

Measuring up: improving the collection of neurological data and intelligence

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Foreword

When I came to the Neurological Alliance in 2011, it was after 13 years working in the cancer world where my focus had been on research and policy. In this past professional life, data had been at the centre of everything I did; I awarded no research grant, put forward no policy position and ran no campaign which wasn't underpinned and driven by it.

It was therefore a huge shock to me to on arriving at the Neurological Alliance to discover that national data on people with neurological conditions simply is not captured, analysed and made available. It was, and remains, inconceivable to me that the millions of people living with these complex and life changing conditions are effectively an unknown quantity to Government and the NHS. How can expenditure in this growing patient population be monitored to ensure value for money in a cash strapped system? How can the health service be sure that their care is safe? How can the NHS be confident that neurological admissions are at an appropriate level? And how can any part of the NHS be held to account for neurological service performance?

The neurological community has been challenging policymakers with these exact questions for very many years and when I became one of their ranks in 2011, I joined in their tireless efforts for better data collection, making it one of the Alliance's primary campaigning objectives. Three years later, I am delighted that our efforts are starting to bear fruit; the first national neurological dataset was published in March 2014 and the launch of the Neurology Intelligence Network, as part of the Mental Health, Dementia and Neurology Intelligence Networks, is set to follow this summer.

Whilst these promising developments are to be wholeheartedly welcomed, Government and the NHS must resist the temptation to think that these initiatives mean that the job is done; far from it. The dataset and Intelligence Network are the first steps on a much longer journey to ensuring that the health and social care system in England has all the data, intelligence and evidence it needs to provide high quality, continuously improving care and support for people with neurological conditions.

This paper sets out what this journey will involve and why it must be travelled. In presenting the latest statistics on neurological prevalence and expenditure, we are providing policymakers with the vital contextual information they need to identify the positive impact that greater neurological data and intelligence can make to the health service and the lives of people with neurological conditions.

It is crucial that having taken on the challenge of neurological data capture and analysis, Government, NHS England and Public Health England commit to seeing it through; we promise to be there in support of this task every step of the way.

Arlene Wilkie
Chief Executive, Neurological Alliance

Introduction

One of the central principles of the Government's vision for the NHS is that information drives improvement. To date, neurological conditions have lagged behind other condition areas in terms of having accurate, consistent and regularly collected data and intelligence to benchmark services and measure progress in achieving improved outcomes. Despite the Public Accounts Committee's (PAC) assessment in 2012 that neurological services are delivering 'poor outcomes for people with neurological conditions and poor value for money for the NHS', the continued lack of neurological data has been one of the key barriers to driving improvement in this area. Without it, neurological conditions cannot be properly represented in quality, improvement, accountability and incentive mechanisms of the reformed NHS, as we set out in a recent report¹.

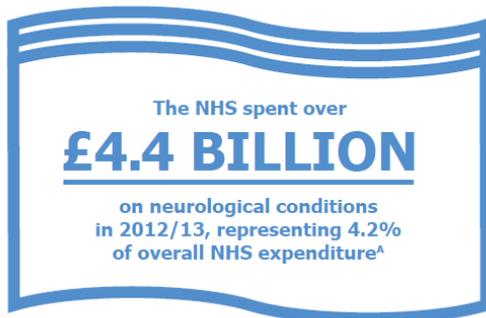
Included in this paper are the latest figures on the prevalence and burden of neurological conditions, revealing that there are now an estimated 12.5 million neurological cases in England, costing the NHS almost £4.5 billion annually². Neurological conditions are almost all unpreventable and lifelong from onset, and in the context of an ageing population, the rapid growth of this patient population is set to continue. There is a clear imperative for Government and the NHS to improve neurological data collection and analysis to understand more about how people with neurological conditions interact with our health and social care services, identify and address areas of underperformance and achieve value for money.

It is clear that momentum behind neurological data improvement is building; the first national neurological dataset was published in March this year³ and the Neurology Intelligence Network, which will be one of the three networks comprising the Mental Health, Dementia and Neurology Intelligence Networks, is also due to be launched at the start of the summer. It is vital that these become the foundations of a comprehensive neurological data and intelligence capture system across England.

In this paper, we present the rationale for improving neurological data and intelligence and the short, medium and long term goals that Government, NHS England, Public Health England and the Health and Social Care Information Centre need to achieve to bring data on neurology up to the standard of other major condition areas. We look forward to working with all the relevant system players and the National Clinical Director for Neurological Conditions to realise these ambitions in the months and years ahead.

Chapter 1: Rationale for improving the collection of neurological data and intelligence

Transforming the way that NHS information is accessed, collected, analysed and used has been a key ambition of the Government since 2010⁴. The Coalition set out how it intends to achieve this in its 10 year information strategy, which included plans to publish more information on NHS, public health and social care services, including information on the quality and range of services available, so that patients can make properly informed choices about their care⁵.



Articulating how this ambition will be made a reality for people affected by neurological conditions is yet to be fully tackled by policymakers however, with neurological conditions failing to measure up with other condition areas when it comes to the collation and publication of data and intelligence. There have been limited examples of information gathering for neurological conditions previously, including hospital episode statistics, a small number of national clinical audits and third-sector

led research programmes looking to uncover service standards and variations, but the general poor degree of neurological awareness among policy makers, some clinicians and the general public has failed to see such initiatives take hold.

The findings of the research we present in this paper on the economic and societal burden of neurological conditions aim to help to address this awareness deficit and affirm the real and significant impact of neurological conditions on our health and social care services⁶.

This chapter sets out the rationale for improving the collection of data and intelligence on neurological conditions. We look in turn at each of the following areas:

- Assessing the impact of neurological conditions on the individual, families and carers;
- Understanding and managing the cost of neurological conditions;
- Tackling avoidable neurological hospital admissions;
- Enabling system wide accountability and improvement.

Assessing the impact of neurological conditions on the individual, families and carers

Neurological conditions are indiscriminate and can affect people of all ages, cultures and ethnicities. Some neurological conditions are life threatening, with many severely affecting people's quality of life and causing lifelong disability. This can impact on a person's employment, family life and social activities. Caring for someone with a neurological condition can often become a full-time role, and this in turn can have financial and social repercussions for families.



**OVER 700,000
EMERGENCY ADMISSIONS**

were recorded for people with a neurological diagnosis in 2012/13, costing the NHS over £750 million^b

The lack of awareness and understanding of neurological conditions among commissioners, NHS and social care services and policymakers can mean that people are unable to access the services and support that they vitally need at the time they need it.

It is only through the consistent collection of data and intelligence that the health and social care system can assess whether people affected by neurological conditions are receiving the care and support that they need, identify and address problem areas and ensure that the whole system is working to support individuals and carers to achieve the best outcomes.

Understanding and managing the cost of neurological conditions

The NHS spent over £4.4 billion on treating neurological conditions in 2012/13⁷. This is almost as much as expenditure on respiratory conditions for the same year and represents the seventh biggest Department of Health category spend at 4% of its total expenditure⁷.

Furthermore, overall expenditure on neurological conditions increased by over 200% between 2003/4 and 2012/13⁸. Added to this is the estimated £2.4 billion which is spent each year on social care services for people with a neurological condition⁹, accounting for just under 14% of all adult social care spend¹⁰.

Overall NHS expenditure
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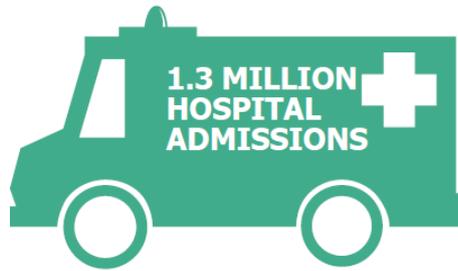
With high quality health services expected to be delivered by an NHS that is already struggling to make £20 billion of efficiency savings by 2014/15¹¹, understanding whether money spent on neurological services is being used appropriately is of the utmost importance. The NHS and local authorities are likely to be operating in tough financial circumstances for the foreseeable future, meaning that spending must be closely scrutinised.

In the context of an ageing population and given the nature of the vast majority of neurological conditions as both unpreventable and long term, the health and social care spend on neurology is set to grow. Without appropriate data and intelligence on neurological services and outcomes, it is impossible to assess accurately why costs are rising at such a rate, what action can be taken to curb unnecessary expenditure and how to ensure money invested in neurological services are delivering the maximum outcomes.

Tackling avoidable neurological hospital admissions

To help address unprecedented financial cuts and targeted efficiency gains, the importance of reducing the number of avoidable neurological hospital admissions cannot be understated. Unplanned admissions come at a higher cost than other forms of care and put increasing pressures on hospital waiting times. Furthermore, a high rate of emergency admissions is often a sign that the rest of the health and social care system may not be working as it should.

In the five years between 2007-08 and 2011-12, there has been an almost 50% increase in the rate of neurological hospital admissions where a neurological condition was mentioned in diagnosis (see Annex 2¹²). Of particular concern is the rise in emergency neurological admissions with an increase of over 150,000 (41%) in this five year period. In the last year (2012-13), emergency admissions where there was any mention at all of a neurological condition totaled over 700,000¹³, out of 5.3 million emergency admissions nationally¹⁴.



were recorded for people with a neurological diagnosis in 2012/13 - this represents an increase of more than 500,000 over a five year period¹⁵

The average length of stay in hospital for a neurological admission is also just shy of two weeks¹⁵. This represents a significant amount of resource allocated in an expensive acute setting where

often patient outcomes and value could potentially be better achieved if investment was channeled towards more tailored, community based services. Indeed, a startling 11 million bed days were recorded for people with a neurological diagnosis in 2012/13 alone¹⁶, increasing from just under 6.5 million in 2007-08, an alarming and currently unexplained increase of approximately 4.5 million over a five year period¹⁵.

These figures provide clear evidence of the major impact that neurological conditions have on NHS services and the absolute necessity of routinely publishing accurate and comparable data on the flow of patients in and out of care settings. This will enable the identification of improvement areas and help services to respond to local needs and take appropriate



An estimated £2.4 billion is spent each year on social care services for people with a neurological condition⁶

mitigating action. As with other long term conditions, care planning and supported self-management have key roles to play in preventing avoidable emergency admissions and commissioners must plan appropriately to ensure all necessary community services and support is available to people with neurological conditions. Tracking the number of bed

days and the average length of stay in a care setting in particular is an important means of benchmarking progress in helping people to recover from episodes of ill health.

Enabling system wide accountability and improvement

Our audit of neurological condition prevalence data (see Annex 1) reveals that the number of neurological cases in England has now reached approximately 12.5 million – this equates to 59,000 cases per clinical commissioning group (CCG)¹⁷. As the PAC stated in 2012, the failure of the previous Department of Health strategy to improve neurological services, the National Service Framework for Long Term Conditions, was in part due to 'no monitoring of progress, and local commissioners...not [being] held to account'¹⁸. The importance of national accountability for neurological services at all levels of the NHS is indisputable and yet the absence of neurology data and intelligence is holding back efforts to drive improvements so desperately needed in this area.

An examination of the quality, accountability and improvement mechanisms of the reformed NHS¹⁹ vividly illustrates the degree to which neurology has been side-lined. These mechanisms form the basis of what is prioritised by NHS England, CCGs and local authorities. Neurological conditions can only be appropriately represented across the system if high quality data and intelligence on neurological conditions are routinely collected and analysed; otherwise progress against identified improvement areas simply cannot be measured.

The consequence of a lack of accountability for neurology has already been played out over the last nine years under the National Service Framework for Long Term Conditions;

comprehensive data capture and analysis on neurological conditions must be achieved if the reformed NHS is to ensure that all levels of the health service are accountable for and incentivised to enhance neurological services.

Neurological data and intelligence: making it happen

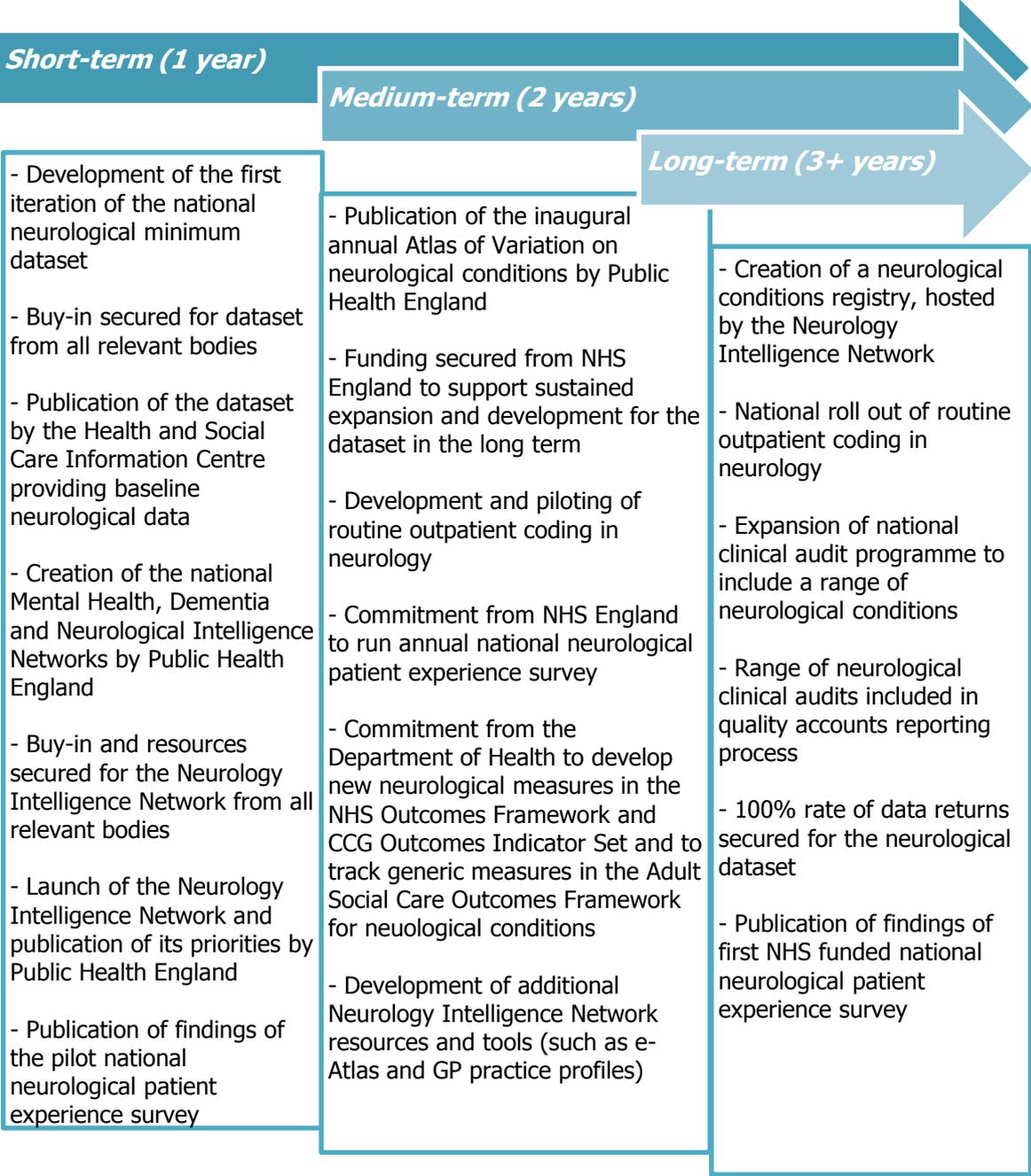
Given the clear case for the central and routine collection and analysis of neurological data, we enthusiastically welcome the recent work undertaken by the Health and Social Care Information Centre on the first national minimum dataset for neurological conditions, which was published in March 2014²⁰ and fulfils the Government's 2012 commitment to the PAC, and Public Health England's commitment to establish a Neurology Intelligence Network, due to be launched at the start of the summer.

We view the development of both the dataset and Intelligence Network as central to the drive to improve the collection of data and intelligence on neurological conditions in the future, but we are just the beginning of the journey towards achieving data parity for neurological conditions. Further work will be needed and funding made available to ensure that these resources are used by clinicians, commissioners and policy-makers to make a real difference to people affected by neurological conditions. A roadmap for improving and deploying neurological data and intelligence in the years ahead is presented in the following chapter.

Chapter 2: A roadmap for improving the collection of neurological data and intelligence

This chapter sets out our roadmap for ensuring that the collection and application of neurological data and intelligence is the best that it can be. We recognise that there will have to be a phased approach to this and we have therefore divided our ambitions into short, medium and long term goals. These are summarised in the following diagram and explained in more detail below.

Ambitions for improving the quality of neurological data and intelligence



Short term goals

The **establishment of a national minimum neurological dataset** is central to developing our understanding of the quality of neurological services and outcomes, and how these can be improved. The recent publication of the first iteration of this vital resource represents a huge step forward.

The inaugural dataset comprises indicators that are easy to measure through the current system of NHS reporting, such as hospital episode statistics, and focuses on care in acute settings. We see this very much as a first step that will be built upon and improved through further iterations of the dataset over the coming years.

It is essential to **secure buy-in for the dataset from all relevant bodies** to ensure that it is a resource that is valued and widely utilised. NHS England must retain overall ownership of the dataset and commit to its future development and improvement through appropriate funding. The **publication of baseline neurological data** will also ensure that we know where we are starting from and have a reference point from which to measure improvement in subsequent years.

What do we want the neurological dataset to include in the long term?

- ✓ The outcomes that matter most to people affected by neurological conditions. Annex 3 provides a useful starting point for this.
- ✓ All aspects of care utilised by people affected by neurological conditions, including primary, secondary, community, social and specialised care.
- ✓ All types of neurological condition, including sudden onset, intermittent, progressive and stable conditions.

What do we want the dataset to achieve?

- ✓ Publication of national and local baseline data from which future progress can be measured.
- ✓ A resource that can be interrogated and utilised by all those with an interest in neurological conditions.
- ✓ Evidence with which to hold NHS providers and commissioners to account for the quality of neurological services and outcomes.
- ✓ A better understanding of the relationship between specific NHS and social care interventions and patient outcomes to inform clinical practice and overarching NHS policy and guidance.

The creation of a national **Neurology Intelligence Network** will bring together the different parts of the neurological community, including clinicians, researchers and patient organisations, to produce high quality, validated information and intelligence. This is a model that has worked particularly well in relation to cancer, and has also more recently been committed to for cardiovascular disease. It is vital that **the network is sufficiently resourced** both initially and in the longer term to fulfil its remit. We would expect to see the early **publication of the Network's priorities and strategy**, and these should be informed by the baseline data that have been published in the first dataset.

Medium term goals

The **publication of an annual Atlas of Variation on neurological conditions** by Public Health England would serve to identify and highlight unwarranted variation in the quality of neurological services and outcomes. The NHS Atlas of Variation series has proved an extremely valuable tool in helping clinicians and commissioners to understand what is going

on in their local area and where to focus attention to improve the care that they provide. Work is currently underway to develop a series of themed atlases focusing on specific conditions or populations, such as diabetes, liver disease and respiratory disease, in more depth. Neurological conditions should be incorporated into this list; given the high prevalence and significant impact of neurological conditions, the case for their inclusion is clear and compelling.

One of the obstacles to recording how people are being treated across the whole of the patient pathway is that neurological outpatient care is in the majority of cases not coded in anywhere near the same level of detail as inpatient care. This is an area that needs attention if we are to be able to publish data from across the whole pathway. We are therefore calling for the **development and roll out of routine outpatient coding in neurology**.

Patient experience surveys currently used within the NHS do not capture the detail that is required to gather information about the specific experiences of people with neurological conditions. We believe collating and publishing information on patient experience is an essential element of the drive to improve the quality of neurological data. NHS England should therefore **commission a national neurological patient experience survey**, similar to the Cancer Patient Experience Survey, to gather insights into the care experienced by people affected by neurological conditions. This will also allow for neurological patient experience measures to be included in future iterations of the NHS and adult social care outcomes frameworks. We are looking to pilot a national patient experience survey in 2014. We believe this will be an important contribution towards improving the availability of data and intelligence and will provide a useful model for NHS England²¹ to emulate.

Further to the earlier recommendation, in year three we would expect to see the publication of findings from the first NHS England-led national neurological patient experience survey and for these findings to inform service design and delivery at the national and local level. We would then want to see this exercise repeated on an annual basis.

The establishment of the dataset and a neurological patient experience survey should enable a new raft of **neurological measures to be included in the NHS Outcomes Framework, CCG Outcomes Indicator Set and Adult Social Care Outcomes Framework**. This is essential to ensure that neurological conditions are no longer under prioritised locally and nationally. Our recently published paper sets out in more detail our recommendations on how to achieve this specific ambition²².

The Neurological Intelligence Network should look to **develop resources and tools**, additional to the dataset, to help commissioners and providers to monitor and improve care for people with neurological conditions. Models such as the Cancer e-Atlas (which provides local area data on cancer incidence, mortality and survival) and GP practice profiles (which provide comparative information for benchmarking and reviewing variations at a general practice level) could be used as a starting point.

Long term goals

As highlighted in this paper, there is limited evidence available on the prevalence of neurological conditions. We therefore propose the **creation of a neurological conditions registry** to measure incidence and prevalence of the whole spectrum of neurological conditions. This will help health and social care commissioners and providers to measure need and plan services accordingly. It will also help people with a neurological diagnosis to

be able to access the services that they need and for care to be better integrated across different systems.

National clinical audit is designed to improve patient outcomes across a wide range of condition areas. Its purpose is to engage all healthcare professionals in systematic evaluation of their clinical practice against standards and to support and encourage improvement in the quality of treatment and care. To date, neurological conditions have not been a major focus for clinical audits. We propose the **expansion of the national clinical audit programme to include a range of neurological conditions, including an audit for rarer neurological conditions**, so that the NHS can have a better understanding of a patient population with growing prevalence, complex and expensive care, and for which services are currently underperforming.

It will also be important for these audits to be **embedded in the Department of Health's quality accounts reporting process**. All health service providers have to submit quality accounts each year – a report about the quality of their services. Providers are required to include a statement in their quality account which details the national clinical audits they have participated in during the year. Having neurology properly represented in quality accounts will demonstrate that providers have a better understanding of how they are meeting the needs of people with neurological conditions in their local area.

Now that the dataset is up and running, it is important to ensure that it includes data for all services across the country that are involved in providing care for people affected by neurological conditions. In time we would therefore want to see a **100% rate of data returns secured for the dataset** and recognition from professionals that the information published in the dataset accurately reflects what is happening in their local services, underpinned by the development of accurate and reliable reporting and coding mechanisms.

Our commitment

The NHS has done great things with data and intelligence for patient communities such as cancer and cardiovascular disease and with the right systems in place it has the opportunity to do similarly great things for people with neurological conditions. Developing comprehensive data capture and analysis systems across the spectrum of neurological conditions will not be a short term project; it will need multi-agency commitment, investment and a great deal of hard work. This is, however, the only option; the NHS cannot afford the consequences of anything less than this and we cannot accept anything less on behalf of the millions of people living with neurological conditions that our members represent. We are in this project for the long haul and commit the collective support, expertise, drive and enthusiasm of our community to realising the aspirations of this paper in full.

Annex 1: Neuro Numbers data tables

Condition	Categorisation	Prevalence (England)	Reference	Incidence
Acoustic neuroma	Progressive	845	British Acoustic Neuroma Association http://www.bana-uk.com/	-
Ataxia	Progressive	8,400	Ataxia UK http://www.ataxia.org.uk/ AT Society http://www.atsociety.org.uk/	-
Batten disease	Progressive	170	Batten Disease Family Association http://www.bdfa-uk.org.uk/about-batten-disease	-
Brain tumour	Progressive	-	Brain Research Trust http://www.brt.org.uk/brain-tumours Brain Tumour UK http://www.braintumouruk.org.uk/	13,000 diagnoses each year
Cavernoma (includes symptomatic brain cavernoma)	Intermittent	75,730	Cavernoma Alliance UK http://www.cavernoma.org.uk/cavernoma.html	-
Cerebral palsy	Stable with changing needs	24,620	Scope http://www.scope.org.uk/help-and-information/cerebral-palsy/introduction-cerebral-palsy	-
Charcot-Marie-Tooth disease	Progressive	19,320	CMT UK http://www.cmt.org.uk/What-is-cmt.php	-
Cluster headache	Intermittent	80,260	Migraine Trust http://www.migrainetrust.org/factsheet-cluster-headache-10908	-
Congenital hemiplegia	Stable with changing needs	53,500	HemiHelp http://www.hemihelp.org.uk	-
Dementia (includes Alzheimer's)	Progressive	665,070	Alzheimer's Society http://www.alzheimers.org.uk/statistics	-
Dystonia	Progressive	58,800	Dystonia Society http://www.dystonia.org.uk/index.php/introduction ADDER http://www.actionfordystonia.co.uk/	-

Encephalitis	Sudden onset	-	The Encephalitis Society http://www.encephalitis.info/information/the-illness/frequently-asked-questions/	6,000 cases in England each year
Epilepsy	Intermittent	504,000	Epilepsy Action https://www.epilepsy.org.uk/press/facts) Epilepsy Society http://www.epilepsysociety.org.uk/ Joint Epilepsy Council http://www.jointepilepsycouncil.org.uk/ SUDEP Action https://www.sudep.org/	-
Essential tremor	Progressive	1,417, 960	National Tremor Foundation http://www.tremor.org.uk/ Patient UK http://www.patient.co.uk/health/Essential-Tremor	-
Fibromyalgia	Stable with changing needs	1,638,000	FibroAction http://www.fibroaction.org/Pages/About-Fibro.aspx	-
Guillain-Barre syndrome	Sudden onset	800	Gain Charity http://www.gaincharity.org.uk/	-
Huntingdon's disease	Progressive	6,580	Huntingdon's Disease Association http://www.hda.org.uk/	-
Idiopathic intracranial hypertension	Sudden onset	800	IhaveIIH Foundation http://www.ihaveiih.com/	-
Meningitis	Sudden onset	-	Meningitis Research Foundation http://www.meningitis.org/facts	3,200 cases per year in UK
Migraine	Intermittent	6,720,000	Migraine Trust http://www.migrainetrust.org/key-statistics	-
Motor neurone disease	Progressive	3,750	MND Association http://www.mndassociation.org/what-is-mnd/Brief+guide+to+MND.htm	-
Multiple sclerosis	Progressive	84,000	MS Society http://www.mssociety.org.uk/what-is-ms MS Trust http://www.mstrust.org.uk/	-
Multiple system atrophy	Progressive	2,520	Multiple System Atrophy Trust http://www.msatrust.org.uk/understanding-msa/what-is-msa/	-

Muscular dystrophy	Progressive	58,800	Muscular Dystrophy Campaign http://www.muscular-dystrophy.org/about_muscular_dystrophy Action Duchenne http://www.actionduchenne.org/	-
Myalgic encephalomyelitis (ME)	Stable with changing needs	215,000	Action for ME http://www.actionforme.org.uk/ National ME Centre http://www.nmec.org.uk/	-
Myasthenia gravis	Progressive	6,300	Myasthenia Gravis Association http://www.mga-charity.org/information-mg/myasthenia-gravis/77-home/84	-
Narcolepsy	Stable with changing needs	21,000	Narcolepsy UK http://www.narcolepsy.org.uk/about-narcolepsy/who-does-it-affect	-
Neurofibromatosis	Progressive	21,860	The Neuro Foundation http://www.nfauk.org/what-is-neurofibromatosis	-
Neuromyelitis optica	Progressive	840	NMO Specialised Services http://www.nmouk.nhs.uk/what-is-nmo/more-about-nmo	-
Parkinson's disease	Progressive	106,680	Parkinson's UK http://www.parkinsons.org.uk/content/about-parkinsons Cure Parkinson's Trust http://www.cureparkinsons.org.uk/what-is-parkinsons	-
Post-Polio syndrome	Progressive	100,800	British Polio Fellowship http://www.britishpolio.org.uk/ Polio Survivors Network http://www.poliosurvivorsnetwork.org.uk/	-
Progressive supranuclear palsy	Progressive	5,880	PSP Association http://www.pspassociation.org.uk/what-is-bsp/	-
Rett syndrome	Progressive	2,250	NHS Choices http://www.nhs.uk/conditions/Rett-syndrome/Pages/Introduction.aspx	-
Spina bifida and hydrocephalus	Stable with changing needs	-	NHS Choices http://www.nhs.uk/conditions/Hydrocephalus/Pages/Introduction.aspx	1 in 1,000 born in Britain
Spinal tumour	Progressive	-	Macmillan Cancer Support http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Spinalcord/Spinalcordtumours.aspx	4,700 per year in the UK

Stroke (includes ischaemic and hemorrhagic)	Sudden onset	316,080	Stroke Association http://www.stroke.org.uk/news/stroke-facts-and-statistics-your-area Fighting Strokes http://www.fightingstrokes.org/ Different Strokes http://www.differentstrokes.co.uk/	-
Tourette syndrome	Stable with changing needs	252,000	Tourette's Action http://www.tourettes-action.org.uk/67-what-is-ts.htm	-
Transverse myelitis	Stable with changing needs	3,820	Transverse Myelitis Society http://www.myelitis.org.uk/treatment-and-recovery.html	-
Traumatic brain injury (defined as ranging from minor brain injuries to severe injuries causing long-term disability)	Sudden onset	-	Headway https://www.headway.org.uk/key-facts-and-statistics.aspx UKABIF http://www.ukabif.org.uk/	170,000 per year in the UK
Traumatic spinal injury (includes falls and road traffic accidents and sporting accidents, such as through horse riding, diving and rugby)	Sudden onset	31,200	Every Eight Hours Campaign http://www.everyeighthours.com/about-spinal-cord-injury	-
Trigeminal neuralgia	Sudden onset	-	Trigeminal Neuralgia Association http://www.tna.org.uk/	Annual incidence of new cases in England of 7,000
Tuberous sclerosis	Progressive	6,720	Tuberous Sclerosis Association http://www.tuberous-sclerosis.org/about_TSC.html	-

Annex 2: Summary of admissions and cumulative bed days for a neurological diagnosis

Figure 1: Elective and Emergency Admissions by PCT: 2007/08 to 2011/12¹²

	Primary diagnosis			Secondary diagnosis			Total
	Elective	Emergency	Other	Elective	Emergency	Other	
2007-08	157,795	107,088	6,022	148,952	261,049	20,823	701,729
2008-09	174,826	113,746	6,016	168,989	294,287	21,724	779,588
2009-10	185,498	122,187	5,242	197,245	333,474	23,375	867,021
2010-11	193,533	123,260	5,868	239,942	378,055	27,183	967,841
2011-12	199,769	122,106	5,655	267,982	396,893	28,750	1,021,155

Figure 2: Number of Finished Admission Episodes (All, Elective and Emergency) for Neurological Conditions by England (2012-13)¹⁹

HSCIC	Total Admissions		Elective Admissions		Emergency Admissions	
	Mention	Primary	Mention	Primary	Mention	Primary
2012-13	1,318,461	521,024	496,090	252,718	768,954	245,221

Figure 3: Count of bed days for patients with primary and secondary diagnoses of neurological conditions by PCT: 2007/08 to 2011/12¹⁴

	Primary diagnosis			Secondary diagnosis			Total
	Elective	Emergency	Other	Elective	Emergency	Other	
2007-08	351,427	986,522	220,502	637,283	3,712,751	584,749	6,493,234
2008-09	334,569	1,026,256	240,933	668,706	4,051,728	571,693	6,893,885
2009-10	365,723	1,060,680	209,383	698,454	4,357,002	616,256	7,307,498
2010-11	344,762	1,010,048	204,154	852,545	4,557,029	645,350	7,613,888
2011-12	318,026	1,011,523	194,540	818,062	4,658,881	623,736	7,624,768

Figure 4: Number of Bed Days for Neurological Conditions for England (2012-13)¹⁹

HSCIC	Total Bed Days		Elective Bed Days		Emergency Bed Days	
	Mention	Primary	Mention	Primary	Mention	Primary
2012-13	11,135,560	4,428,983	1,287,567	611,677	8,598,442	3,120,189

Annex 3: 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 outcome measures that should be incorporated into 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 	<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: Health-related quality of life for carers 	<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

			<ul style="list-style-type: none"> - Proportion of people with a neurological condition able to remain in employment
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: An indicator to be derived from the survey of bereaved carers (to address improving the experience of care for people at the end of their lives) - 4.8: An indicator to be derived from a Children's Patient Experience Questionnaire (to address improving children and young people's experience of healthcare) 	<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: Patient safety incidents reported - 5b: Safety incidents involving severe harm or death - 5.1: Incidence of hospital-related venous thromboembolism (VTE) - 5.2: Incidence of healthcare associated infection (HCAI) - i MRSA and ii C. difficile - 5.3: Incidence of newly-acquired category 2, 3 and 4 pressure ulcers - 5.4: Incidence of medication errors causing serious harm - 5.6: Incidence of harm to children due to 'failure to monitor' 	<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

About us

The Neurological Alliance is the collective voice of more than 80 national and regional brain and spine organisations working together to make life better for the millions of people in England with a neurological condition. We campaign for access to high quality, joined up services and information for every person diagnosed with a neurological condition, from their first symptoms, and throughout their life.

The Neurological Alliance is a charity registered by the Charity Commission for England and Wales (registration number 1039034) and a company limited by guarantee registered in England (registration number 2939840).

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