Halton Joint Strategic Needs Assessment 2018

Long-term Neurological Conditions

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Description	The document constitutes an update on the 2016/17 JSNA chapter on long-term neurological conditions. It describes the policy context, estimated prevalence, risk factors and sub-groups of need, current service provision and national best practice in relation to long term neurological conditions in Halton.
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Related documents	Children's JSNA 2014 Disabilities and Complex Health Needs JSNA: Physical & Sensory Disabilities (Adults) Physical Disabilities amongst adults of work age strategy

Please quote the JSNA

We would like to know when and how the JSNA is being used. One way, is to ask people who use the JSNA when developing strategies, service reviews and other work to quote the JSNA as their source of information.

Abbreviations

ABI/TBI	Acquired Brain Injury/ Traumatic Brain Injury
AEDs	Antiepileptic drugs
BMI	Body Mass Index
CCG	Clinical Commissioning Group
CNS	Central Nervous System
DLA	Disability Living Allowance
EOL	End of Life
GP	General Practitioner
HDIS	HES Data Information Service
HES	Hospital Episode Statistics
HNA	Health Needs Assessment
HRG	Healthcare Resource Group
IB	Incapacity Benefit
ICD-10	International Classification of Disease, version 10
JSNA	Joint Strategic Needs Assessment
LOS	Length of Stay
LTNC	Long term neurological condition
MCM	Major congenital malformations
MND	Motor neurone disease
MS	Multiple sclerosis
NAO	National Audit Office
NHS	National Health Service
NHSE	NHS England
NICE	National Institute for Health and Clinical Excellence
ONS	Office for National Statistics
PCT	Primary Care Trust
PD	Parkinson's disease
PHE	Public Health England
QOF	Quality Outcomes Framework
RNA	Regional Neurological Alliances
SDA	Severe Disablement Allowance
SPOT	Spend and Outcomes Tool
WHO	World Health Organisation

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Key issues for consideration by commissioners

Priority	Goal	Description
Intelligence	Intelligence for long-term neurological conditions (LTNC) that is fit for purpose	Apart from epilepsy there is no routinely collected local data on LTNC. The original Health & Social Care Information Centre dataset was taken over by Public Health England's Neurological Intelligence Network. Their updated dataset has been useful in putting the JSNA together. However, it has now been suspended. It would be useful to develop an agreed dataset with the commissioners and ensure arrangements are made for any additional data collection needed. This should include primary care, community healthcare, secondary care and social care as well as consideration of the wider social needs of people with LTNCs.
Prevention	Access to lifestyle services and advice	Although unlike other long term conditions there is no opportunity for primary prevention, the JSNA does highlight lifestyle issues that may exacerbate or speed the progress of LTNC. As such appropriate lifestyle advice and access to services should be routinely given.
Primary Care	Ensure those with epilepsy receive the appropriate care interventions	The only QOF disease register for LTNCs is for epilepsy. This no longer includes any management/ treatment indicators. Previous data suggested wide variation and lower overall performance than external comparators. Diagnosed prevalence of epilepsy is marginally lower than the estimated prevalence which may indicate a small level of under diagnosis. However, caution is needed in interpreting this as it may simply be an artefact of local population differences compared to national. Prescribing costs (NiC per 10,000) for diseases of the CNS are lower than England. However, Spend on epilepsy medications are higher than for any other CNS-related condition. Halton CCG has amongst the highest prescribing costs for epilepsy in England.
Secondary care	Reduce the level of emergency admissions	Emergency admissions for LTNCs continue to be higher in Halton than nationally whilst the rate for planned admissions is lower. Total costs per 1,000 population are higher, especially when considering those for emergency admissions. Day case admissions are also higher. All GP practices except Upton Rocks had emergency admission

Priority	Goal	Description
		rates above the England average. Halton overall had 76.7% of its admissions for neurological conditions via the emergency route. Apart from Upton Rocks practice, all practices had more than half of such admissions via the emergency route.
Social needs	Support those with LTNC claiming benefits back to work	There are significant numbers of Halton residents claiming disability and incapacity benefits. Welfare reforms may mean a substantial proportion of these will face reductions in benefits. Dealing with their medical condition and potential skill gaps may put people with LTNC at a disadvantage in the labour market and efforts should be made to support people back to work where possible.
Quality of care	Realise improvements in health and social care for all with LTNCs	The National Audit Office report identified a number of improvements that have been made, but noted that wide variation continues to exist. This means the improvements identified in the 2005 National Service Framework have not been realised uniformly. The latest Neuro Alliance patient survey shows there remains considerable improvements needed, with a reduction in the percentage of respondents satisfied with the services they receive.

1. Introduction

Neurological conditions make up 20% of all Long Term Conditions and include a wide range of illnesses. A Long Term Neurological Condition (LTNC) results from injury, damage to, or disease of the nervous system (brain, spinal cord, peripheral or autonomic nervous system). Around 2 million people in the UK have a neurological condition (excluding migraine sufferers – of which there are about 8 million). A third of visits to GPs and a fifth of all acute hospital admissions are related to neurological conditions. An estimated 350,000 people with neurological conditions in the UK need help with their daily activities and around 850,000 people care for someone with such a condition.[1]

There are many types of LTNCs, and people's experiences, disease course, needs for services and support varies significantly. LTNCs can be categorised as those that are:

- of sudden onset e.g. acquired or traumatic brain injury
- intermittent and unpredictable conditions e.g. epilepsy
- progressive conditions e.g. multiple sclerosis (MS), Parkinson's disease (PD) or motor neurone disease (MND) where deterioration over time may increase the need for services
- stable conditions with changing needs due to age e.g. cerebral palsy in adults

Although this chapter focuses primarily on 5 key LTNCs – epilepsy, multiple sclerosis, Parkinson's disease, motor neurone disease and acquired brain injury - service provision and commissioning considerations are often common across a wide spectrum of LTNCs. The chapter does not include stroke as there is a separate report on this as part of cardiovascular disease JSNA work.

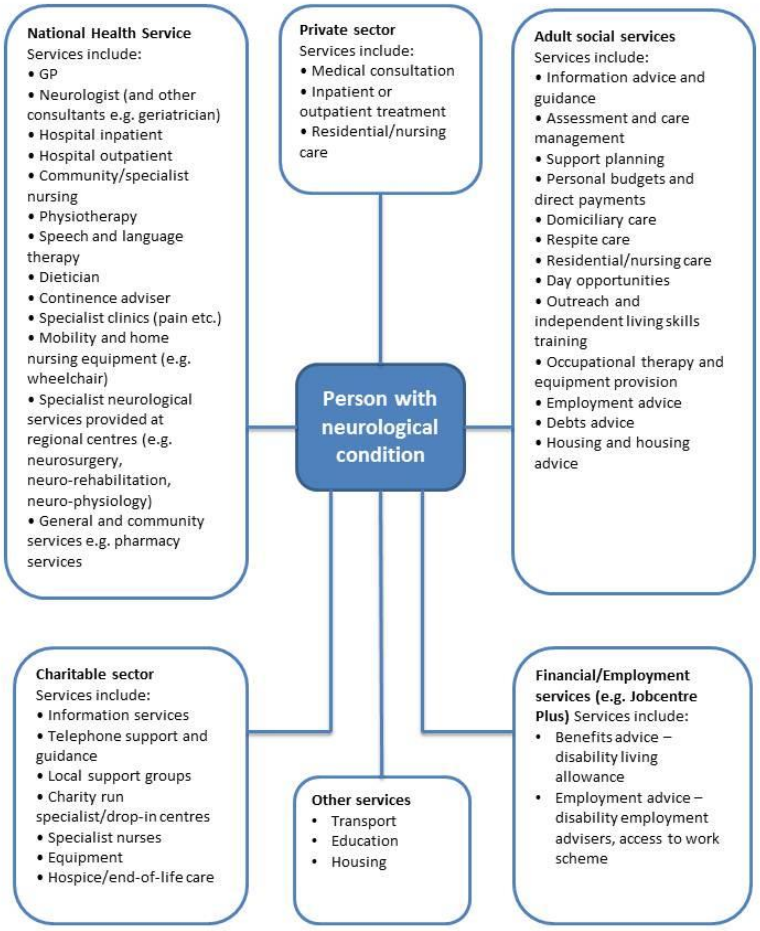
LTNCs produce symptoms such as:

- Physical or motor problems – paralysis, immobility, incontinence, sexual dysfunction
- Sensory problems –loss of vision, pain or altered sensation
- Cognitive/ behavioural problems – lapses in memory, planning, problem solving, confusion
- Communication - speaking, using written communication
- Psychological and emotional effects – potential personality changes, anxieties, depression

It is likely, therefore, that those with a neurological condition will require a range of agencies and services over time to optimise their health and exercise their independence. It would perhaps be beneficial to involve input from health and social care, the voluntary and independent sector as well as services such as transport, housing, employment, education, benefits and pensions.

The requirement for services and support will vary due to fluctuating symptoms, differing levels of disability and rates of disease progression. Caring for those with LTNCs can be very demanding, both physically and emotionally. Carers can experience high levels of stress and mental health issues e.g. depression and anxiety and may also be adversely financially affected.

Figure 1: Range of services for people with LTNC



Source: reproduced from NAO 2011,

Good outcomes for those with LTNCs depend on:

- Diagnosis - ensuring people with symptoms receive a timely and accurate diagnosis in order to receive high quality treatment, care and support and information as early on as possible
- Early management - an organised, proactive, multi-disciplinary approach to their management – that focuses on prevention and early intervention to help establish good control of the condition, minimise effects of the disease, reduce complications and enable people to remain as well and independent as possible for as long as possible
- Ongoing care and living with a LTNC - individuals and their carers are supported to develop the knowledge, skills and confidence to care for themselves and their condition effectively
- Emergency/acute management and management of complications, relapses and crisis - People with LTNCs need to have access to appropriate expertise and services at the right

time to support them when circumstances change or if their condition deteriorates. This prevents unnecessary admissions to hospital and/or reduces time spent in hospital

- Palliative and End of Life (EOL) Care - those with LTNCs approaching the EOL - and their carers - need to have access to a comprehensive range of services and support to manage symptoms, meet their needs for personal, social, psychological and spiritual support and enable them to be able to die with dignity in the place of their choice and cared for by those with appropriate knowledge and skills

2. Policy Context

2.1 The Equality Act (2010)

The Equality Act 2010 (Government Equalities Office, 2013) protects people from unlawful discrimination, harassment and victimisation in relation to services and public functions, work, associations, premises and education. It also places a duty on public authorities to give due regard to the need to: eliminate discrimination, harassment and victimisation; advance equality (remove or minimise disadvantage, meet people's needs, take account of disabilities and encourage participation in public life); and to foster good relations (tackle prejudice and promote understanding). The protection is in relation to eight characteristics: age, disability, gender re-assignment, pregnancy and maternity, race, religion and belief, sex and sexual orientation. The protected characteristic of marriage and civil partnership also applies in respect of work.

2.2 National Service Framework: Long Term Conditions (2005)

This 10 year strategy lays out best practice guidelines for the health and social care of adults with long term neurological conditions, creating 11 quality requirements to improve the quality, consistency and responsiveness of services and personalised care (Figure 2).

The National Service Framework is underpinned by several key principles: allowing people with long-term neurological conditions to live as independently as possible, challenging discrimination, reducing inequalities, treating people with respect and dignity, and listening to and acting on their views (Department of Health, 2005).

Figure 2: The National Service Framework for Long Term Conditions Quality Requirements

Criteria for good quality care were published around:

1. A person-centred service
2. Early recognition, prompt diagnosis and treatment
3. Emergency and acute management
4. Early and specialist rehabilitation
5. Community rehabilitation and support
6. Vocational rehabilitation
7. Providing equipment and accommodation
8. Providing personal care and support
9. Palliative care
10. Supporting family and carers
11. Caring for people with neurological conditions in hospital or other health and social care settings

2.3. Services for people with Neurological Conditions (2012)

Following publication of the National Service Framework (NSF) in 2005, this report by the Commons Public Accounts Committee raised concerns that standards of care had not improved adequately. In fact, there had been a 32% increase in emergency admissions, and an increased rate of readmissions

to hospital within 28 days from 11.2% to 14%. Spending on neurological services had increased by 38% in real terms, from £2.1 billion in 2006-07 to £2.9 billion in 2009-10.

The Public Accounts Committee emphasised the importance of stronger leadership, both centrally and locally, and stated that commissioners need to be held to account for outcomes in order to improve outcomes for people with neurological conditions and provide value for money for the NHS.

The report concluded that the implementation of the NSF had lacked focus and direction; that data on this population group was inadequate to measure the effectiveness of services; that the quality of neurological services varied across the country (and was insufficient in some areas); that health and social services were poorly integrated; and that individual care is often poorly coordinated with few patients having a care plan in place.

Recommendations for action included: appointing a National Clinical Lead for neurology; establishing local neurological networks; developing a neurological data set, and including key indicators in the NHS and Adult Social Care Outcomes Frameworks; joint health and social care commissioning of neurological services; ensuring that every person with a neurological condition is offered a personal health and social care plan, coordinated by a single professional; and that NICE should develop a generic Quality Standard for neurological conditions (House of Commons Committee of Public Accounts, 2012).

2.4. Services for people with Neurological Conditions: Progress Review (2015)

A review of the progress since the 2012 Public Accounts Committee report was published this year, which reported mixed progress on the recommendations.

Positive changes include the establishment of the mental health, dementia and neurological conditions Strategic Clinical Network, the publication of a compendium of neurology data by the Health and Social Care Information Centre and a new Neurology Intelligence Network. New Quality Standards for neurological conditions are currently being produced.

However, there is still a lack of drive for improvement of services for neurological conditions, with few Joint Strategic Needs Assessments or Joint Health and Wellbeing Strategies referring to neurology at all. The NHS and CCG outcomes indicator sets both only have one related indicator (relating to epilepsy in people under 19 years old). There was little evidence of joint commissioning between health and social care and still only a small proportion of patients with an individualised care plan (National Audit Office, 2015).

2.5. Fulfilling Potential – Outcomes and Indicators Framework Second Annual Progress Report (2015)

As per the recommendations of the United Nations Convention on the Rights of Persons with Disabilities (2006), the UK has a framework for improving the lives of people living with a disability.
The Fulfilling Potential – Making it Happen strategy and action plan were published in 2013. This framework highlighted the need for cross-sector partnerships with disabled people and

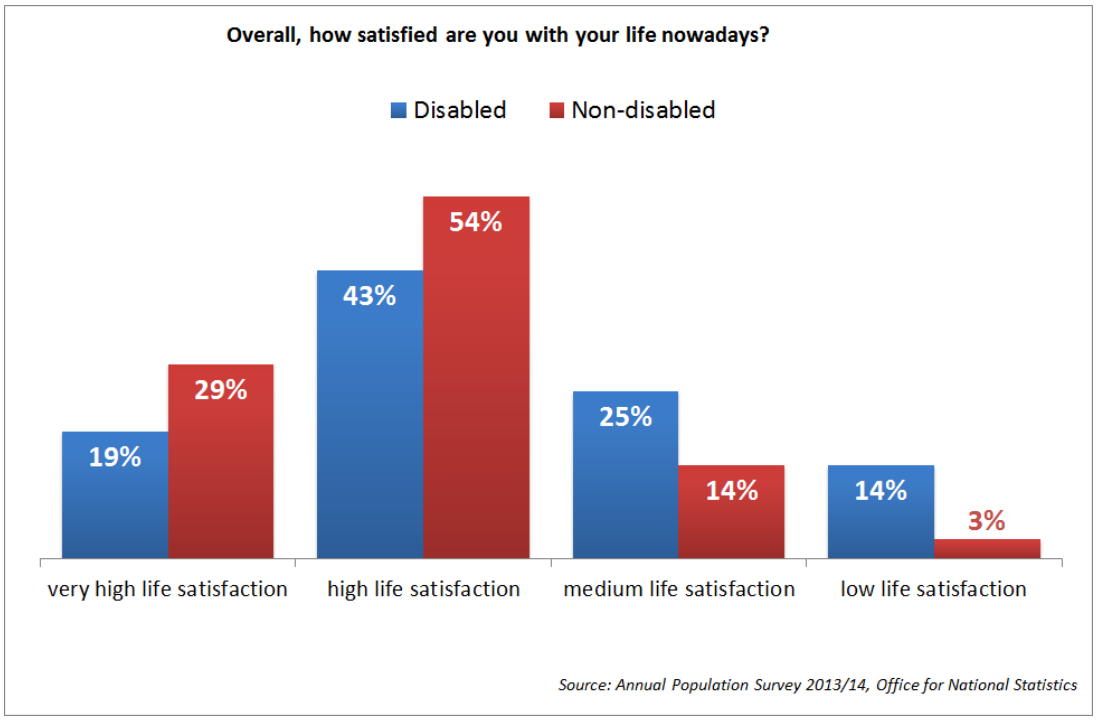
organisations in order to support disabled people to fulfil their potential and have equal opportunities to realise their aspirations.

The framework provides indicators on which to collect data to monitor progress. These include education, employment, income, health and wellbeing, choice and control, housing, transport, social participation, friends and family, information and access, and attitudes.

The report highlights a significant disparity between levels of disabled and non-disabled people's satisfaction with their lives; 22% point gap between the proportion of disabled people (62%) reporting 'very high' or 'high' satisfaction with their lives compared to non-disabled people (84%).

Whilst improvements have been made in these indicator areas since 2013, significant inequalities still exist and need to be addressed (Department for Work and Pensions and Office for Disability Issues, 2015).

Figure 3: Levels of Life Satisfaction in Disabled vs Non-Disabled people



3. Who is at risk and why?

Unlike other Long Term Conditions:

- There is usually no opportunity for primary prevention or modifiable risk factors
- There is no link with deprivation, except for epilepsy where there is 25% higher prevalence of epilepsy in socially deprived areas – this is important when commissioning services
- There is a link between increasing age and prevalence of some neurological conditions i.e. Parkinson's disease but they can occur at any age and incidence is higher within certain age ranges e.g. MS 20-40 age range.

3.1. Epilepsy: The most common and serious neurological condition is defined as a tendency to have recurrent seizures. There are around 40 different types of seizure and a person may have more than one type. Epilepsy can affect anyone at any age and from any walk of life. However it is most often diagnosed before the age of 18 or after the age of 65 and many people who are diagnosed before the age of 20 are not affected as an adult. Incidence is high in the child population, decreases in the adult population and rises again amongst older people.[2]

Epilepsy is more common in people with a learning disability than in the general population. About 30% of people (nearly 1 in 3) who have a mild to moderate learning disability also have epilepsy. The more severe the learning disability, the more likely it is they will also have epilepsy. Around 20% of people (1 in 5) with epilepsy also have a learning disability. [3]

The causes of epilepsy can be put into 3 main groups: symptomatic (where there is a known cause, such as a head injury, infection or a tumour); idiopathic (due to genetics); or cryptogenic where the cause cannot be found.

3.2. Multiple Sclerosis (MS): This is a progressive condition most often diagnosed in people between the ages of 20 and 40. MS affects three times more females than males and is a highly complex condition that can have significant psychological and psychosocial impacts. The long term nature of the condition, coupled with its complexity and unpredictability, means those with MS, their carers and families, often live with changing levels of need, and support. The cause of MS is unknown, although research points towards a combination of environmental and genetic factors.

3.3. Parkinson's Disease (PD): This is a progressive neurodegenerative condition, caused by the loss of dopamine producing nerve cells in the part of the brain that controls movement. There is no cure for Parkinson's, and symptoms and progression vary significantly from person to person. Care and support focuses on keeping people as well as possible and limiting complications (e.g. falls, infections) which could lead to unplanned admissions to hospital. Mainly diagnosed at an older age, Parkinson's often presents around the age of 50-60 years and prevalence increases with age (although around 1 in 20 will be under the age of 40 when they are diagnosed).

3.4. Motor neurone disease (MND): This is a rapidly progressive condition that can affect people of all ages; however, most people are diagnosed over the age of 40, with the highest incidence occurring between the ages of 50-70 years. The number of people living with MND at any one time is approximately 7 in every 100,000. Men are affected twice as often as women and although between 5-10% of people diagnosed may have an inherited or familial condition, in most cases the cause is unknown. Care and support is aimed at managing symptoms and reducing complications and distress. The speed at which MND can progress can provide a challenge to services given it is likely that the person will have rapidly changing needs, and a timely response will be required

3.5. Acquired brain injury/ traumatic brain injury (ABI/TBI): The sudden onset condition with varying levels of recovery which can affect anyone at any age. This is the impairment of brain function. Common causes are brain lesions caused by traumas such as car accidents, falls, assaults or sports injuries. Brain lesions that cause brain injury can also be due to tumours, bleeding and infections of the brain or due to poisoning from alcohol, drugs or via exposure to toxic chemicals. People with brain injury may experience a wide range of difficulties depending on the nature, location and severity of their brain injury.

4. Population health needs

4.1 Incidence and Prevalence

Although as a group LTNCs are relatively common, the number of people with individual conditions is rarely measured locally and it is difficult to obtain accurate data on specific conditions. Epilepsy is the only neurological condition where there is local data available from the General Practice Quality and Outcomes Framework (QOF).

It is therefore necessary to estimate the number of local cases using national research from various sources applied to the local population. Rates are available for ***incidence*** **-** which is the number of new cases diagnosed each year - and ***prevalence*** **-** which is the number of people living with the condition at any one time. Table 1 summarises incidence and prevalence estimates based on several pieces of national research. More detailed estimates are provided in Appendix 1.

Table 1: Estimated number of Halton residents with main LTNCs 2014 and projected to 2021 (rounded to nearest half and whole number)

Condition	Estimated incidence (number new cases per year)		Estimated prevalence (total number of cases)	
	2014	2021	2014	2021
Epilepsy[4]	63	65	888 - 1014	905 - 1034
MS[5]	4.5 - 5	4.5 - 5	136 - 148	138 - 151
PD[6]	5 - 25	5 - 26	127 - 228	129 - 233
MND[7]	2.5	2.5	9	9
ABI[8]	334	340	1522	1552
Other LTNC *(excluding headache category)*	-	-	2577	2628

4.2 Groups at increased risk of developing LTNC

For some LTNCs - e.g. PD - prevalence increases with age. Both PD and MND are more common in men than women. Conversely, women are twice as likely as men to develop MS. Epilepsy rates are 25% higher in the most socio-economically deprived areas.

The report by Emerson et al[9] showed that the risk of epilepsy is at least 20 times higher amongst those with learning disabilities than for the general population. The NHS Information Centre study into access to healthcare found that, of all people with epilepsy, those with learning disability had higher rates of seizures.[10] It was noted that patients with learning disabilities and epilepsy often have many different seizure types, which may be more difficult to treat. Whilst no Halton data is routinely available, analysis of GP records in Sefton and Knowsley demonstrated that this increased prevalence is seen locally as well as nationally. [11]

4.3. QOF epilepsy prevalence

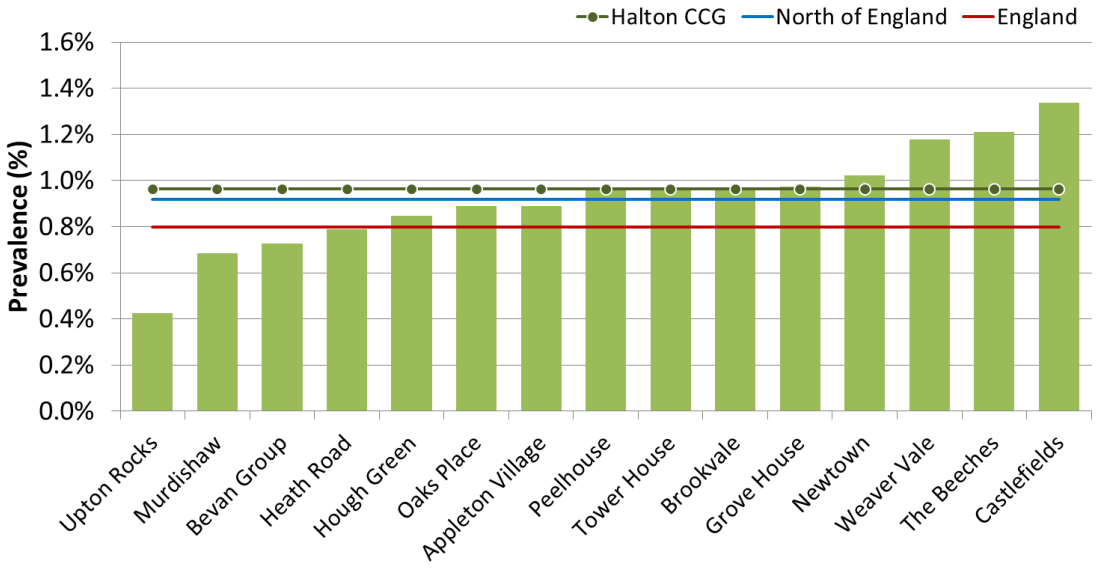
Epilepsy is the only long-term neurological condition which forms part of the GP contract known as the Quality Outcomes Framework (QOF). Within this there are a series of disease registers and national standards for their diagnosis and management within primary care. Good management

enables the individual to lead a normal life without the need for hospital treatment such as emergency admissions to hospital.

Figure 4: Recorded prevalence of Epilepsy (18+) in Halton GP Practices compared to Halton, the North and England, 2016/17

Source: QOF, NHS Digital

Proportion of list size who are on the epilepsy register



QOF prevalence rates across Halton GP practices vary from 0.43% to 1.34%, with an average across Halton CCG of 0.96%. This is slightly higher than the North of England and England rate but slightly below the Cheshire and Merseyside STP rate. This equates to between 11 and 129 patients per practice with a **total of 988 patients aged 18 and over on local GP registers**, an increase on the 2012/13 figure of 928 patients. The number of diagnosed patients sits at the lower end of the estimated prevalence figure. National estimates use age-specific rates that do not enable easy comparison as they do not sit across the same age bands as QOF data. It has therefore not been possible to calculate practice estimates to determine a level of under-diagnosis.

4.4. Mortality

A large prospective cohort study of almost 70,000 people with epilepsy for 40 years compared with their unaffected siblings and the general population found that of the people with epilepsy, 8.8% died prematurely, compared with just 0.7% of the general population. After taking social and demographic factors into account, the researchers estimated that people with epilepsy were 11 times more likely to die prematurely compared with people who did not have epilepsy.

The researchers estimate that epilepsy accounts for 0.7% of the disease burden worldwide and is associated with a substantial premature mortality. Almost half of the deaths associated with

epilepsy are among people aged under 55. Around 16% of all epilepsy-related deaths are caused by accidents (vehicle or otherwise) and 5% of are estimated to be from suicide.[12]

Studies of premature mortality for other LTNCs show similar issues. A Canadian study of nearly 7,000 MS patients found the mortality risk in the cohort was nearly three times greater than in the general population.[13] This level of mortality risk was also found in a UK study, where the standardised mortality ratio was 2.79 (95% CI 2.44 to 3.18), meaning MS patients were almost three times more likely to die prematurely relative to the general population.[14] This three-fold increase was also found in a Danish study.[15] A UK (Glasgow) study of adults hospitalised with mild head injuries found they had greater risk of death in the following 15 years than matched controls. They noted that the extent to which lifestyle and potential chronic changes in neuropathology explain these findings was unclear. Lifestyle factors do contribute to risk of death after mild head injury and this finding has implications for lifestyle management interventions. [16] TBI is also associated with increased mortality in older adults. [17]

The Primary Care Mortality Database (Open Exeter, 2017), showed that there were 56 deaths due to diseases of the nervous system in 2016; this equates to 4.5% of all deaths that year. 14 of these were due to PD and 19 were due to Alzheimer's disease[i]. Numbers of deaths from other types of LTNCs were less than 5 and cannot be published due to confidentiality reasons.

4.4. Lifestyle factors that affect the progression of LTNC

4.4.1. Tobacco Use

Tobacco smoking has been linked to an increased risk of MS. A UK study of 895 patients with a definitive diagnosis of MS found that regular smoking is associated with more severe disease and faster disability progression. In addition, quitting smoking, whether before or after onset of the disease, is associated with a slower progression of disability.[18] Indeed, tobacco smoking can account for some of the excess mortality associated with MS and is a risk determinant for all-cause and MS-related death.[19]

4.4.2. Physical activity

A Swedish study of 1.1 million male conscripts between 1950 and 1987, followed up for 40 years found that low cardiovascular fitness early in life was associated with an increased risk of epilepsy later in adulthood. They therefore suggest that behaviours that increase cardiovascular fitness may act as positive disease-modifiers for the development of epilepsy.[20]

4.4.3. Obesity

Obesity has been found, in a pooled analysis of 2 cohort studies, to be associated with an increased risk of MS. The body mass index (BMI) of 238,371 women in the US were obtained at age 18 and

[i] See annual dementia profile for Halton published by the Public Health Evidence & Intelligence Team

followed up in 40 years. Those with a BMI of ≥30 kg/m^2 and a large body size at age 20 years were associated with an increased risk of MS.[21] Although this association is not apparent in those found to be obese later on in adulthood, it suggests that obesity in young adulthood may contribute to the development of MS.

4.4.3. Alcohol

A systematic review and meta-analysis of the association between alcohol consumption and epilepsy was performed to examine the causality of unprovoked seizures. A strong and consistent association was found with a relative risk of 2.19 (95% confidence interval 1.83-2.63). A dose-response relationship was also found with the amount of alcohol consumed and the probability of onset of epilepsy, meaning that the more alcohol consumed, the higher the risk. Although no pathogenic mechanism has been proven, it was found that in most of the relevant studies, many alcohol users with epilepsy would qualify for the criteria of alcohol dependence.[22]

When looking at head traumas, The National Clinical Guideline Centre 2014 report on Head Injuries, commissioned by NICE, found that alcohol may be involved in up to 65% of adult head injuries in the UK.[23] Wernicke encephalopathy is a medically recognised consequence of alcohol abuse, characterised by the classic triad of nystagmus and ophthalmoplegia, mental status change, and ataxia. Korsakoff syndrome is an irreversible complication of Wernicke encephalopathy and is reported to develop in 85% of patients. [24] The consequences are long lasting and results in chronic abnormal memory function and learning.

4.4.4 Diet

Vitamin D has been shown in a few studies to have a possible role to play in the development of MS. In 2 cohorts of 187,563 women from the US, vitamin supplements were inversely associated with a risk of MS. [25] In support of this, a case-control study with 148 cases and 296 controls amongst US military personnel showed that high circulating serum levels of vitamin D are associated with a lower risk of multiple sclerosis amongst Caucasians (but not Blacks or Hispanics). [26] As vitamin D is available in sunlight, research has been performed around place of residency in early life. It was found that increasing distance from the equator correlated positively with a higher disease incidence of MS. Migration from a higher-risk area to a lower-risk area in childhood is associated with reduced risk. Although the inverse is also true, it was suggested that this risk relationship exists as long as the migration is made before the age of 15. [27] Like obesity, this is another factor in early life which may have a role to play in the development of MS.

Based on a prospective cohort study 24,773 Finnish men and 26,153 women aged 25-74 years without a history of PD and stroke at baseline were followed for a mean of 18.1 years. It was found that an increasing risk of PD was associated with increasing levels of serum total cholesterol in 25-54 year olds, irrespective of smoking status. No association was found between risk of PD and serum total cholesterol levels among patients ≥55 years old at baseline. [28]

5. Service Provision

Many different organisations, groups of staff, and others will be involved in the care of people with LTNCs. For most people this will mean looking after themselves with the support of a carer or carers. It could also mean receiving community support from voluntary, community and faith agencies; and receiving advice on how to manage their condition from a self-help group, or an 'Expert Patient Programme' which is designed to give them the confidence, skills and knowledge to be independent and take control of their lives. Depending on which condition a person has they should be on their GP's records and receive regular reviews to make sure they are still happy with their treatment and any medications they receive remain appropriate.

People with more complex needs - perhaps involving multiple conditions - will have support from more specialist services.

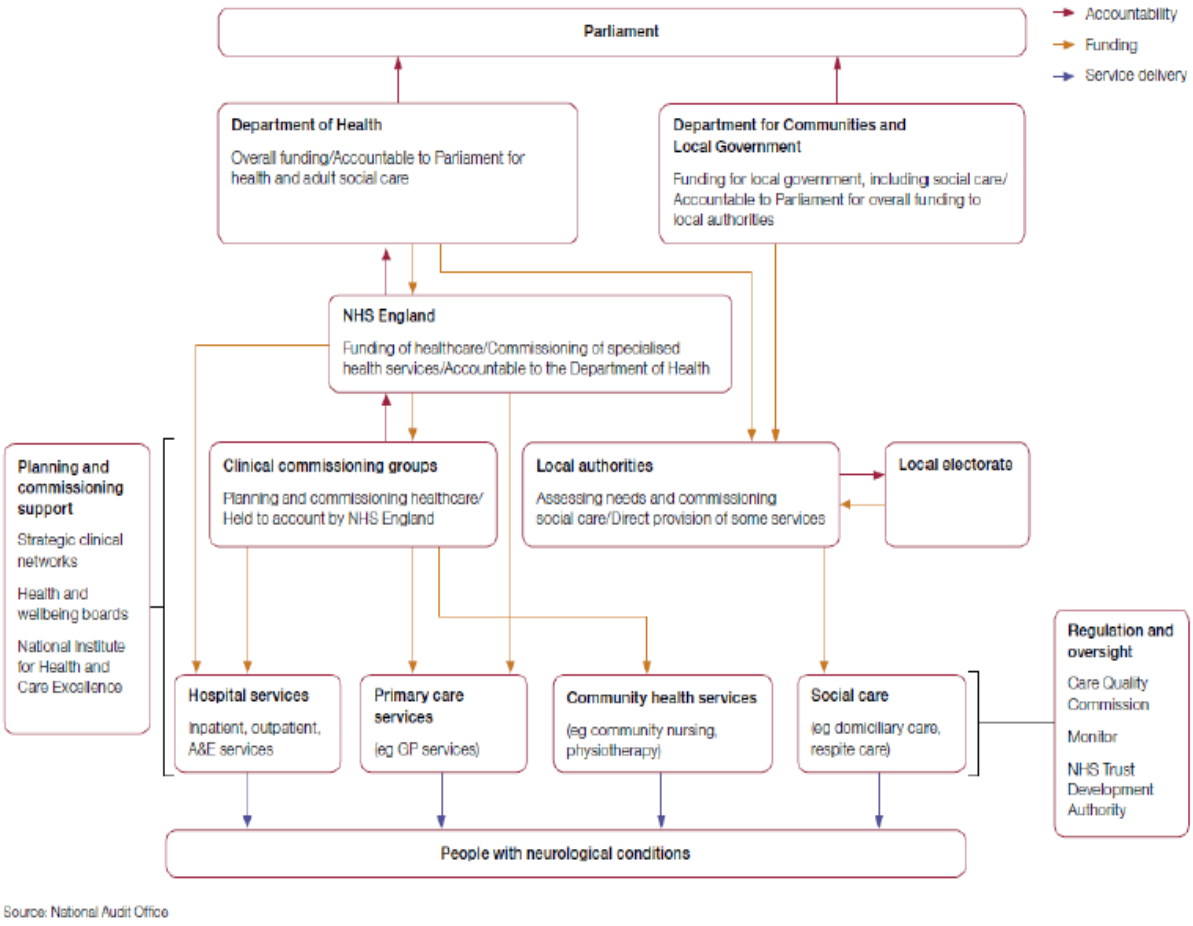
Specialist care is provided by consultant neurologists working within a network of specialist nurses, neurophysiotherapists, occupational therapists, speech and language therapists, neuropsychologists, psychotherapists, physicians and surgeons, including GPs with a special interest in conditions such as epilepsy, PD or headache. The Royal College of Physicians recommends that the patient with a neurological illness should be able to easily access a neurology network that includes services at a district general hospital, neuroscience centre and regional neurosciences centre.[29]

5.1. National Service Configuration for Neurological Conditions

Figure 5 gives an overview of the different domains of services provided for people with neurological conditions, and the accountability and funding structures for these services nationally.

This illustrates that health services are commissioned by clinical commissioning groups and specialised commissioners in NHS England, whilst social care services are commissioned by local authorities

Figure 5: Accountability and funding of neurological services



Source: National Audit Office

Support is provided to commissioners from various sources, including Strategic Clinical Networks and Public Health Teams in local authorities.

The Invisible Patients: Revealing the State of Neurology Services, 2015

This national report by the Neurological Alliance provides a perspective on neurological services from a large service-user survey with over 6,900 respondents, and an audit of commissioning of neurological services across the country.

While there are positive findings about the quality of care received by patients after they have received a formal diagnosis, the report raises concerns that neurological services remain under-prioritised and under-resourced, with significant variation in the quality and accessibility of services in different areas.

The report highlights concerns around the commissioning of services, with only 20.4% of Clinical Commissioning Groups (CCGs) actively assessing the number of people using neurological services

locally, and only 14.7% of CCGs having made an assessment of the local costs of providing neurology services, the impact of which is summarised below:

'If CCGs do not assess their patient populations and the burden of neurological conditions, they cannot be in a position to accurately and reliably ensure the infrastructure is in place to support the appropriate provision of local services. Furthermore, without understanding the number of patients using services locally, or the outcomes being achieved, CCGs will struggle to assess needs and priorities for improvement, or to accurately and reliably measure service quality and effectiveness.'

The report makes recommendations to be considered at both national and local levels, including the importance of CCGs improving their understanding of this patient group and the services currently being provided, and ensuring this is under regular review:

- Every CCG should collate up to date and accurate local neurology data underpinned by routine and rigorous assessments of the prevalence of neurological conditions and of the number of people using neurological services locally
- The Department of Health and NHS England should ensure that the time taken to reach a stable and accurate neurological diagnosis following first consultation is tracked and scrutinised with information shared widely to encourage and identify best practice
- NHS England should develop a robust action plan, building on the work of NHS Improving Quality, to raise usage of care plans nationally
- Local and national commissioners should regularly review utilisation of the care and support services available to patients and ensure that every person with a neurological condition has appropriate and rapid access to the full range of services that they need
- All CCGs should ensure that mechanisms are put in place to encourage and capture patient feedback and input in regards to the quality and development of local neurology services
- CCGs should work in partnership to identify clinical and research trial opportunities locally and support the appropriate sharing of information on such opportunities with patients
- Every CCG should ensure that it has made a full assessment of costs relating to the provision of neurology services to people in their area including a clear understanding of wider costs for services commissioned by NHS England
- CCGs should engage in regular communication with their NHS England area team about the commissioning of neurological services, taking a proactive approach to ensuring a shared and full understanding of neurological service commissioning, sharing information with the Neurology Intelligence Network
- People with neurological conditions have a range of needs, many of which are supported from outside of formal neurological services
- CCGs should engage with their local dementia, mental health and neurology SCN regarding their local neurological strategy, with NHS England establishing a formal requirement for them to do so

5.2. Care in General Practice

As stated in section 4.3, part of the GP contract involves offering standardised management packages based on best available evidence.

Work by the Neurological Alliance[30] showed that:

- Most people with a LTNC saw their GP five or more times before they were referred to a neurological specialist
- The majority waited more than 12 months from first noticing their symptoms to seeing a neurological specialist

A follow on report[31] to examine in more detail the issues affecting patients' transition from primary to secondary care explored some key issues:

- confidence in assessment and referral
- training needs
- access to services
- system architecture

The results strongly suggested that there are significant issues affecting the primary care transition for people with neurological conditions. GPs do not have confidence that the people they refer with a suspected neurological condition are accessing services in a timely manner, with significant concerns around levels of access to secondary care services including neurological specialists, multidisciplinary teams (MDTs), and CT and/or MRI scans. Furthermore, our findings indicate that the significant majority of GPs feel that they may benefit from further training and support on identifying the signs and symptoms of neurological conditions and how to best manage them.

The report made a number of recommendations including:

- Easy to access 'watch list' of signs and symptoms to look out for
- Improvements in initial medical education and in practice support
- Collection of case studies housed by NHS England's Academic Health Science Networks and Clinical Networks across the country
- Introduction by NHS England of a national minimum access standards, plus, ensuring the effective roll-out of commissioning for value data packs to hold both commissioners and service providers to account
- CCGs to give an appropriate level of consideration to the service pathway for people with neurological conditions, including the transition from primary to secondary care, and ensure that neurology is included in short and long-term strategic planning
- The role of specialist nurses in freeing up the capacity and resources of neurologists, who receive such referrals, within secondary care should be locally assessed and augmented
- Continuation and further development of the Public Health England and NHS England funded Neurology Intelligence Network dataset

5.2.1. QOF

Within QOF, the disease register for epilepsy no longer includes any routine management indicators.

However, there are a range of NICE neurological conditions pathways:

- Epilepsy
- Headaches including migraine
- Motor Neurone Disease
- Multiple sclerosis
- Neuropathic pain
- Parkinson's Disease

All contain actions for primary care including medicines management.

5.2.2. Prescribing

As shown in Table 2, Halton CCG spends more on prescribing (relative to its population size) than the England average.

Table 2: NHS Prescribing data for Central Nervous System (CNS) related conditions, Total NiC[ii] per 10,000 population, National Outcome and CCG Difference from National Outcome, 2016/17

Prescription Group	Halton CCG	England	Difference from England
Analgesics	£131,900	£95,125	£36,775
Antidepressant Drugs	£56,475	£46,770	£9,705
Antiepileptics	£167,604	£101,433	£66,171
CNS Stimulants and drugs used for ADHD	£2,420	£9,227	-£6,807
Dementia	£3,004	£4,878	-£1,874
Nausea And Vertigo	£9,884	£6,540	£3,343
Park'ism/Related Disorders	£26,614	£21,857	£4,756
Psychoses & Related Disorders	£9,725	£15,068	-£5,343
Substance Dependence	£12,692	£9,826	£2,866
Treatment of Obesity	£3,739	£1,651	£2,088
Hypnotics And Anxiolytics	£16,571	£11,683	£4,888
Total	£440,628	£324,059	£116,569

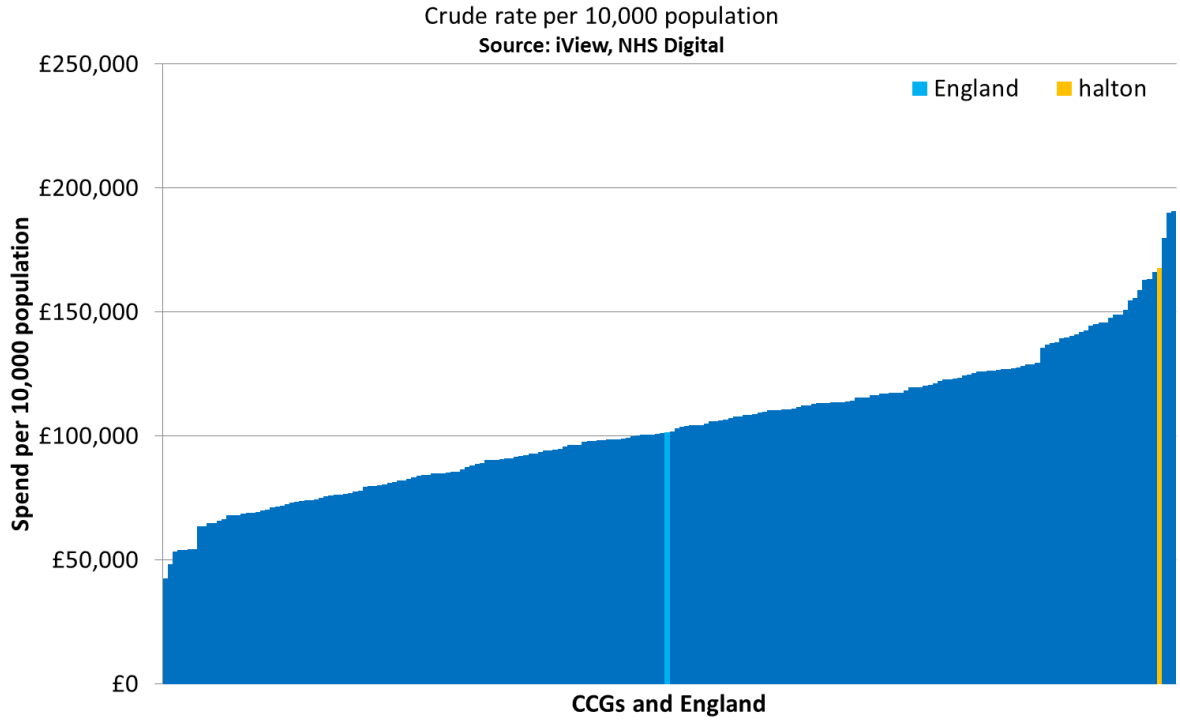
Source: iView, NHS Digital, 2017

Spend on Epilepsy medications are higher than for any other CNS-related condition. Figure 6 shows that Halton CCG has amongst the highest prescribing costs for Epilepsy in England. The rate of spend

ii *NiC is the basic cost of drugs. It does not take account of discounts, dispensing costs, fees or prescription charges income.*

on antiepileptic prescriptions ranges from £42,492 for NHS Aylesbury Vale CCG to £190,658 for NHS Knowsley CCG.

Figure 6 Prescribing data for Antiepileptics Total NiC[ii] per 10,000 population - England and CCG 2016/17



5.3 Community healthcare

Neurological Rehabilitation Service (HNRS) – Halton

The Neurological Rehabilitation Service (HNRS) for Halton is provided by Bridgewater Community Healthcare NHS Foundation Trust. It is a community-based team of experienced health professionals with the knowledge and skills to provide highly specialist assessments, advice, support and rehabilitation for people with neurological conditions and their families.

The core focus of the service is to improve the quality of life for people living with the effects of long term neurological conditions (including acquired brain injury), by supporting them to achieve their optimal cognitive, physical, behavioural, and emotional levels of functioning with the goal of maximising their re-integration into the community.

The service can be accessed by adults over 18 years who have a Halton GP. Referrals can be made by any health or social care professional. Self-referrals can be made but contact will be made with the GP or Consultant to confirm a neurological diagnosis and to gather relevant medical history. The service can be offered in the patient's own home, place of work or at the Independent Living Centre in Runcorn.

Information accessed from http://www.bridgewater.nhs.uk/haltonsthelens/neurologicalrehabilitationservice/
On 18 January 2018

5.4. Hospital Admissions

The latest data with national comparators is for 2015/16. It shows that for inpatient and day-case admissions with a mention of neurological conditions, the rate per 1,000 population registered with a GP practice in Halton was above the England average. In particular, ordinary inpatient admissions for patients in Halton CCG was the 8th highest of all the CCGs in England.

Figure 7: Rate of day case admissions and ordinary inpatient admissions, patients aged 20 and over with mention of neurological condition by CCG, 2015/16

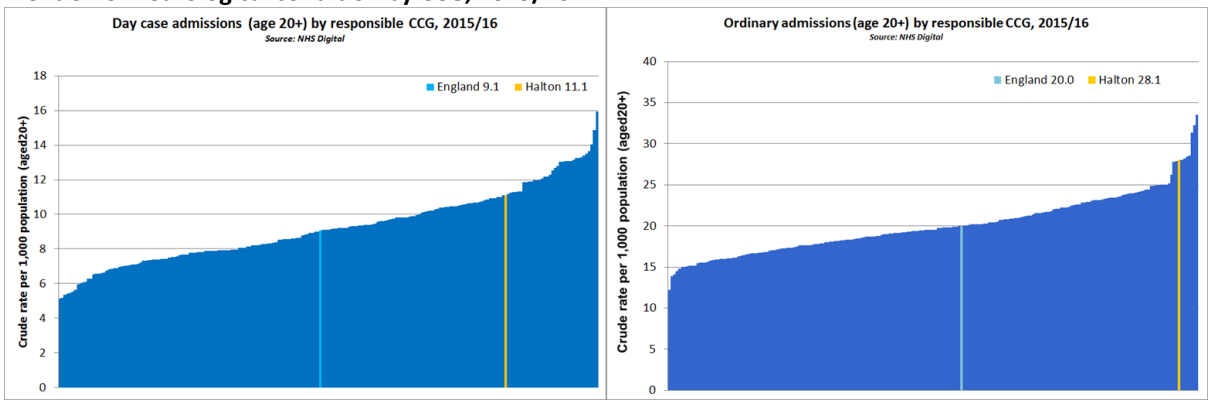
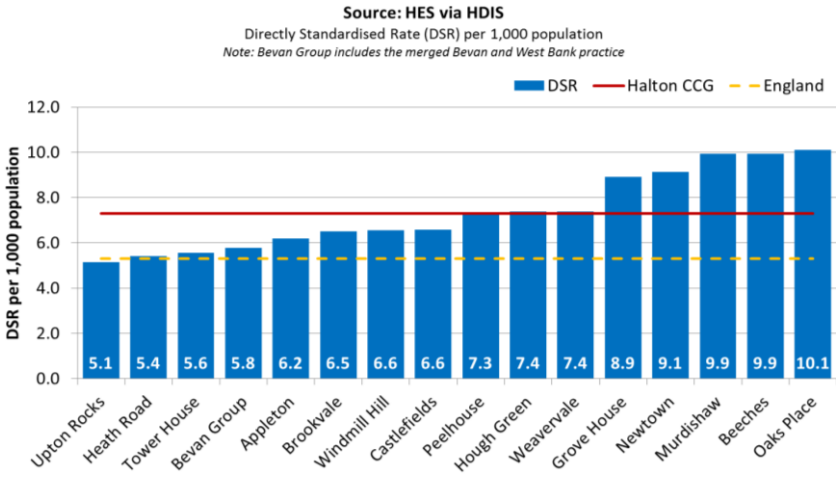


Figure 8 illustrates the rates (per 1,000 population) of admissions by patients at Halton GP practices, due to LTNCs. The actual number of such admissions ranged from 15 to 102 across the Halton practices. The rates however ranged from 2.9 at Upton Rocks, to 10.1 at Oaks Place. The rate was higher in 15 of the 16 Halton GP practices than it was in England (5.3 per 1,000 population) and, as a result the Halton CCG overall rate (7.3 per 1,000 population) was higher than England.

Figure 8: Standardised admission rates for LTNC[iii], Halton practices and comparators 2016/17, rate per 1,000 population



[iii] *Criteria for Long-Term Conditions (LTNCs) is based on that defined on Page 79, NHS RIghtCare Commissioning for Value Focus Pack: Neurological, April 2016*

However, the picture changes slightly when we focus on emergency admissions for LTNCs. Although Upton Rocks remains the practice with the lowest rate of admissions 2.4 per 1,000 population), Murdishaw has the highest rate of emergency LTNC admissions (8.4 per 1,000 population). For all apart from Upton Rocks, the vast majority of the LTNC admissions came through an emergency route; particularly for Windmill Hill (100%) and Grove House (92.4%).

Figure 9: Standardised emergency admission rates for LTNC, Halton practices and comparators 2016/17, rate per 1,000 population

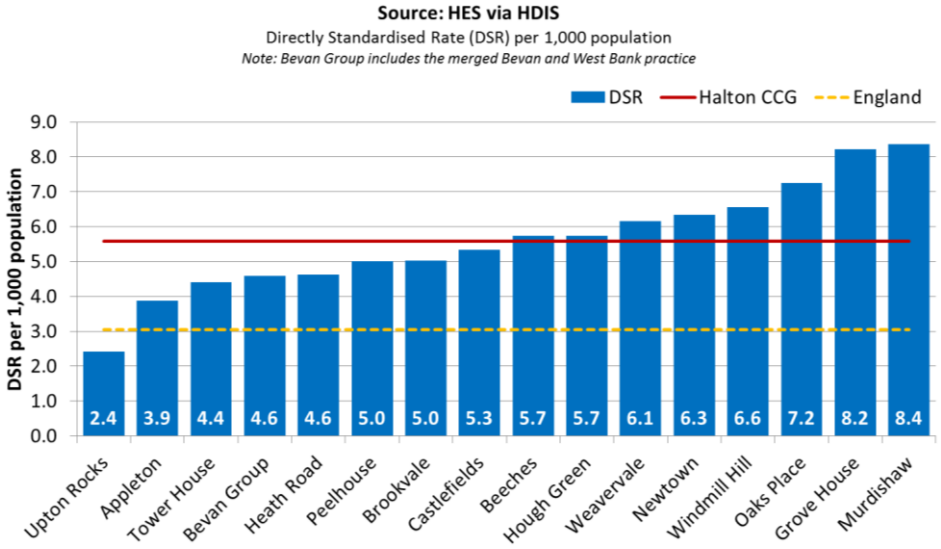


Table 3: Total and emergency admissions, by GP practice, 2016/17

GP Code	GP Name	Total	Emergency	% Emergency
N81651	Upton Rocks	16	8	50.0%
N81037	Beeches	77	46	59.7%
N81035	Appleton	63	41	65.1%
N81045	Peelhouse	102	71	69.6%
N81064	Newtown	66	47	71.2%
N81619	Oaks Place	29	21	72.4%
N81011	Bevan Group	82	64	78.0%
N81096	Brookvale	51	40	78.4%
N81119	Hough Green	29	23	79.3%
N81057	Tower House	74	59	79.7%
N81019	Castlefields	75	60	80.0%
N81054	Weavervale	65	54	83.1%
N81072	Murdishaw	66	56	84.8%
N81618	Heath Road	15	13	86.7%
N81066	Grove House	92	85	92.4%
Y02512	Windmill Hill	16	16	100.0%
	Halton CCG	918	704	76.7%

Source: HES via HDIS

Apart from ABI/TBI, neurological conditions tend not to initially present as an emergency/unplanned admission in their own right (primary diagnosis). It is often a complication of the condition which precipitates a deterioration of the condition (secondary diagnosis).

When comparing people with MND, MS and PD to the general population, those with LTNC have longer stays in hospital than their non-LTNC peers irrespective of the primary reason for the admission. This could be because when the person is managed in a non-neurological setting, the staff do not have the specialist knowledge nor access to neurological expertise, are unaware of care plans and/or do not have the requisite equipment. In particular, timely medication management for people with PD is important to avoid destabilisation of the condition.

The average length of stay (LOS) following an emergency admission where there is a mention of a neurological condition(s) is lower in NHS Halton CCG than Cheshire & Merseyside, but higher than England.

Table 4: Estimated inpatient discharges and length of stay (LOS in days) on admissions with a mention of a neurological condition, England STPs, age 20+ (discharges where length of stay is less than 100 days)

		NHS Halton CCG	Cheshire & Merseyside	England
2012/13	Bed usage	15,175	266,042	1,073,029
	Discharges	2,074	34,958	197,629
	Mean LOS (Days)	**7.32**	**7.61**	**5.43**
2013/14	Bed usage	15,612	280,466	1,107,176
	Discharges	2,125	37,508	205,327
	Mean LOS (Days)	**7.35**	**7.48**	**5.39**
2014/15	Bed usage	16,295	297,632	1,137,172
	Discharges	2,383	40,813	213,266
	Mean LOS (Days)	**6.84**	**7.29**	**5.33**
2015/16	Bed usage		326,168	1,166,123
	Discharges		42,893	221,836
	Mean LOS (Days)		*7.60*	5.26

Source: Public Health England, Neurology Intelligence Network

The highest rate of emergency admissions was for headache & migraine, followed by epilepsy. Most often the primary reason for admission is not the neurological condition itself. Excluding mentions of headaches & migraines, urinary tract infections are especially associated with admissions amongst people with LTNC.[32][33] These are potentially preventable as well as treatable in primary care if caught early enough. It has been suggested that investing in anticipatory services could reduce unnecessary admissions and patient distress, and improve patient care. These anticipatory measures could include improved education of both people with LTNCs and their GPs as well as expanding the availability of specialist nurses and continence advisors.

Table 5: Emergency hospital admissions with a mention of a neurological condition, NHS Halton CCG, persons age 20+

CCG of responsibility and primary diagnosis on admission episode	2012/13	2013/14	2014/15	2015/16
NHS Halton CCG	**1,920**	**1,971**	**2,211**	**2,248**
Ataxia	0	0	*	*
CNS infections	17	15	16	21
Cranial nerve disorder	18	23	20	15
Development disorders	*	*	*	*
Epilepsy	192	159	182	158
Functional Disorders	*	*	*	9
Headaches and migraine	229	223	270	291
Motor neurone disease and Spinal muscular atrophy	*	*	*	*
Multiple sclerosis and inflammatory disorders	6	*	*	9
Neuromuscular diseases	12	12	*	*
Parkinsonism and other Extrapyramidal disorders/Tic disorder	16	13	11	15
Peripheral nerve disorders	*	16	8	10
Rare and other neurological diseases	46	45	36	56
Sleep disorders	0	*	0	0
Spondylotic myelopathy and Radiculopathy	18	25	37	27
Traumatic brain and spine injury	57	64	53	72
Tumours of the nervous system	17	23	10	24
Other primary diagnosis on admission	1,279	1,339	1,549	1,531

Source: Public Health England, Neurology Intelligence Network

Table 6: Inpatient discharges and length of stay (LOS) on admissions with a mention of a neurological condition, England CCGs, age 20+ (by neurological condition group - emergency admissions)

Emergency admissions	2012/13			2013/14			2014/15		
	Bed usage	Discharges	Mean LOS (Days)	Bed usage	Discharges	Mean LOS (Days)	Bed usage	Discharges	Mean LOS (Days)
All neurological conditions	**15,175**	**2,074**	**7.32**	**15,612**	**2,125**	**7.35**	**16,295**	**2,383**	**6.84**
Ataxia	30	*					8	*	
Central nervous system infections	134	16	8.38	316	22	14.36	182	18	10.11
Cranial nerve disorder	74	24	3.08	27	20	1.35	42	24	1.75
Development disorders	5	*		90	*		106	*	
Epilepsy	548	196	2.80	655	168	3.90	489	191	2.56
Functional Disorders	31	*		62	6	10.33	73	7	10.43
Headaches and migraine	386	260	1.48	373	247	1.51	428	300	1.43
Motor neurone disease and Spinal muscular atrophy	2	*		38	*		25	*	
Multiple sclerosis and inflammatory disorders	60	6	10.00	157	6	26.17	162	7	23.14
Neuromuscular diseases	131	12	10.92	280	14	20.00	23	*	
Parkinsonism and other Extrapyramidal disorders/Tic disorder	590	26	22.69	221	15	14.73	409	22	18.59
Peripheral nerve disorders	73	9	8.11	204	22	9.27	160	10	16.00
Rare and other neurological diseases	324	43	7.53	303	47	6.45	602	53	11.36
Sleep disorders				4	*		2	*	
Spondylotic myelopathy and Radiculopathy	99	23	4.30	142	30	4.73	245	35	7.00
Traumatic brain and spine injury	616	60	10.27	629	65	9.68	484	51	9.49
Tumours of the nervous system	154	23	6.70	270	27	10.00	177	16	11.06
All other primary diagnosis	11,918	1,365	8.73	11,841	1,427	8.30	12,678	1,635	7.75

Source: Public Health England, Neurology Intelligence Network

Mean LOS has decreased slightly despite an increase in bed usage and discharges. There is significant variation in LOS across individual LTNCs reflecting the wide variety of conditions within the category. For some conditions average LOS has increased, notably central nervous system infections, MS and inflammatory disorders, peripheral nerve disorders, tumours of the nervous system and rare and other neurological disorders.

5.5. Outpatients appointments

Outpatient data also shows all but one practice in Halton (Windmill Hill) had outpatient standardised rates higher than that of England. The rate in Halton was 118.7 per 1,000 population, which was significantly higher than the rate of England. In fact 15 of the 16 practices in Halton had a significantly higher rate of such attendances than England.

Table 7: Outpatient attendances for Neurological treatment specialties by patients aged 16+, 2016/17

GP Name	Total	DSR
Brookvale	421	143.9
Weaver Vale	471	130.7
Castlefields	624	130.6
Beeches	411	130.2
Oaks Place	151	129.9
Murdishaw	353	125.0
Peelhouse	696	120.5
Grove House	530	117.3
Bevan	670	116.1
Appleton Village	495	115.4
Tower House	584	108.0
Hough Green	157	106.0
Upton Rocks	118	101.9
Heath Road	108	101.2
Newtown	300	98.9
Windmill Hill	47	55.7
Halton CCG	6136	118.7
England	2489105	56.7

Source: HES via HDIS

Table 8: Number of outpatient attendances for Halton CCG for Neurological Treatment Specialties, by age group, 2016/17

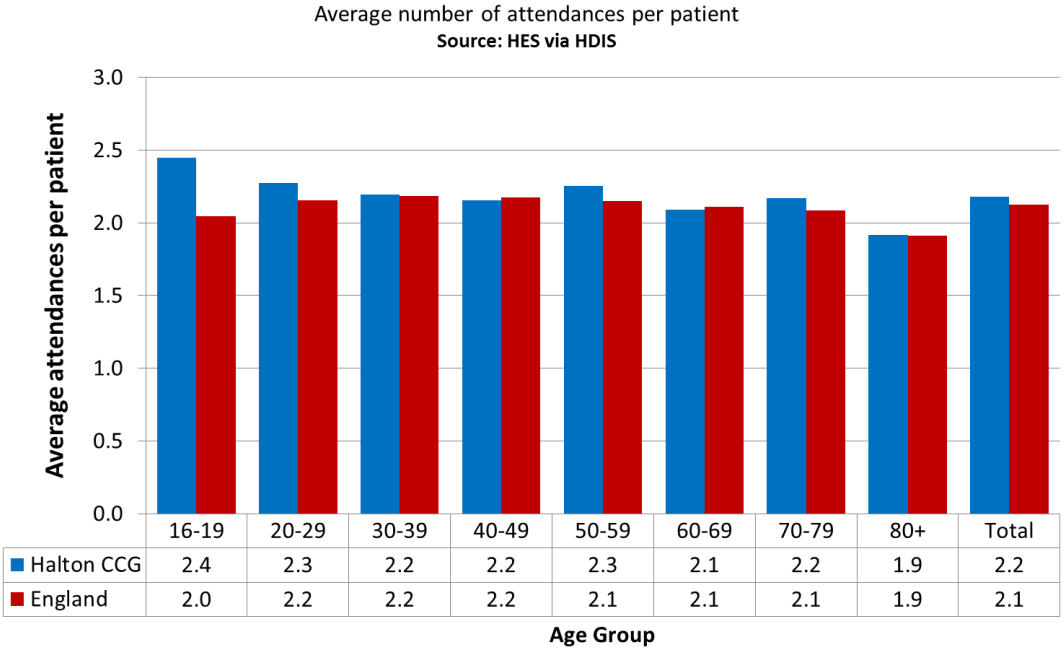
	Outpatient Appointments		Distinct Neurology outpatients	
Age Group	Number	% of total	Number	% of total
16-19	247	4.0%	101	3.5%
20-29	636	10.3%	287	9.9%
30-39	853	13.9%	397	13.8%
40-49	1203	19.6%	571	19.8%
50-59	1239	20.1%	569	19.7%
60-69	1048	17.0%	513	17.8%
70-79	668	10.9%	314	10.9%
80+	255	4.1%	135	4.7%
Total	6149		2887	

Source: HES via HDIS, 2018

There is very little difference in the average number of attendances per patient across the age bands specified. The lowest was 1.9 attendances per patient for those aged 80 and over and the highest was 2.4 for those aged 16-19. The one trend that does appear is that as the age groups increase in

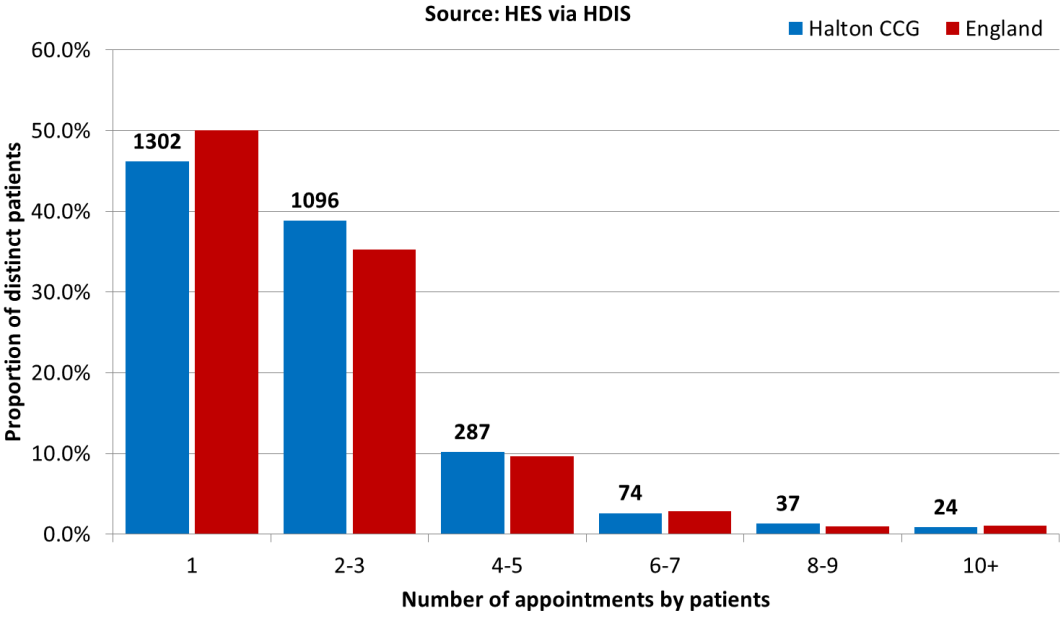
Halton CCG, the average number of attendances per patient reduces slightly. The only discernible difference was the higher number of appointments per patient in the 16-19 age group in Halton CCG (2.4 per patient) compared to England (2.0 per patient).

Figure 10: Average number of outpatient appointments per patient in each age band, 2016/17



	16-19	20-29	30-39	40-49	50-59	60-69	70-79	80+	Total
Halton CCG	2.4	2.3	2.2	2.2	2.3	2.1	2.2	1.9	2.2
England	2.0	2.2	2.2	2.2	2.1	2.1	2.1	1.9	2.1

Figure 11: Number and proportion of distinct patients and outpatient appointments per patient for all Neurological Treatment Specialties, England and CCG 2016/17



Three providers make up 97% of all outpatient appointments, with the Walton Centre NHS Foundation Trust being the largest single provider (80.3%). This is a specialist neurology and pain centre located in Fazakerley, Liverpool and is the only specialist neurosciences NHS Trust in the UK.

Their specialist staff offer a world class service in diagnosing and treating injuries and illnesses affecting the brain, spine, peripheral nerves and muscles; and in helping people suffering from long term neurological conditions.

The other two main providers are the district general hospitals that service the borough. The breakdown can be seen in Table 9.

Table 9: Top 3 providers for all Neurological Treatment Specialties, outpatient appointments for Halton CCG registered population 2012/13

Provider Name	Total	% of Total
The Walton Centre NHS Foundation Trust	4935	80.3%
Warrington And Halton Hospitals NHS Foundation Trust	624	10.1%
St Helens And Knowsley Hospitals NHS Trust	405	6.6%
Total Top 3	5964	97.0%
Total Halton CCG	6149	

5.6. NHS Spend and Outcomes

Spend per programme area is collated by NHS England. The latest available year is currently 2013/14. It shows that proportionately a larger amount is spent on prescribing and on non-elective care within the neurological conditions category than the overall budget for NHS Halton CCG.

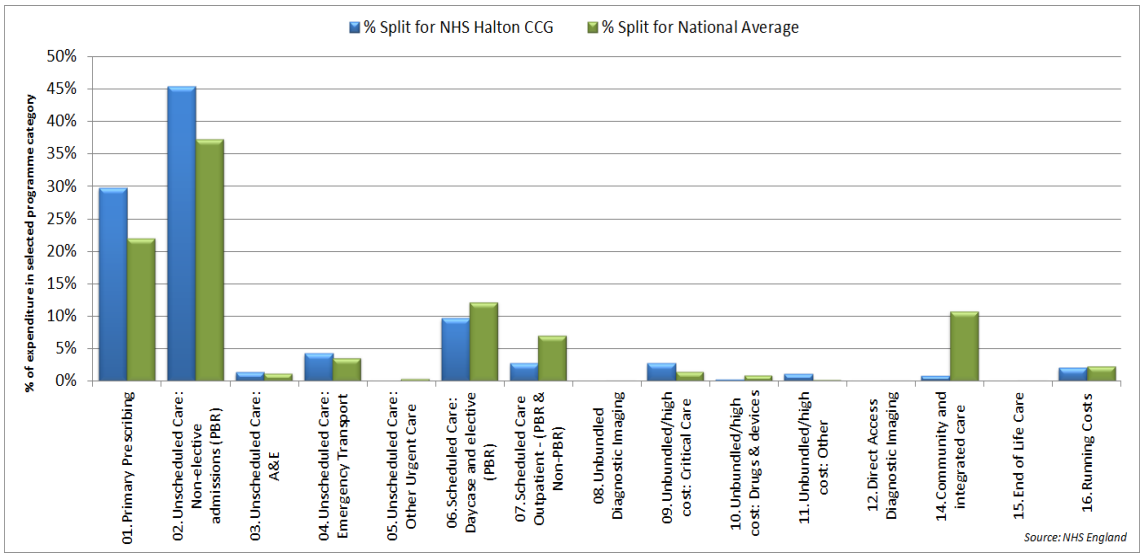
Table 10: Programme Budgeting: NHS Halton CCG expenditure for neurological conditions, £ per 100,000 population and as a percentage per care setting, total programme and subcategories, 2013/14

Programme Budgeting category	07.Neurological		07a.Chronic pain		07x.Neurological (Other)		Total CCG Expenditure	
	spend per 100,00 population (£)	% per care setting	spend per 100,00 population (£)	% per care setting	spend per 100,00 population (£)	% per care setting	spend per 100,00 population (£)	% per care setting
Primary Prescribing	1,448,682	*29.7%*	146,601	*8.2%*	1,302,081	*42.2%*	15,506,330	*13.4%*
Unscheduled Care: Non-elective admissions (PBR)	2,213,557	*45.4%*	1,138,872	*63.6%*	1,074,684	*34.8%*	19,250,433	*16.7%*
Unscheduled Care: A&E	65,713	*1.4%*	-	*0.0%*	65,713	*2.1%*	3,122,021	*2.7%*
Unscheduled Care: Emergency Transport	208,392	*4.3%*	15,209	*0.9%*	193,183	*6.3%*	2,946,498	*2.6%*
Scheduled Care: Daycase and elective (PBR)	469,343	*9.6%*	299,895	*16.8%*	169,448	*5.5%*	13,048,185	*11.3%*
Scheduled Care Outpatient - (PBR & Non-PBR)	132,506	*2.7%*	101,743	*5.7%*	30,764	*1.0%*	10,693,411	*9.3%*
Unbundled/high cost: Critical Care	134,093	*2.8%*	-	*0.0%*	134,093	*4.3%*	2,546,256	*2.2%*
Unbundled/high cost: Drugs & devices	12,584	*0.3%*	-	*0.0%*	12,584	*0.4%*	2,204,334	*1.9%*
Unbundled/high cost: Other	54,483	*1.1%*	31,946	*1.8%*	22,536	*0.7%*	1,497,500	*1.3%*
Community and integrated care	38,897	*0.8%*	19,257	*1.1%*	19,640	*0.6%*	39,487,949	*34.2%*
Running Costs	97,969	*2.0%*	36,093	*2.0%*	61,875	*2.0%*	1,923,436	*1.7%*
Total	4,876,219	*100%*	1,789,617	*100%*	3,086,602	*100%*	115,477,559	*100%*

Source: NHS England

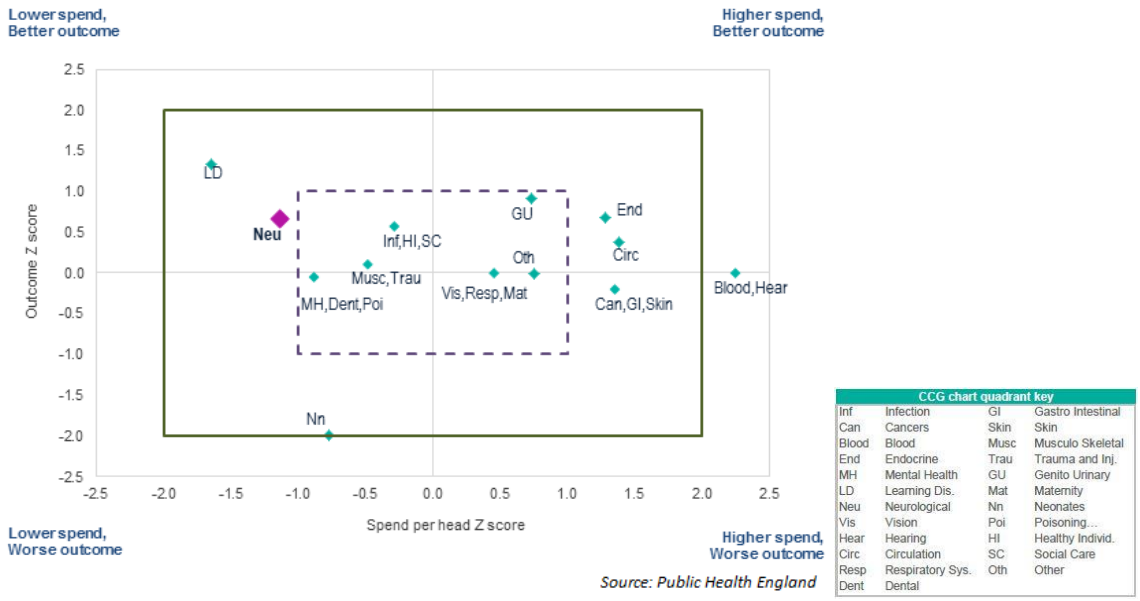
Compared to England the CCG spends a higher proportion of its neurological budget on prescribing and non-elective care, but less on elective care and community & integrated care.

Figure 12: Expenditure percentage splits across care settings, NHS Halton CCG compared to England, 2013/14



In terms of spend on LTNCs compared to outcomes, the Spend & Outcomes Tool (SPOT) developed by the Association of Public Health Observatories (now part of Public Health England) shows that Halton CCG had similar spend relative to other CCGs for 2015 and resulted in better outcomes (see Figure 13). SPOT uses mortality from epilepsy under age 75 as the outcome measure against which overall spend for LTNC is compared.

Figure 13: Spend and outcome for NHS Halton CCG relative to England's other CCGs, by programme area 2015



5.7. Social Care

Social care commission and provide a significant amount of care for those with LTNCs. However the focus is on client groups, levels of disability and need rather than on medical diagnosis.

Many of the services accessed by those with LTNCs are also generic services. Data submitted as part of annual returns is divided into two broad age categories, 18-64 and 65+. Data on long-term support is also split into primary support needs, including physical needs. Although those with LTNCs will only constitute a small proportion of those receiving social care for this reason, the data nevertheless demonstrates a high level of need in Halton, compared to the North West and especially compared to England.

Table 11: Adult Social Care clients accessing Long Term support, by age band and primary support reason being physical support, 2016/17, crude rate per 100,000 population

		18-64	65+
Physical support combined	England	218.91	2919.30
	North West	247.54	3327.24
	Halton	281.78	3570.79
Physical support: access and Mobility	England	49.14	434.09
	North West	60.37	529.14
	Halton	117.95	1616.96
Physical support: personal care support	England	169.78	2485.22
	North West	187.17	2798.10
	Halton	163.82	1953.83

Source: NHS Digital

Services provided need to be adaptable to meet individual need and respond effectively to changes in the patients' condition. Links with self-care and their resources for this group of patients is vital to improving self-management of their disease.

The promotion of access to timely palliative care for patients can enable those diagnosed as end of life, the access to symptom control, adequate pain relief and provide personal, social and spiritual support.

5.8. Third Sector Organisations

One of the real difficulties for commissioners aspiring to improve services for people with neurological conditions relates to the many disparate conditions this term embraces. How to gather intelligence about prevalence of different conditions? How to plan services which need to be tailored to individual needs? How to avoid inefficient use of scare resources? How to access information that can really make a difference? Regional Neurological Alliances (RNAs) represent an opportunity to access patient perspectives and collaboration, in the development and commissioning of neurological services. For Merseyside and Cheshire this operates via ***Neurosupport.*** They offer advice and support to people newly diagnosed, those managing their condition as well as for their carers, family and friends. The service is based in Liverpool and details are available on their website at **http://www.neurosupport.org.uk/**

6. Impact of LTNCs on the individual and society

Some neurological conditions are life threatening, many severely affect quality of life and cause lifelong disability. The effects of neurological conditions can result in reduced independence and have an impact on education, family, social relationships and a person's ability to work. They also have a significant impact on the carers and families of those living with the condition. Caring for someone with a debilitating illness often means that carers have to give up their own employment, in addition to the person with the condition being unable to continue to be economically active. This will have a devastating impact on the family's economic situation.

People with LTNCs who do not access work, who fail to return to work after injury or onset or who are encouraged to relinquish work prematurely may be financially disadvantaged, more prone to bankruptcy,[34] have a poorer quality of life[35] and suffer adverse health outcomes such as anxiety and depression.[36][37] For example, returning to work or education is a major goal for many people who sustain a traumatic brain injury (TBI) but only about 41% are in work at one and two years post injury.[38] These consequences result in increased consumption of health resources including GP services and consultant contacts. Despite protection from discrimination by the Equality Act 2010, they are also less likely to be gainfully employed and more likely to be in poorly paid jobs, disadvantaged in promotion and to take early retirement than their peers.[39]

It is important to recognise the wider determinants of health and their role in enabling people to live as independently as possible. This may include access to housing adaptations or relocation, and support in claiming benefits. The current welfare reforms are likely to impact on people with neurological conditions, particularly those retired or claiming long-term sickness/disability benefits.

6.1. Disability Living Allowance

The most recent data on benefits is for February 2014 and so uses the old classifications of Disability Living Allowance (DLA) and Incapacity Benefit/ Severe Disablement Allowance (IB/SDA). Data from NOMIS shows there are a total of 140 people on DLA due to Epilepsy, 80 due to MS, 30 due to PD, 50 due to chronic fatigue syndromes and 280 due to neurological diseases.

Table 12: Number of Halton DLA claimants by specific Neurological Condition and age group, at May 2017[iv]

	<16		16-24		25-49		50-65		65+	
Disabling condition	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male
Epilepsy	80	60	20	10	~	~	30	20	20	10
Multiple Sclerosis	50	20	~	~	~	~	10	10	20	10
Parkinson's Disease	10	20	~	~	~	~	~	~	~	~
Chronic Fatigue Syndromes	40	10	~	~	~	~	10	~	20	~
Neurological Diseases	130	140	30	40	10	10	30	30	30	30

~ These figures are nil or negligible.

Source: ONS via NOMIS

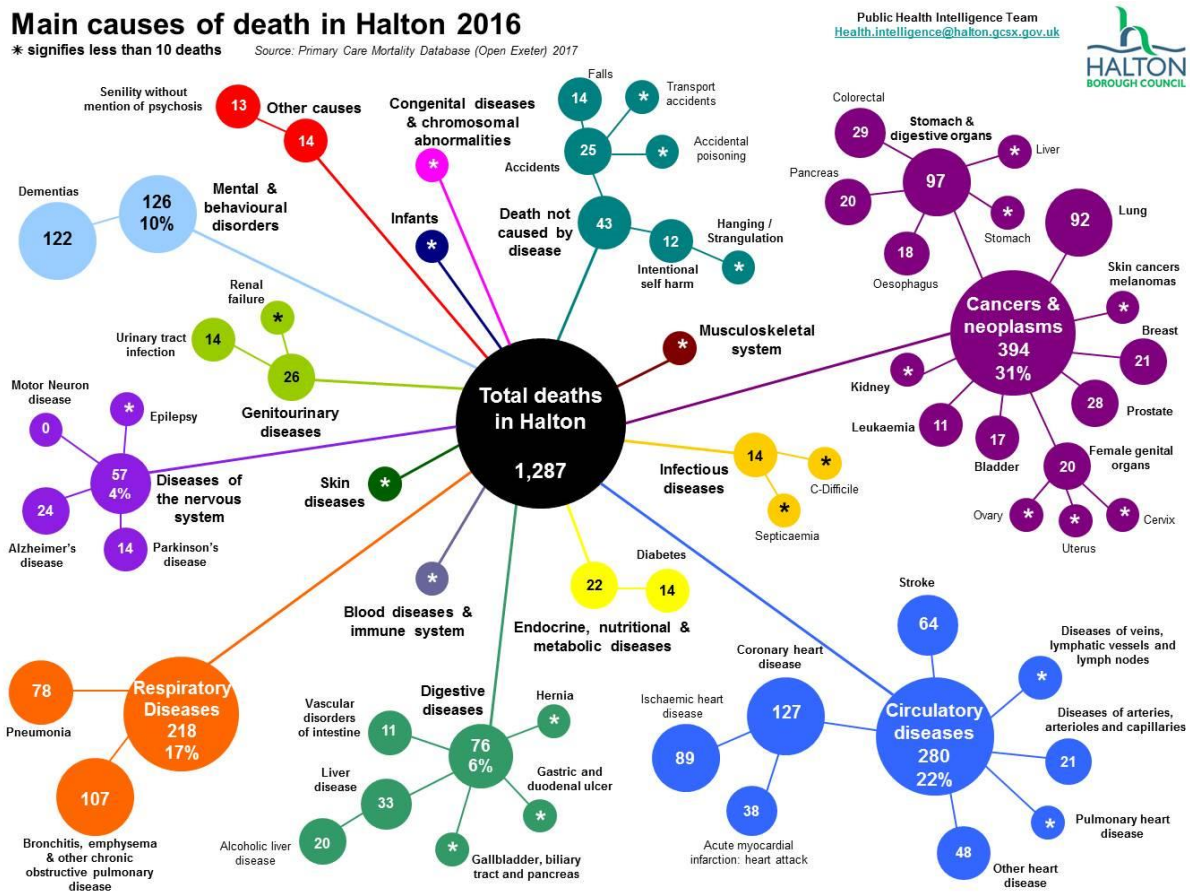
[iv] *Please note: Figures in table 12 may not match those stated in the text, as figures have been rounded and some supressed to maintain confidentiality.*

Data on IB/SDA uses broader categories and follows the WHO ICD-10 classifications. There were approximately 560 Halton residents claiming Disability Living Allowance (DLA) as of May 2017, as a result of Epilepsy, MS, PD, Chronic Fatigue Syndrome (CFS) or other neurological diseases. There were approximately 20 Halton residents claiming IB/SDA as a result of diseases of the nervous system.

6.2. Deaths

Deaths from long-term neurological conditions are rare compared to other causes of death. In 2016, there were 57 deaths from conditions of the nervous system. This accounted for just 4% of the total number of deaths that year amongst Halton residents.

Figure 14: Causes of death amongst Halton residents, 2016



Analysis at a national level[40] shows that 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.

This translates to an upward trend compared to a drop in the overall death rate. 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%.

Deaths with a mention of Parkinson's Disease constituted the largest single sub-category. Of the local deaths due to diseases of the nervous system, the largest single cause is Alzheimer's. Parkinson's Disease accounts for the largest subcategory of LTNC. This has consistently been the case since 2009.

Nationally, 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. Deaths related to respiratory disease are more prevalent in those with many LTNCs, including epilepsy, MND, MS, PD and neuromuscular diseases than the proportion associated with all deaths. Deaths related to falls account for a significant proportion of deaths due to traumatic brain and spine injury.

7. Projected service use and outcomes in 3-5 years and 5-10 years

The predicted increases in the age of the population are likely to be associated with corresponding increases in some LTNCs e.g. Parkinson's disease and epilepsy.

Due to people living longer there will be a corresponding increase in the number of people living with LTNCs and also with those with multiple co-morbidities. This may result in increased need for care and support and it is therefore important to address the recommendations in the Strategy to improve outcomes and ensure sustainability of services.

The numbers of people with neurological conditions will also grow sharply in the next two decades due to improved survival rates, increased longevity and improved diagnostic techniques.

8. Service Quality and patient views

There have been a number of improvements in health care for people with LTNCs since the introduction of the National Service Framework in 2005.[41] These include for example:

- Reduced waiting time for elective inpatient procedures
- Reduced waiting times for outpatient neurology clinics
- Reduced emergency bed days

However, the number of people admitted to hospital as an emergency has increased significantly and overall, the achievement of the quality requirements within the Framework has been poor. The National Audit Office report[42] concluded that there remain significant problems with current services. Similar issues have previously been raised in reports on other conditions:

- People experienced varying quality of the diagnosis process
- Information and advice to patients and carers is poor
- Ongoing care is fragmented and poorly coordinated
- Access to services for people with neurological conditions and their carers varies significantly depending on where they live
- People with neurological conditions admitted to hospital as an emergency often receive care from health professionals without neurological training
- There are examples of good practice which are delivering better services for patients, but they are often poorly supported
- Physiotherapy was rarely offered or only available short term
- Difficulty with obtaining appropriate aids and equipment
- Difficulty with obtaining benefits

The first patient experience survey, conducted by the Neurological Alliance, showed that many people with a neurological condition were not receiving good quality health and care services.

Invisible Patients: Revealing the State of Neurology Services[43] highlighted the fragmented patient pathways and variable experience of care across England.

A repeat of the survey focussing on (1) the pathway to diagnosis and (2) on-going experience of care, revealed that at every stage patient care experience is falling short of what was reported in 2014.[44]

Neurological conditions have a major impact on the lives of patients. 71% (n=4,661) of 2016 survey respondents experience moderate, severe or extreme pain or discomfort and 70% (n=4,561) of patients are restricted in their activities frequently, most or all of the time.

The establishment of the new National Neuro Advisory Group, a commitment to redevelop the specialised neurology service specification, the dissemination of Right Care Neurology Focus Packs, and the development of a new NICE guideline for suspected neurological conditions in primary care are all positive developments but will take time to deliver results.

Over half of patients surveyed (53%, n=2,497) reported problems or delays in accessing health care services. This headline figure, while on its own suggests poor patient experience, hides the variety of experience across the neurological patient group on the pathway to diagnosis.

Just over 4 out of 10 respondents stated that they saw their GP five or more times before seeing a neurological specialist. This was an increase from 3 out of 10 people in the 2014 survey. It varied considerably depending on the type of condition. Not all patients will need to be referred to a specialist, or at least not until it is clear that their condition needs more detailed investigation and treatment.

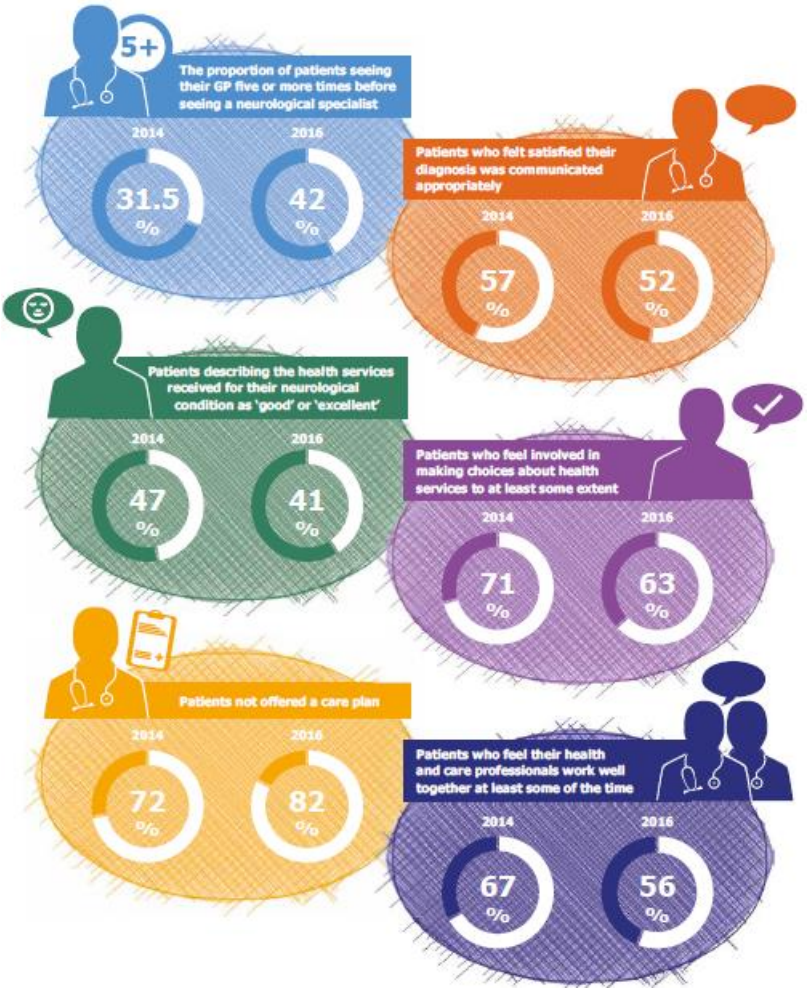
GP knowledge can affect referral patterns. LTNCs are rare compared to other LTCs. Availability of NICE guidelines on referral can affect speed of referral e.g. epilepsy and PD respondents typically saw their GP once or twice before referral.

Research carried out by the Neurological Alliance in 2016 found that 84% of GP respondents felt they could benefit from further training on identifying and managing people presenting with neurological conditions. Furthermore, the proportion of GPs who said they felt confident about making an initial assessment of and referring people with neurological conditions – even relatively common conditions such as epilepsy – was lower than for making an assessment and referral for non-neurological conditions such as diabetes.

The survey also illustrates that the process of diagnosis can be lengthy even with the input of a neurological specialist. 22% (n=1,375) of patients waited six months or more for a diagnosis even after seeing a neurological specialist. This highlights the difficulty in diagnosing some neurological conditions – even for a specialist. In order to provide a reliable and accurate diagnosis of a neurological condition, a multi-disciplinary approach is often required.

Further findings are shown in Figure 15.

Figure 15: Neurological Alliance national patient experience survey: comparison of 2014 and 2016 results



9. Evidence based practice

NICE produces a range of guidance, pathways and quality standards. For neurological conditions this covers:

- Brain cancers
- Cerebral palsy
- Delirium
- Dementia
- Epilepsy
- Faecal incontinence
- Headaches
- Metastatic spinal cord compression
- Motor neurone disease
- Multiple sclerosis
- Neurological conditions: general and other
- Neuropathic and persistent pain
- Parkinson's disease
- Spasticity
- Spinal conditions
- Transient loss of consciousness
- Urinary incontinence

This includes:

- Parkinson's disease: diagnosis and management in primary and secondary care. (2006)
- Multiple sclerosis: Management of multiple sclerosis in primary and secondary care. (2003)
- Motor neurone disease The use of non-invasive ventilation in the management of motor neurone Disease (2010)
- The epilepsies: The diagnosis and management of the epilepsies in adults and children in primary and secondary care (2004)

NICE pathways:

- Epilepsy
- Headaches including migraine
- Motor Neurone Disease
- Multiple sclerosis
- Neuropathic pain
- Parkinson's Disease

Other sources include:

- Motor Neurone Disease Association (MNDA): Standards of Care (2010)
- The Royal College of physicians: Medical Rehabilitation in 2011 and beyond (2010)
- British Society of Rehabilitation Medicine: Rehabilitation following acquired brain injury National clinical guidelines (2003)
- Department of Health: National Service Framework for long term conditions (2005)
- Further evidence can be easily accessed via NHS Evidence – Neurological Conditions which includes: Guidelines (NICE, SIGN, ABN and other relevant national and international guidelines); Systematic Reviews (especially Cochrane reviews and those published in a selection of the leading neurology journals); Health Technology Assessments and Economic Evaluations; policy and other relevant documents

10. Unmet needs and service gaps

Several factors which limit people with LTNCs to live as independently as they wish, are associated with comparatively high rates of unplanned admission to hospital, potentially requiring long term residential care. [45] These factors include: community services struggling to provide support during critical phases of the illness; need for double-up carers in the absence of a technical solution to transfers; and inability to provide complex care at night.

There is a lack of routinely collected data on the number of people in Halton who have LTNCs. Halton is not unique in this. However, it does present challenges in being able to accurately determine the scope and scale of need in the borough.

QOF prevalence rates across Halton GP practices vary from 0.43% to 1.34%, with an average across Halton CCG of 0.96%. This is slightly higher than the North of England and England rate but slightly below the Cheshire and Merseyside STP rate. The number of diagnosed patients sits at the lower end of the estimated prevalence figure. National estimates use age-specific rates that do not enable easy comparison as they do not sit across the same age bands as QOF data. It has therefore not been possible to calculate practice estimates to determine a level of under-diagnosis.

The QOF for epilepsy no longer includes any management indicators. It is not therefore possible to determine any variation against recommended care processes.

Halton CCG has moved from the high spend, better outcomes quadrant of the SPOT tool (where outcome is under-75 mortality rate for epilepsy) to the lower spend better outcomes quadrant (2015 SPOT compared to previous 2011/12 data). Secondary care continues to account for the majority of spend with non-elective (emergency) admissions accounting for 45.4% of spend alone. Primary care prescribing accounts for just under 30%, proportionately above the national average. The proportional level of spend on outpatient and community care remains below the national average.

Appendix 1: Estimated prevalence of the main LTNCs

Incidence = number of new cases per year									
		Multiple Sclerosis*		Parkinson's#			Epilepsy		
Year	Popn.	3.5 rate	6.6 rate	17 rate	4 rate	20 rate	50 rate	40 rate	70 rate
2017	130,860	5	9	22	5	26	65	52	91
2022	132,386	5	9	23	5	27	66	53	93
2030	134,013	5	9	23	5	27	67	54	94
Prevalence = total cases in a population									
		Multiple Sclerosis*		Parkinsons ##			Epilepsy		
	Popn.	100 rate	120 rate	160 rate	100 rate	180 rate	750 rate	500 rate	1,000 rate
2017	130,860	130	156	208	130	234	976	650	1,301
2022	132,386	132	159	212	132	239	993	662	1,324
2030	134,013	134	161	214	134	241	1,005	670	1,340
Age Specific Prevalence of Parkinson's**						MND		ABI/TBI	
	60+ population		80+ population		popn.	incidence	prevalence	incidence	prevalence
Year	Popn.	5 per 1,000	Popn.	20 per 1,000		2 rate	7 rate	175 rate	1,200 rate
2017	30,049	150	5,027	101	130,860	3	9	228	1,561
2022	32,966	164	5,613	112	132,386	3	9	232	1,589
2030	36,819	184	7,443	149	134,013	3	9	235	1,608

** NICE guidance on MS estimates the incidence (new cases each year) to be between 3.5-6.6 per 100,000 of the population*

The guidance estimates the prevalence (old and new cases over a given time period, usually a year) to between 100 - 120 per 100,000 of the population

 # According to the NSF for Long term Conditions the incidence of parkinson's is 17 per 100,000 of the population

NICE guidance on the diagnosis, treatment and management of parkinson's estimates the incidence rate to be between 4-20 per 100,000 population

The Parkinson's Disease Society estimate the prevalence to be 160 per 100,000 of the population

NICE guidance on the diagnsis, treatment and management of parkinson's estimates the prevalence rate to be between 100-180 per 100,000 population

*** Prevalence of Parkinson's increases with age. According to Patient UK 5 in every 1000 people aged over 60 will develop the disease. This rises to 20 in every 1000 of those aged 80+*

MND and ABI/TBI incidence and prevalence from Neuro Numbers

2017 population figures from NHS Digital for CCG population; 2022 and 2030 are ONS CCG population projections percentage increases applied to 2017 figures

Appendix 2: Estimated prevalence of other LTNC

National prevalence of various LTNC per 100,000 population (source Neuro Numbers 2003 unless otherwise indicated). Halton estimates based on ONS mid-year population projections.

Group	Condition	National prevalence per 100,000 population	Estimated number in Halton 2017 (pop 130,860)	Estimated number in Halton 2022 (pop est. 132,386)	Estimated number in Halton 2030 (pop est. 134,013)
Intermittent	Epilepsy	500	654	662	670
	Migraine	15,000	19,629	19,858	20,102
	Cluster headache	100	131	132	134
	Paroxysmal hemicrania	10	13	13	13
	Chronic migraine	3,000	3,626	3,972	4,020
	Chronic tension-type headache	2,000	2,617	2,648	2,680
Progressive	Ataxia (incl. Friedrichs ataxia)	10[i]	13	13	13
	Ataxia-Telangiectasia	0.3	0.4	0.4	0.4
	Charcot-Marie-Tooth Disease	40	52	53	54
	Dystonia (primary idiopathic)	65	85	86	87
	Essential tremor	850	1,112	1,125	1,139
	Huntingtons disease	13.5	18	18	18
	Motor neurone Disease (MND)	7	9	9	9
	Multiple sclerosis (MS)	100 [ii]	131	132	134
	Myalgic encephalopmyelitis (ME)	400	523	529	536
	Myasthenia gravis	30	39	40	40
	Parkinson's disease	100 [iii]	131	132	134
	Progressive supranuclear palsy	6	8	8	8
	Transverse myelitis	1	1.3	1.3	1.3
Stable with changing needs	Fibromyalgia	2,900 - 4,700 [iv]	3,795 - 6,150	3,839 - 6,222	3,886 - 6,299
	Cerebral Palsy	186	243	246	249
	Encephalitis	396	518	524	531
	Spina Bifida and congenital Hydrocephalus	24	31	32	32
Sudden Onset (Non-Stroke)	Acquired brain injury and traumatic brain injury	1,200	1,570	1,589	1,608
Sudden Onset (Stroke)	Stroke	500	654	662	670
Total expected number of people with LTNC (excluding migraine and headaches)			**9,601 - 11,956**	**9,717 - 12,097**	**9,833 - 12,246**
Total expected number of people with LTNC			**35,604 - 37,959**	**36,324 - 38,707**	**36,769 - 39,182**
i = Ataxia UK. (2009). Management of the Ataxias: towards best Clinical Practice. London: Ataxia UK.					
ii = NICE guidance (date)					
iii = Parkinson's Disease Society (date)					
iv based on 2.9%-4.7% of UK population (ONS 2017 estimate 66,029,900)			http://www.fmauk.org/dmdocuments/Medical%20Pack.pdf		

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