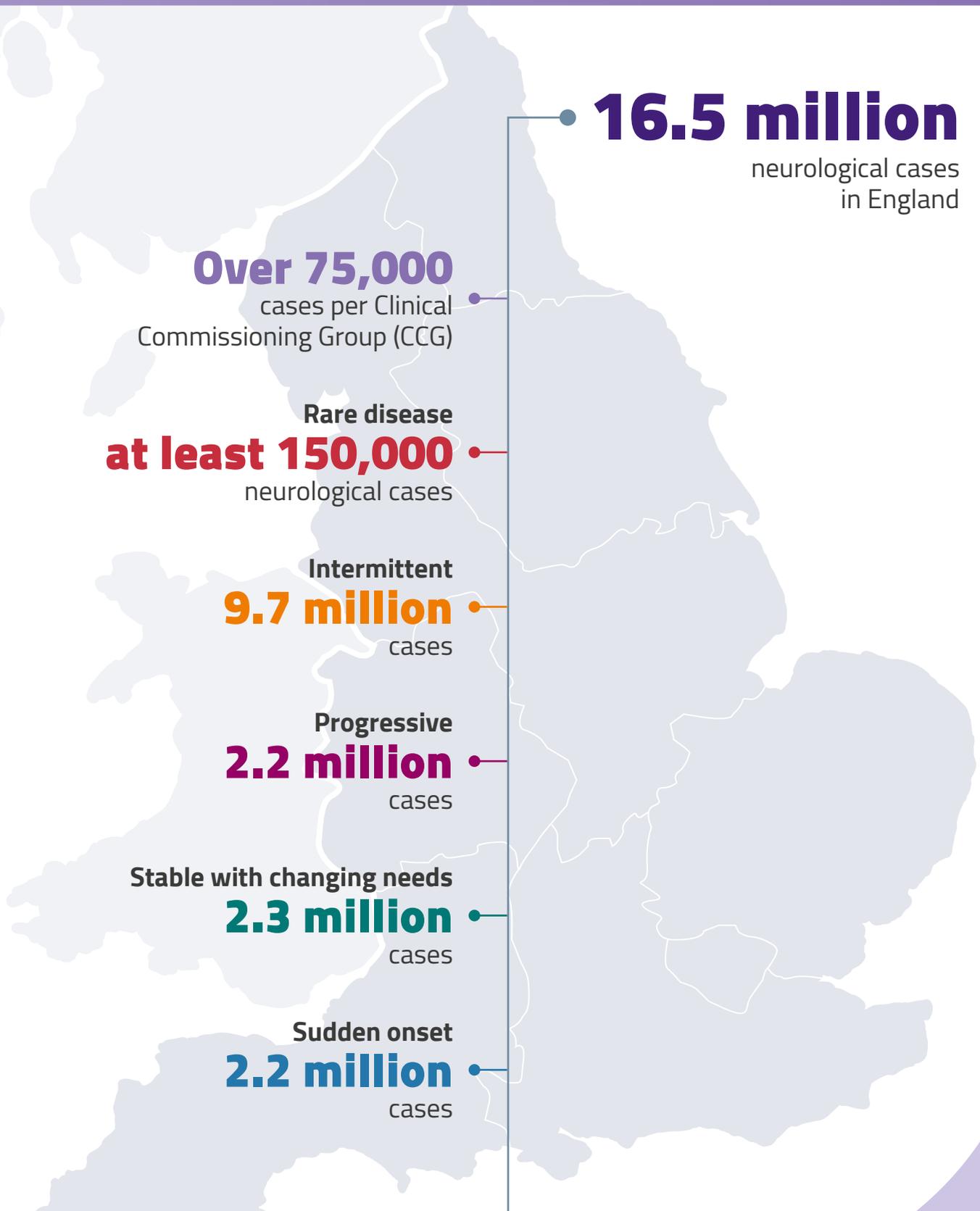
⁴ Extract from inpatient data compendium, dementia and stroke are additional extracts from HES. Neurology Intelligence Network, Public Health England.

⁵ Extract from inpatient data compendium, dementia and stroke are additional extracts from HES. Neurology Intelligence Network, Public Health England.

⁶ Length of UK inpatient stays 2015, NHS Confederation. www.nhsconfed.org/resources/key-statistics-on-the-nhs

⁷ Deaths associated with neurological conditions in England, 2001–2014, National Neurology Intelligence Network, National End of Life Care Intelligence Network.

Prevalence data



Figures based on estimations of condition prevalence using the references detailed in the accompanying data table overleaf. Where only UK prevalence figures were available a calculation has been made based on the Office for National Statistics estimation of UK and England populations, 'Overview of the UK population, November 2018'.

Prevalence and incidence of neurological conditions

Condition	Categorisation	Prevalence (England)	Reference	Incidence (England unless otherwise stated)
Acoustic neuroma	Progressive	27,800	British Acoustic Neuroma Association www.bana-uk.com	
Ataxia	Progressive	8,600	Ataxia UK www.ataxia.org.uk	
Autism	Stable with changing needs	580,000	Autistica www.autistica.org.uk	
Batten disease	Progressive	105	Batten Disease Family Association www.bdfa-uk.org.uk	
Brain, CNS and other intracranial tumours	Progressive	85,927	The Brain Tumour Charity www.thebraintumourcharity.org	7,810
Carpal tunnel syndrome	Progressive	Not known		
Cavernoma	Intermittent	90,000	Cavernoma Alliance UK www.cavernoma.org.uk	335 (symptomatic)
Cerebral palsy	Stable with changing needs	25,273	Scope www.scope.org.uk	1,800
Charcot-Marie-Tooth disease	Progressive	19,376	Charcot-Marie-Tooth UK www.cmt.org.uk	
Chronic fatigue syndrome (ME)	Stable with changing needs	210,606	Action for M.E. www.actionforme.org.uk	
Chronic inflammatory demyelinating polyneuropathy	Progressive	3,329	Guillain-Barre and Associated Inflammatory Neuropathies gaincharity.org.uk	600
Cluster headache	Intermittent	111,200	Organisation for the Understanding of Cluster Headache (OUCH UK) ouchuk.org	
Dementia (includes Alzheimer's)	Progressive	759,000	Alzheimer's Research UK www.alzheimersresearchuk.org	180,000
Dystonia	Progressive	58,970	The Dystonia Society www.dystonia.org.uk	
Encephalitis	Sudden onset	–	Encephalitis Society www.encephalitis.info	5,000
Epilepsy	Intermittent	526,000	Epilepsy Action www.epilepsy.org.uk Epilepsy Research UK www.epilepsyresearch.org.uk SUDEP Action sudep.org The Daisy Garland www.thedaisygarland.org.uk	32,000

Prevalence and incidence of neurological conditions (continued)

Condition	Categorisation	Prevalence (England)	Reference	Incidence (England unless otherwise stated)
Essential tremor	Progressive	842,424	National Tremor Foundation www.tremor.org.uk	
Fibromyalgia	Stable with changing needs	1,167,600	Versus Arthritis www.versusarthritis.org	
Functional neurological disorder	Intermittent	Not known	FND Action www.fndaction.org.uk FND Hope fndhope.org	
Guillain-Barre syndrome	Sudden onset		Guillain-Barre and Associated Inflammatory Neuropathies gaincharity.org.uk	1,200
Hemiplegia	Stable with changing needs	55,600	Hemihelp www.hemihelp.org.uk	
Huntington's disease	Progressive	6,739	Huntington's Disease Association www.hda.org.uk	
Hydrocephalus (congenital)			Shine Charity www.shinecharity.org.uk	1 per 1,000 live births
Idiopathic intracranial hypertension	Sudden onset	6,060	IIH UK www.iih.org.uk	23,182
Meningitis	Sudden onset		Meningitis Research Foundation www.meningitis.org	2,148
Migraine	Intermittent	7,945,633	Migraine Trust www.migrainetrust.org	
Motor neurone disease	Progressive	3,962	Motor Neurone Disease Association www.mndassociation.org	1,132
Multiple sclerosis	Progressive	90,590	MS Trust www.mstrust.org.uk MS Society www.mssociety.org.uk	4,120
Multiple system atrophy	Progressive	2,354	Multiple System Atrophy Trust www.msatrust.org.uk	321
Muscular dystrophy	Progressive	58,970	Muscular Dystrophy UK www.musculardystrophyuk.org Action Duchenne www.actionduchenne.org	
Myasthenias	Intermittent	10,109	Myaware www.myaware.org	
Myelopathy	Progressive	Not known	Myelopathy.org www.myelopathy.org	

Prevalence and incidence of neurological conditions (continued)

Condition	Categorisation	Prevalence (England)	Reference	Incidence (England unless otherwise stated)
Narcolepsy	Stable with changing needs	22,250	Narcolepsy UK www.narcolepsy.org.uk	
Neurofibromatosis	Progressive	24,093	Nerve Tumours UK nervetumours.org.uk	
Neuromyelitis optica	Progressive	842	Transverse Myelitis Society www.myelitis.org.uk	
Parkinsons disease	Progressive	121,927	Parkinson's UK www.parkinsons.org.uk Spotlight Young Onset Parkinsons spotlightyopd.org	For people aged 45 or over: 18,461
Post-Polio syndrome	Progressive	100,800	Polio Survivors Network poliosurvivorsnetwork.org.uk	
Progressive supranuclear palsy	Progressive	6,500	PSP Association www.pspassociation.org.uk	2,040
Restless legs syndrome	Intermittent	1,056,400	Restless Legs Syndrome UK rls-uk.org	
Rett syndrome	Progressive	1,264	Rett UK www.rettuk.org	
Spina bifida	Stable with changing needs		Shine Charity www.shinecharity.org.uk	200
Spinal cord injury	Sudden onset	34,303	Spinal Injuries Association www.spinal.co.uk	858
Spinal muscular atrophy	Progressive	660	SMA Support UK smasupportuk.org.uk	138 diagnosed with 5qSMA per year
Stroke – ischaemic and hemorrhagic	Sudden onset	1,000,000	Different Strokes www.differentstrokes.co.uk Stroke Association www.stroke.org.uk	80,000
Tourette syndrome	Stable with changing needs	252,000	Tourettes Action www.tourettes-action.org.uk	
Transverse myelitis	Sudden onset	3,820	Transverse Myelitis Society www.myelitis.org.uk	253
Traumatic brain injury	Sudden onset	1,095,152	UKABIF www.ukabif.org.uk	900,000 A&E attendances per year in the UK
Trigeminal neuralgia	Sudden onset	50,000	Trigeminal Neuralgia Association UK www.tna.org.uk	6,000
Tuberous sclerosis complex	Progressive	6,720	Tuberous Sclerosis Association www.tuberous-sclerosis.org	
		14,675,879		

About Neuro Numbers

Neuro Numbers brings together all the latest pan-neurological data that is available for England. It is intended to be a 'consensus document' about neurological conditions.

Previous editions of Neuro Numbers have been quoted extensively by charities, health care professionals, academics and policy makers when referencing neurological data. There are two main categories of data and intelligence included in Neuro Numbers:

- 1** Data that is collected and analysed nationally by public bodies such as NHS England or the Neurology Intelligence Network at Public Health England.
- 2** Prevalence (and where available, incidence) estimates collated and synthesised by The Neurological Alliance with the support of charities providing support to people with specific neurological conditions.

Nationally collected data is referenced within the document and included with permission from the originating organisation.

PREVALENCE: The number of individuals in a population who have a disease at a specific time.

INCIDENCE: The number of individuals who are newly diagnosed with a disease during a particular time period.

Prevalence estimates have been sought mainly from national patient groups representing each condition. Patient groups have generally sourced prevalence (and where available incidence) figures from academic peer reviewed publications.

The originating sources are available from the charities who can be contacted via their websites, referenced within this publication. Where prevalence ratios were only available as a range, we use the lowest figure in this publication.

The number of neurological cases has increased

There is a large increase in the figure for the total number of neurological cases in this 2019 edition of Neuro Numbers, compared with the 2014 edition. Although it is widely accepted that overall prevalence is increasing, we caution against direct comparisons. There are a number of factors affecting changes in prevalence data and the overall accuracy of neurological prevalence estimates.

Methodological reasons

- 1** A number of neurological conditions were not included in Neuro Numbers 2014. Amongst these were conditions with high prevalence such as autism (580,000), restless legs syndrome (1,056,400) and traumatic brain injury (1,095,152), which have been included in 2019.
- 2** For some conditions such as functional neurological disorder, there are still no reliable prevalence estimates. Yet, we know prevalence is high and that it often occurs co-morbidly with another neurological condition.
- 3** In many disease areas prevalence estimates

About Neuro Numbers (continued)

are improving all the time. A large proportion of the overall increase in the number of cases is due to the increase in migraine prevalence figures. This is because of new prevalence ratio estimates having been developed in the last few years.

- 4 In some condition areas, such as narcolepsy, it is believed that many cases still go unreported, meaning prevalence is much higher than current estimates suggest.

Demographic reasons

- 5 The population of England has increased from 53 million (2011–12 – the year upon which the 2014 Neuro Numbers prevalence estimates were based) to 55.6 million (2018 Office for National Statistics data, the basis for this publication).
- 6 For some neurological conditions, risk factors include high blood pressure (e.g. stroke) or obesity (e.g. ITH). This means that the prevalence of these conditions is increasing at a faster rate than population growth alone, given the increasing occurrence of these risk factors in the general population.
- 7 Some increased prevalence can be accounted for by an ageing population. Advances in treatments for other diseases such as cancer means that people are living longer. As such they are more likely to be living with a neurodegenerative condition such as Parkinson's or dementia.
- 8 A small proportion of increased prevalence can be attributed to advances in neo-natal care.

Health service reasons

- 9 Improvements in scanning and other diagnostic techniques mean that diagnosis of neurological conditions is improving. This also means that some conditions – such as cavernoma – are diagnosed asymptotically, with a resulting increase in prevalence figures.
- 10 The number of neurologists has also increased over the last decade. This also means more neurological diagnoses are made.
- 11 A few conditions are declining in prevalence where primary prevention measures are possible and have been successful – e.g. meningitis, due to vaccinations.

For some conditions, such as Motor Neurone Disease (MND), the number of people living with the disease suggests the condition is rare according to the internationally recognised definition of rare disease, but this is because MND is life limiting and the time from diagnosis to death is often only a few years. The lifetime risk of developing MND is around 1 in 300 which makes it about as common as conditions such as Multiple Sclerosis (MS).

Please note that Neuro Numbers does not include an exhaustive list of neurological conditions. The Neurology Intelligence Network describes adult neurological diseases in 16 main condition categories, with an additional catch all category which covers rare and other neurological disease. These categories cover 473 International Classification of Disease Codes.

Annex: Summary of recommended neurological outcome measures

NHS Outcomes Framework domain	Relevance to neurological conditions	NHS Outcomes Framework indicators that should be disaggregated for neurological conditions	Additional neurological outcome measures that could complement the framework
1: Preventing people from dying prematurely	<ul style="list-style-type: none"> Reducing premature mortality due to poor management of symptoms 	<ul style="list-style-type: none"> 1a: Potential years of life lost from causes considered amenable to healthcare 1.5: Excess under 75 mortality rate in adults with common mental illness 	<ul style="list-style-type: none"> Under 75 mortality rate for people with neurological conditions
2: Enhancing quality of life for people with long-term conditions	<ul style="list-style-type: none"> Quick and accurate diagnosis Prompt and equitable access to appropriate specialists and treatment Access to high quality information Support to self-manage the condition Maintaining functional ability Coordinated health and social care support Enhancing quality of life for carers 	<ul style="list-style-type: none"> 2: Health related quality of life for people with long-term conditions 2.1: Proportion of people feeling supported to manage their condition 2.2: Employment of people with long-term conditions 2.3: Unplanned hospitalisation for chronic ambulatory care sensitive conditions (all ages) 2.4: Health-related quality of life for carers 2.7: Health-related quality of life for people with three or more long-term conditions 	<ul style="list-style-type: none"> Time taken to reach a stable neurological diagnosis following first consultation due to symptoms Unplanned hospitalisation for people with long-term neurological conditions Attendances at A&E for people with long-term neurological conditions Proportion of patients with a neurological condition who see a specialist who understands their condition within 24 hours of being admitted to hospital Proportion of people with a neurological condition who have a personal care plan Proportion of people with a neurological condition who have access to a clinical nurse specialist Proportion of people with a neurological condition given access to counselling/psychological support
3: Helping people to recover from episodes of ill health or following injury	<ul style="list-style-type: none"> Helping people to recover their independence and functional ability Reducing emergency admissions and length of stay Helping people to return to work 	<ul style="list-style-type: none"> 3a: Emergency admissions for acute conditions that should not usually require hospital admission 3b: Emergency readmissions within 30 days of discharge from hospital 3.6: Proportion of older people who were still at home 91 days after discharge from hospital into reablement/rehabilitation services 	<ul style="list-style-type: none"> Hospital bed days for people with long-term neurological conditions, following emergency and elective admissions Proportion of people with a neurological condition given access to rehabilitation services within two weeks of referral Time taken to return to a near-baseline level of functional ability for people with neurological conditions Proportion of people with a neurological condition able to remain in employment

Annex: Summary of recommended neurological outcome measures (continued)

NHS Outcomes Framework domain	Relevance to neurological conditions	NHS Outcomes Framework indicators that should be disaggregated for neurological conditions	Additional neurological outcome measures that could complement the framework
4: Ensuring that people have a positive experience of care	<ul style="list-style-type: none"> Improving people's experience of care across all care settings Access to a clinical nurse specialist Provision of a personal care plan Dying well 	<ul style="list-style-type: none"> 4a: Patient experience of primary care – (i) GP services and (ii) GP out of hours services 4b: Patient experience of hospital care 4.1: Patient experience of outpatient services 4.2: Responsiveness to in-patients' personal needs 4.3: Patient experience of accident and emergency services 4.4.i: Access to GP services 4.6: Bereaved carers' views on the quality of care in the last 3 months of life 4.7: Patient experience of community mental health service 4.8: Children and young people's experience of inpatient services 4.9 People's experience of integrated care 	<ul style="list-style-type: none"> Additional measures to be derived from national neurology patient survey
5: Treating and caring for people in a safe environment; and protecting them from avoidable harm	<ul style="list-style-type: none"> Getting the right medicines at the right time Timely access to assistive equipment (including wheelchairs) 	<ul style="list-style-type: none"> 5a: Deaths attributable to problems in healthcare 5b: Severe harm attributable to problems in health care 5.1: Deaths from VTE related events within 90 days post discharge from hospital 5.2: Incidence of healthcare associated infection (HCAI) – (i) MRSA and (ii) C. difficile 5.3: Proportion of patients with category 2, 3 and 4 pressure ulcers 5.4: Hip fractures from falls during hospital care 5.6: Patient safety incidents reported 	<ul style="list-style-type: none"> Proportion of people with a neurological condition who receive information about the side effects and potential adverse effects of their treatment Proportion of people with a neurological condition admitted to a hospital or care home who are given their medication on time Time taken between referral and being provided with appropriate assistive technology (including wheelchairs) or adaptations for people with a neurological condition



THE NEUROLOGICAL ALLIANCE

About us

The Neurological Alliance is a coalition of more than 80 organisations working together to transform outcomes for the millions of people in England with a neurological condition. We campaign for high quality care and support to meet the individual needs of every person with a neurological condition, at every stage of their life. Our work is shaped by the experiences of people with neurological conditions and aims to address the causes of poor care.

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