Merton Long Term Neurological Conditions Health Needs Assessment

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Contents

List of figures

List of tables

Executive Summary

Background

The Merton Long Term Neurological Conditions (LTNC) Health Needs Assessment (HNA) was commissioned by Merton Clinical Commissioning Group as part of the on going work of the Early Detection and Management Priority Area Delivery Group. The purpose of the LTNC HNA is to analyse health and social care needs due to neurological conditions locally in order to inform the commissioning of services and service development in Merton.

Aims, objectives and methodology

The Merton LTNC HNA aims to:

- assess the current prevalence of long-term neurological conditions (LTNCs) in Merton.
- assess current levels of service usage for LTNCs across different care settings.
- assess current spend and outcomes data for LTNCs and benchmark Merton against regional and national comparators.
- seek the views of stakeholders on the needs of people in Merton with LTNCs, including service users, carers and a range of professionals involved in the management of these conditions.
- detail the services currently available to support individuals with LTNCs in Merton, assessing local service provision against quality indicators and the current evidence base for effective interventions.
- identify gaps in service provision and make recommendations as to how they may be addressed.

The review focuses primarily on the ten groups of conditions set out below.

Intermittent
- Epilepsy
- Migraine and headaches

Progressive
- Parkinson's disease (PD)
- Motor neurone disease (MND) and spinal muscular atrophy
- Multiple sclerosis (MS) and inflammatory disorders
- Neuropathies
- Other progressive diseases (Comprising; dystonia, Huntingdon's disease, neuromuscular disease, tremor and other movement disorders)

Stable with changing needs
- Cerebral palsy (CP)
- Central nervous system infections

Sudden onset
- Traumatic brain injury

The LTNC HNA includes an in-depth analysis of data from a range of sources, consultation with service users, carers and wider stakeholders, and a review of the literature.

The picture of LTNCs in Merton

Overall, Merton CCG does well on measures relating to LTNCs, with a slightly higher spend for better outcomes compared with CCGs nationally. Outcomes measured nationally tend to focus on epilepsy, therefore little can be concluded on outcomes for other neurological conditions.

Commissioning structures for neurological services are complex, with responsibilities for healthcare commissioning being split between NHS England Specialised Commissioning and local CCGs.

Non-elective inpatient care currently represents the highest proportion of the total neurology budget in Merton at 37%, reflecting the national picture, however numbers of emergency admissions for neurology have been falling at a faster pace in Merton than in London as a whole. Expectations for population growth[1] are likely to be reflected in increased demand for local services in the coming years.

Comorbidities play a significant role in the care needs of people with LTNCs, with over four times the number of admissions where a neurological condition is mentioned in the diagnosis code compared with those for which it is the primary diagnosis. Neurological conditions affect individuals of all ages, with a high proportion of admissions being in people of working age. This has significant implications for the health, social care and wider support needs of these individuals if they are to be supported to live independently.

Key points

Overall:

- There is limited local data on the prevalence of LTNCs in Merton, with conservative estimates suggesting a total of 4,626 people in Merton with a LTNC (excluding migraine and headache).
- Merton CCG has a lower prevalence of epilepsy in adults than London, England and all comparator CCGs except Wandsworth. The data suggest a level of underdiagnosis of epilepsy, particularly in West Merton, however it may also reflect the known link between epilepsy and deprivation, with lower prevalence observed in less deprived areas.
- Admission rates vary by condition, with a high proportion of emergency admissions and emergency bed days for epilepsy and Parkinson's disease.
- Neuropathies have the highest level of spend on admissions, which is to be expected given the high number of elective admissions. Epilepsy is second to this, followed by MS.
- Where Merton is doing well:
    - Merton CCG has a slightly higher spend on neurology for marginally better outcomes.

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[1] Merton Joint Strategic Needs Assessment 2013-14

    - The number of neurology admissions has fallen year on year since 2009/10, with the proportion of emergency admissions reducing more rapidly in Merton CCG than in London as a whole.
    - Merton has a lower rate of emergency bed day use than the London benchmark for all analysed conditions.
    - Merton CCG has a lower spend on drugs for epilepsy and Parkinson's disease per 10,000 people than England.
- Where Merton is not doing so well
    - The proportion of patients with epilepsy recorded as being seizure free in the last 12 months is slightly lower in Merton than comparators.
    - There is local variation in the proportion of female epilepsy patients receiving information and counseling, with five practices at 50% or below.
- Merton spends a much lower proportion of the neurology budget on community and integrated care than the national average, with a higher proportion spent on outpatient care.
- While the volume of prescribing for both epilepsy and PD has risen since 2011/12, the cost of prescribing has declined slightly overall.

Health inequalities in Merton:

Gender

- Rates of admissions for LTNCs in Merton vary by gender, with significantly higher admission rates among females than males for neuropathies and migraine and headaches.

Age

- Admissions are spread across a wide range of ages, with 57% of admissions in working age adults. This has significant implications for the range of support required to help manage the impact of these conditions and support independent living.
- Among children and young people with epilepsy, there are higher rates of admissions among 0-4 year olds than older age groups.

Ethnicity

- Significantly higher rates of admissions are seen in people from other ethnic backgrounds for all categories of LTNC except sudden onset conditions. Significantly higher rates are also seen for white groups than Asian and Black groups for intermittent and progressive conditions.
- Other and black ethnicities are overrepresented in admissions for epilepsy in children and young people

Deprivation

- An association is found between emergency admission rates for LTNCs and deprivation, with significantly higher rates of emergency admission for people in areas with higher levels of deprivation.
- There is also a higher observed prevalence of epilepsy in the more deprived areas of Merton.

Service user consultation

A local service user survey was undertaken to complement results from a national pilot survey in order to provide insight into the experience of people in Merton living with LTNCs.

Key themes emerging from the surveys included:

- The substantial impact of LTNCs on daily activities
- The diagnosis process and variable degree of personalized care planning
- Communication between professionals
- Access to ongoing care and treatment
- The broader needs of the individual and holistic approach necessary to care.

Qualitative work: semi-structured interviews

A number of prominent themes emerged from interviews with carers and wider stakeholders to add to the views of service users.

These included;

- High value placed on the role of specialist nurses in supporting the management of LTNCs.
- Variation in access to the range of services required by people with LTNCs, including therapies, equipment and social services.
- Concerns over the extent to which neurological needs are met when individuals access other types of care.
- A need for greater mental health support for people who are diagnosed with LTNCs to assist with the difficulties in coming to terms with limitations in ability and functioning.
- The potential for more systematic coordination of care across agencies, enabling more comprehensive support to be given, in particular to those with complex needs.

What are the gaps in Merton?

Evaluating all of the evidence gathered, the following gaps have been identified in Merton in relation to LTNCs.

1 Primary care

1.1 Variation is observed in the primary care management of epilepsy in Merton, with QOF measures indicating considerable variation between practices.

1.2 Merton is slightly below the London and England average for epilepsy patients (18+) on drug treatment who have been seizure free for the last 12 months, with two practices demonstrating particularly low rates.

1.3 Merton CCG does well overall for the proportion of female epilepsy patients 18-54 years old with a record of contraception, conception and pregnancy advice in the last 12 months, however five practices have proportions of 50% or less.

1.4 Variation is also demonstrated between practices in the recorded prevalence of epilepsy, ranging from 0.25% to 0.73%. All practices have a lower observed prevalence compared with that which would be expected based on national prevalence.

1.5 The service user survey indicated that the process of diagnosis is often lengthy, with feedback from service providers and primary care staff suggesting that limited awareness of the presentation of neurological conditions contributes to delays in diagnosis and access to specialist care. While this was understood by stakeholders to reflect inherent difficulties in diagnosis, the historic focus on stroke and dementia at the expense of other conditions was believed to be a factor in this.

2 Community care

2.1 Patients with cerebral palsy and traumatic brain injury appear to be under-represented in the Community Neurotherapy Team caseload when accounting for estimated prevalence, with anecdotal evidence of few referrals for these condition groups. This may indicate a lower need for services, however it may also indicate that individuals with these conditions are ‘slipping through the net’ between primary, secondary and community care.

2.2 Capacity in community services was reported by stakeholders to be limited at times. While these services were highly valued, capacity issues were understood to limit the ability of individuals to access on going care. This finding was also reported in the service user survey, where a high number of individuals had experienced problems or delays in accessing care and treatment. Access to on going physiotherapy, occupational therapy and speech and language therapy is highlighted in best practice guidelines as important in reducing the impact of LTNCs on an individual’s life.

2.3 There is a perceived lack of knowledge among non-specialist community care staff about the needs of people with neurological conditions. Professional stakeholders reported this to be a gap that contributed to unnecessary admissions.

3 Secondary and tertiary care

3.1 A high proportion of emergency admissions and emergency bed days relate to particular neurological conditions. Notable are epilepsy and Parkinson’s disease. While Merton CCG has performed well in comparison to London regarding reductions in emergency neurology admissions, there remains scope for further reductions.

3.2 Provision of specialist nursing support is patchy, with variation between hospitals. Most notably, there is currently no MND specialist nurse role in local hospitals and no epilepsy nurse at St Helier Hospital. NICE guidelines recommend that specialist nurses form part of the multi-disciplinary team coordinating the on going treatment and management of these patients.

3.3 Feedback from service providers and carers suggests a gap in the knowledge of general hospital staff in the management of neurological conditions. This was reported as a concern of both professionals and carers, contributing to deteriorations in people’s conditions when admitted to hospital for other reasons.

4 *Inequalities*

4.1 ***Ethnicity***: There are high rates of total admissions of people from ‘Other’ ethnic backgrounds for intermittent, progressive and stable neurological conditions and for epilepsy in 0-19 year olds.

4.2 ***Deprivation***: There are higher rates of emergency admissions for neurological conditions for people living in more deprived areas. This pattern is reflected for epilepsy admissions in children and young people. There is also a significantly lower rate of elective admissions from Index of Multiple Deprivation (IMD) quintile 5 (least deprived) than from IMD 2.

5 *Planning and continuity of care*

5.1 The service user survey and stakeholder engagement exercise suggest that comprehensive care planning currently only occurs in some cases. Best practice guidelines advocate the use of individualised care plans to address a person’s comprehensive health and social care needs, however it appears that these are not yet being used routinely for all LTNCs in Merton. While examples of good practice in collaborative working exist in Merton, such as the links provided by specialist nurses to a range of support services, it appears that there is scope for more integrated working between health and social care agencies in the management of care for people with LTNCs.

6 *Further gaps expressed by stakeholders*

A number of other gaps were identified by stakeholders in the consultations.

- Limited access to lower level mental health and psychosocial support for people with LTNCs was reported. Given the impact of LTNCs on the lives of individuals and their families, the provision of appropriate support in this regard is crucial to enabling people to live as independently as possible.
- There was a perception that vocational rehabilitation and support is lacking for those not meeting the eligibility criteria for current services. This is a particular concern given the high proportion people in Merton with LTNCs who are of working age.
- Access to equipment was reported to be variable, with a general pattern of good access through reablement services but long waits when the need is less urgent. There also appears to be no set process for accessing equipment where there is a specific health need.
- There was general agreement that the needs of carers are not being as comprehensively addressed as they should be.
- The difference in level of service provision from paediatric to adult services was understood to have the potential to cause significant difficulties if not managed well, particularly for young people with epilepsy and cerebral palsy.

7 *Data gaps*

7.1 As with most areas of the country, Merton has very little information on the numbers of people living with LTNCs in the local area. This makes service planning inherently challenging as the full extent of the needs cannot be fully understood.

Health and social care recommendations

1 Primary care

1.1 Provide opportunities for the up skilling of GPs with regards to more common LTNCs including epilepsy and Parkinson’s. This would serve to support the diagnosis process and is particularly important in view of the role played by GPs in the on going management of epilepsy.

2 Community care

2.1 Review the capacity of community rehabilitation services in order to establish whether sufficient capacity exists to enable comprehensive access to on going therapy.

2.2 Facilitate training for the general community services workforce in order to increase awareness of the needs of people with LTNCs to help in the avoidance of hospital admissions.

3 Secondary care

3.1 Consider the local provision and capacity of specialist nursing support for people with LTNCs, considering in particular diseases or geographical areas where support is not currently provided.

3.2 Facilitate training for secondary care staff to increase knowledge of LTNCs so that appropriate support can be provided to patients with neurological conditions when admitted to hospital and other care settings.

4 Inequalities

4.1 Targeted action should be considered with ethnic minority populations and those in more deprived areas to increase knowledge of LTNCs, support access to services and facilitate appropriate management strategies. This would need to be linked with primary care management and training (Recommendation 1.1) and include strategies to raise awareness of LTNCs among these communities, for example through the use of health champions.

5 Planning and continuity of care

5.1 Ensure that everyone diagnosed with a LTNC has access to a key worker and a comprehensive individualised care plan that can be shared between agencies and supports on going coordination of their care.

5.2 Ensure that integrated local pathways across primary, secondary, community and social care exist, addressing relevant support needs for people with neurological conditions. These pathways should enhance communication and ensure strong links between health and social care agencies. Any work on this should link into the work being done by the London Neuroscience Strategic Clinical Network.

5.3 Encourage patients to play an active role in the management of their condition, increasing the opportunities and resources available to support self-management.

6 Addressing wider needs

6.1 Increase opportunities to access mental health and psychosocial support in the community, considering appropriate input from neuropsychologists.

6.2 Review the availability of vocational rehabilitation and general employment support for the large numbers of people with LTNCs in Merton who are of working age.

6.3 Consider the processes through which individuals can access funding for specialist equipment, bearing in mind the potential for individual budgets to give people greater control and choice over the care and support they receive.

6.4 Review what is available for young people with LTNCs through the transition period into adult services to ensure they are appropriately supported.

6.5 Consider mechanisms to ensure that the needs of carers are more comprehensively assessed, with appropriate support provided to help them in their role as a carer and to ensure that their own health and social needs are met.

6.6 Involve service users and carers in commissioning and service development processes as they can provide valuable insight into local needs.

7 Data collection

7.1 Consider the use of data systems to more accurately record information about the numbers of people with LTNCs in the local area. These systems could also be used to support the management of care.

Introduction

Key Points:

- Long-term neurological conditions (LTNCs) are a range of conditions resulting from injury or disease of the nervous system. The conditions each vary in their prevalence and severity but all can have significant impacts on the life of the individual and the people around them.
- There are four categories of LTNCs; intermittent, progressive, stable with changing needs and sudden onset conditions. Potential impacts of LTNCs include physical, motor, sensory and cognitive problems in addition to communication difficulties and emotional and psychosocial impacts.
- A broad range of services are needed to support people with LTNCs in addition to health and social services, such as employment support, benefits, transport, housing and education.
- Neurological disorders account for approximately 10% of emergency medical admissions, 10% of GP consultations and cause disability in one in 50 people in the UK. In 2012/13, NHS expenditure for neurological conditions totaled £4.4 billion, with an estimated £2.4 billion spent on social care services for people with LTNCs.
- This needs assessment uses a combination of methods to assess the local picture in Merton and compare this to best practice and national guidelines in order to identify gaps. Recommendations will subsequently be made for service development and the commissioning of health and social care services for people with LTNCs.

Long-term neurological conditions (LTNCs) consist of a broad range of conditions that result from injury or disease of the nervous system. The term encompasses conditions that vary greatly both in their severity and rarity, from migraines and epilepsy to Huntington’s disease and motor neurone disease. Once acquired, these conditions often have wide-reaching implications for an individual’s life, with potential impacts on career prospects, relationships and expectations for the future.

Merton CCG have prioritised work on a number of long term conditions in order to provide comprehensive assessments to support the commissioning of safe, sustainable and high quality services for the local population. Within this, high priority has been given to ensuring that care across the acute, primary and community settings is fully integrated, providing services that are tailored to the needs of individuals. This is particularly relevant for individuals with LTNCs, whose needs cover a broad spectrum and characteristically change over time. Not only are symptoms diverse, but the course of each condition is variable, with needs dependent both on the severity of the condition as well as subsequent fluctuations and deteriorations.

There are four broad areas under which LTNCs can be categorised;

- Intermittent conditions
- Progressive conditions
- Stable conditions
- Sudden onset conditions

While there are a large number of conditions, this review will focus primarily on the ten groups of conditions set out below. This pragmatic approach reflects the conditions discussed in the National Service Framework for Long Term Conditions, those with the highest prevalence and those for which data is most readily available.

Intermittent
- Epilepsy
- Migraine and headaches

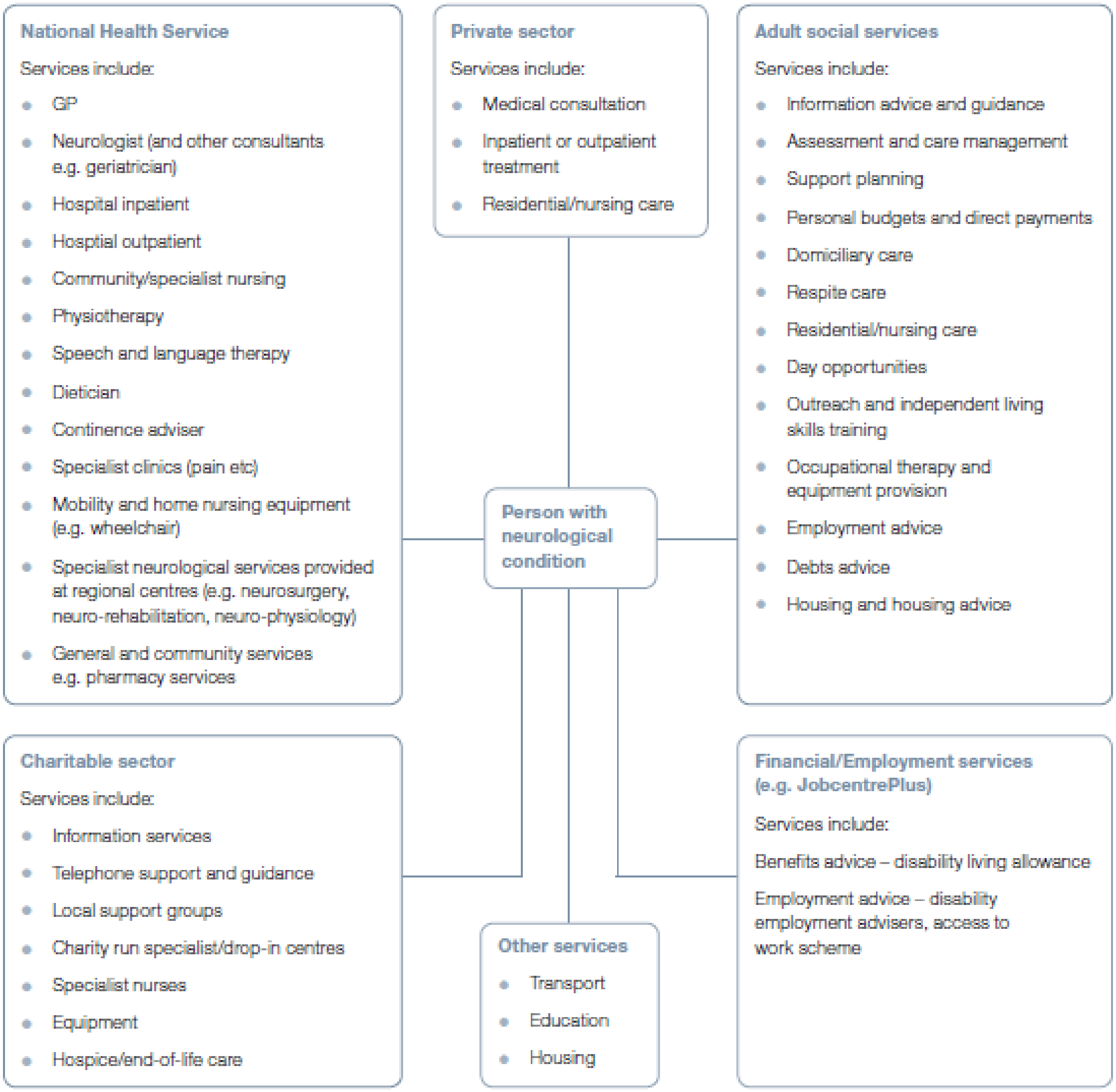
Progressive
- Parkinson’s disease (PD)
- Motor neurone disease (MND) and spinal muscular atrophy
- Multiple sclerosis (MS) and inflammatory disorders
- Neuropathies
- Other progressive diseases (Comprising; dystonia, Huntingdon’s disease, neuromuscular disease, tremor and other movement disorders)

Stable with changing needs
- Cerebral palsy (CP)
- Central nervous system infections

Sudden onset
- Traumatic brain injury

While some LTNCs can be life threatening, others cause lifelong disability and severely affect quality of life. Impacts can include physical, motor, sensory and cognitive problems in addition to communication difficulties and emotional and psychosocial impacts. As a result, the broad range of services needed by people with LTNCs includes health, social services, employment support, benefits, transport, housing and education.

Fig 1. Range of services for people with LTNCs



Source: National Audit Office (2011)

Neurological conditions differ from many other long term conditions in that there is generally no primary prevention aspect to them, with few modifiable risk factors being identified. The focus must therefore be on accurate detection and appropriate management to reduce the impact of the conditions on an individual's life.

Neurological disorders as a whole are very common. A 2011 report found that they accounted for approximately 10% of GP consultations, 10% of emergency medical admissions and cause disability in one in 50 of the UK population. [2] Further to this, data from London indicates that neurology has the highest admission rate out of all 23 NHS programme budget categories.[3] This demonstrates a significant impact of LTNCs on the lives of individuals and their need for care.

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[2] Royal College of Physicians and Association of British Neurologists (2011) Local adult neurology services for the next decade: Report of a working party. London, Royal College of Physicians

[3] London Neuroscience SCN (2014) CCG Neurology Profiles http://www.slcsn.nhs.uk/scn/neuro/london-ccg-neuro-profiles-102014.pdf

A recent report from the Neurological Alliance provides a more detailed summary of statistics relating to health and social care service usage due to neurological conditions, set out in the box below.

In 2012/13;[4]

- Over £4.4 billion was spent on neurological conditions, representing 4.2% of overall NHS expenditure
- Over 700,000 emergency admissions were recorded for people with a neurological condition, costing the NHS over £750 million
- 1.3 million hospital admissions were recorded for people with a neurological diagnosis – an increase of more than 500,000 over a five year period
- Over 11 million bed days were recorded for patients with neurological condition, with an average length of stay of 13 days
- Overall expenditure on neurological conditions was over 200% higher than 2003/4 levels
- An estimated £2.4 billion was spent on social care services for people with a neurological condition

Aims and objectives

This needs assessment will examine research and available data in order to;

- Assess the current prevalence of LTNCs in Merton.
- Assess current levels of service usage for LTNCs across different care settings.
- Assess current spend and outcomes data for LTNCs and benchmark Merton against regional and national comparators.
- Seek the views of stakeholders on the needs of people in Merton with LTNCs, including service users, carers and a wide range of professionals.
- Detail the services currently available to support individuals with LTNCs in Merton, assessing local service provision against quality indicators and the current evidence base for effective interventions.
- Make recommendations for service development and commissioning, taking into account gaps identified and areas where improvements might be made.

Methodology

The needs assessment will take a mixed methods approach, combining a literature review with analysis of primary and secondary data to build up a picture of local needs.

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[4] The Neurological Alliance (2014) Neuro Numbers

Quantitative Data

Quantitative data was obtained from a number of sources to inform the assessment.

- The **Compendium of Neurology Data** - published in March 2014 by the Health and Social Care Information Centre (HSCIC).
- Public Health England's **Neurology Intelligence Network (NIN)**.
- The **London CCG Neurology Profiles**, published in 2014 by the London Neuroscience Strategic Clinical Network.

Additional ad-hoc data was obtained to complement this, including;

- Three years of secondary uses survey (SUS) data (April 2011 to March 2014) providing more detailed demographic information on service users.
- Three years of primary prescribing data (April 2011 to March 2014) for Parkinson's disease and Epilepsy
- Snapshot data from Sutton and Merton Community Services (SMCS) Neurotherapy Team taken on 01/05/2015
- Adult Social Care data on service use for the financial year 2013/14.
- Five years of Primary Care Mortality data (Jan 2010 – Dec 2014)

Limitations of the data

Local data on prevalence is lacking, therefore most of the reported prevalence data is based on estimates drawn from research. The datasets outlined above provide a substantial level of information regarding service use, however it should be noted that the ad-hoc SUS data differs from the published datasets in numbers of admissions for several conditions including Parkinson's, Multiple Sclerosis and neuropathies. It is thought that these differences are likely to be due to the complexities of disease coding and the disaggregation of data for Merton and Sutton CCGs since the PCT split. As SUS data is unpublished and understood to have a degree of unreliability, the published data is used in this analysis where possible.

Service user survey

The Neurological Alliance recently piloted a patient experience survey for people with LTNCs. The survey received a total of 6,916 responses from across England, 634 of which were from people living in London. To add to this data and elicit additional views relevant to Merton, a slightly shortened version of the survey was conducted as part of this needs assessment. The survey was hosted online and advertised through neurology outpatient clinics, on the Council website and through voluntary sector organisations, with paper copies distributed to a number of voluntary sector contacts in order to reach people who were unlikely or unable to access the online version.

A total of 29 respondents completed the local survey. The majority were over the age of 50, with almost equal representation of males and females. 72% of respondents were white, with 10% being from Asian backgrounds and 10% from black backgrounds. The majority of responses were from people with MS (40%) or Parkinson's disease (36%).

The results of the local survey are reported in this assessment alongside an analysis of the London responses to the original pilot survey.

Limitations of the data

While attempts were made to reach as wide an audience as possible, it is acknowledged that not all service users would easily be able to access an online survey and paper copies only reached a small fraction of the target group through dissemination by voluntary sector groups. Additionally the age and ethnicity of respondents does not reflect the Merton population as a whole, with a bias towards older respondents and those from a white background. Consequently the transferability of the results from the local survey to the wider Merton population is limited. Nevertheless triangulating these findings with the Neurological Alliance pilot survey provides a more robust assessment of the views of service users across London.

Qualitative work

Qualitative work was conducted in the form of semi-structured interviews with carers and a wide range of professional stakeholders to gather views on current service provision and support for people in Merton. Interviews were structured around a topic guide based on the 11 quality requirements of the National Service Framework for Long Term Conditions. Thematic analysis was conducted on the data obtained from these interviews.

Interviews with carers

A total of five carers identified by Carers Support Merton were interviewed over the phone, covering individuals with MS, Parkinson’s disease, epilepsy, and cerebral palsy. All carers were female and cared for family members with a neurological condition.

Interviews with wider stakeholders

Semi-structured interviews were held with a wide range of professional stakeholders between March and May 2015. A total of 16 people participated, ranging from Consultant Neurologists, specialist nurses and community therapists to commissioners, social services, GPs and voluntary sector organisations.

Limitations of the data

The range of conditions encompassed by the assessment is very wide, therefore it is acknowledged that the views of the carers included in this report may not represent the broad spectrum of experience likely among all who care for people with LTNCs in Merton. Similarly a large number of professionals are involved in the health and social care of this group of people. Given the timescale for this piece of work, it was not possible to speak to all those who could have contributed valuable opinions to the assessment. Nevertheless the stakeholders who participated in the interviews represent a wide range of organisations and different points in the pathway of care, so it is hoped that the findings reported provide a reasonably accurate account of the extent to which current services meet local needs.

Literature Review

A literature review was also carried out to gather details of current guidelines and best practice in the treatment and management of selected neurological conditions, with a focus on the management and coordination of care and the role of the specialist nurse.

The NICE website was searched to identify best practice guidelines for neurological conditions, with an additional search on Google identifying further best practice documents. All relevant guidelines were eligible for inclusion.

A further search of PubMed, EMBASE, and CINAHL was undertaken to identify relevant articles. Search terms included ‘neurological condition’, ‘neurological condition management’ and ‘neurology specialist nurse’. Inclusion criteria included date of publication (2010 onwards) and articles from England, with articles excluded if they reported individual cases. The titles of 566 articles were identified and screened, with a total of 13 peer-reviewed articles included in the review.

Neurological conditions

Key Points

- There are a large number of neurological conditions, all of which vary greatly in characteristics and affect people at different stages of life.
- Diagnosis of most neurological conditions must be made by a consultant neurologist due to the complexities of diagnosis and the subtleties of presenting symptoms. Diagnosis is primarily based on clinical history and examination, with further diagnostics supporting this where appropriate.
- Treatment and ongoing management requires a multidisciplinary response aimed at optimizing symptoms and enabling the individual to live as independently as possible.

Neurological conditions vary greatly in characteristics and necessary treatment. The following pages provide brief summaries of selected neurological conditions.

Epilepsy

NICE (2012) The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. http://www.nice.org.uk/guidance/cg137
NICE (2014) Clinical Knowledge Summaries : Epilepsy http://cks.nice.org.uk/epilepsy

Classification: Intermittent

Definition
- Epilepsy is characterised by seizures.
- Different types of epilepsy have different causes.
- Approximately two thirds of diagnoses in the UK do not have an identifiable cause.

Symptoms and clinical features
- Seizures manifest themselves as a disturbance of consciousness, behaviour, emotion, motor function or sensation.
- Severity and frequency vary between individuals.

Epidemiology
- Epilepsy affects approximately 362,000-415,000 people in England.
- Epilepsy prevalence has been linked with social deprivation.[5]
- Epilepsy is most often diagnosed before the age of 18 or after the age of 65 and is more common in people with learning disabilities.

Diagnosis
- Anyone with a suspected seizure should be seen within two weeks by a specialist.
- Clinical history and examination is the primary method of diagnosis, however EEG and MRI can be used to support this.
- All individuals should have a comprehensive care plan agreed.

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[5] Pickrell et al (2015) Epilepsy and deprivation, a data linkage study. Epilepsia 56(4) 585-591

Treatment and ongoing management

- Two-thirds of individuals with active epilepsy can control their condition satisfactorily with anti-epileptic drugs (AEDs).
- Surgery and nerve stimulation are alternative options.
- AED treatment strategy should take account of seizure type, epilepsy syndrome, co-medication and co-morbidity, lifestyle and preferences.
- Regular structured review should occur at least yearly with a generalist or specialist.
- The review should facilitate access to: written and visual information; counselling services; information about voluntary organisations; epilepsy specialist nurses.

Parkinson's Disease (PD)

NICE (2006) Parkinson's disease: Diagnosis and management in primary and secondary care.
https://www.nice.org.uk/guidance/cg035

Classification: Progressive

Definition

- A progressive neurodegenerative condition that develops during adulthood, caused by the death of the dopamine-containing cells of the substantia nigra.

Epidemiology

- Rates of PD rise with age and are higher in males than females.
- Symptoms usually appear after the age of 50.

Diagnosis

- Diagnosis is primarily based on clinical history and examination.
- Those with suspected PD should be referred quickly and untreated to a specialist.
- People with suspected mild PD should be seen within 6 weeks.

Symptoms and clinical features

- Primary symptoms are tremors, which usually begin in the upper limbs.
- Bradykinesia and muscle stiffness contribute to movement impairments.
- Psychiatric problems often develop as the condition progresses.
- Other non-motor symptoms include fatigue, constipation, bladder weakness and speech and swallowing difficulties.

Treatment and ongoing management

- Pharmacotherapy forms initial treatment, with the choice of drug based on clinical and lifestyle characteristics and patient preference.
- Adjuvant drugs should be prescribed to reduce motor complications.
- Deep brain stimulation may also be used to treat people with PD.
- PD patients should be seen at regular intervals of 6-12 months, with regular access to clinical monitoring, medication adjustment, a continuing point of contact for support and a reliable source of information about clinical and social matters.
- Ongoing access to physiotherapy, occupational therapy and speech and language therapy should also be available.

Motor Neurone Disease (MND)

NICE (2010) Motor neurone disease: The use of non-invasive ventilation in the management of motor neurone disease. https://www.nice.org.uk/guidance/cg105
Motor Neurone Disease Association http://www.mndassociation.org/

Classification: Progressive

Definition

- A rapidly progressing, fatal neurodegenerative disease characterised by progressive muscle weakness and wasting.

Epidemiology

- MND is more common in males than females, with a ratio of 3:2.
- Usual age of presentation is between 50 and 70, with life expectancy of 2-10 years.

Symptoms and clinical features

- Degeneration of motor neurons leads to progressive muscle weakness.
- Respiratory impairment strongly predicts quality of life and length of survival.
- There are a number of types of MND, with Amyotrophic Lateral Sclerosis (ALS) being the most common type and accounting for approximately 70% of cases.

Diagnosis

- No currently available tests definitively confirm a diagnosis of MND.
- Diagnosis of MND is confirmed by a neurologist with the aid of a range of tests including blood tests, MRI, electromyogram and nerve conduction tests.

Treatment and ongoing management

- Ritulek is recommended as drug therapy for ALS
- Vitamin E can also be taken to slow disease progression.
- Ongoing management and treatment coordinated by a multidisciplinary team, led by a professional with a specific interest in MND and including an MND specialist nurse.

Multiple Sclerosis (MS)

NICE (2014) Multiple sclerosis: management of multiple sclerosis in primary and secondary care https://www.nice.org.uk/guidance/cg186
MS Society http://www.mssociety.org.uk/

Classification: Progressive

Definition

- An acquired chronic immune-mediated inflammatory condition of the central nervous system, affecting both the brain and spinal cord.

Epidemiology

- Most individuals are diagnosed between 20-40 years of age.
- Approximately three times as many women are diagnosed than men.

Symptoms and clinical features

- Early symptoms include visual and sensory disturbances, limb weakness, gait problems and bladder and bowel symptoms.
- Fatigue is the most common ongoing symptom, with other issues such as sexual problems, mood changes and speech and swallowing difficulties often developing.
- Over 4 out of 5 people with MS have relapsing-remitting MS (RRMS). A further 10-15% have primary progressive MS, where symptoms gradually worsen over time. Approximately two thirds of those with RRMS will go on to develop secondary progressive MS.

Diagnosis

- MS should be diagnosed by a consultant neurologist based on established criteria.
- Over 90% of cases are diagnosed following an MRI scan.
- Diagnosis can be a difficult and lengthy process, with mis-diagnosis common.

Treatment and ongoing management

- A number of drug treatments can reduce the severity and frequency of relapses.
- A multidisciplinary approach is necessary, with physiotherapy and occupational therapy supporting rehabilitation following a relapse.

Further summaries of Cerebral Palsy, Traumatic Brain Injury, migraine headaches, neuropathies and CNS infections can be found in Appendix 2.

Outcomes Frameworks

While there are no outcome measures specific to neurological conditions detailed in the current Public Health, NHS or Adult Social Care Outcomes Frameworks, each of the domains in the NHS and ASCOF have direct relevance to the care of people with LTNCs.

Table 1. Domains of the NHS and Adult Social Care Outcomes Frameworks

NHS Outcomes Framework[6]	Adult Social Care Outcomes Framework[7]
• NHSOF 1: Preventing people from dying prematurely • NHSOF 2: Enhancing quality of life for people with long-term conditions • NHSOF 3: Helping people to recover from episodes of ill health or following injury • NHSOF 4: Ensuring that people have a positive experience of care • NHSOF 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	• ASCOF 1: Ensuring quality of life for people with care and support needs • ASCOF 2: Delaying and reducing the need for care and support • ASCOF 3: Ensuring that people have a positive experience of care and support • ASCOF 4: Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm

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[6] Department of Health (2014) The NHS Outcomes Framework 2015/16. London: DH

[7] Department of Health (2014) Adult Social Care Outcomes Framework 2015/16. London: DH

What is the picture of neurological conditions in Merton?

Key Points:

Prevalence and mortality

- There is limited local data on the prevalence of LTNCs in Merton, however estimates suggest that, excluding headaches and migraine, a total of 4,626 people in Merton are living with the LTNCs addressed in this assessment.
- Local data indicates a total of 1114 people aged 18 in Merton with a diagnosis of epilepsy. Prevalence rates vary across the borough, with the highest prevalence rates in practices in East Merton and the lowest rates in the West Merton locality.
- Comparing the ratio of observed to expected prevalence, Merton has a ratio of 0.73. This is suggestive of a level of underdiagnosis, particularly in West Merton, however it may also reflect the lower prevalence of epilepsy in less deprived areas.
- Neurological conditions are associated with a low level of mortality. Primary importance should therefore be placed on reducing morbidity and optimising the quality of life of people with LTNCs.

Primary care

- Variations are seen between practices in epilepsy QOF outcomes relating to seizure control and information for women of childbearing age.
- Compared with geographical and statistical neighbours, the proportion of seizure free patients in the last 12 months is slightly lower in Merton.
- Merton has a higher percent of female patients receiving information on contraception, conception and pregnancy compared with London and England. Despite this, five practices in Merton are well below the England average of 57%.

Secondary and tertiary care

- In the year 2012/13 there were a total of 1,727 hospital admissions in Merton CCG with a primary diagnosis diagnosis of a neurological condition, with a total of 2,940 admissions categorised under the PbR Neurology Programme Budget.
- The number of neurology admissions has fallen year on year since 2009/10, a trend that is entirely down to a fall in emergency admissions. The proportion of emergency admissions has reduced to a greater extent in Merton CCG than in London overall.
- The highest number of emergency bed days for neurological admissions are for epilepsy and Parkinson’s disease, however Merton has lower rates of emergency bed day use than the London average for all conditions examined.

Inequalities

- Rates of admissions for LTNCs in Merton vary by gender, with significantly higher admission rates among females or neuropathies and migraine and headaches.

- Admissions are spread across a wide range of ages, with 57% in working age adults. This has significant implications for the range of support required to help manage the impact of these conditions and support independent living.

- A significantly higher rate of admissions are seen in people from ‘other’ ethnic backgrounds for all categories of LTNC except sudden onset conditions. Significantly higher rates are also seen for white groups than Asian and Black groups for intermittent and progressive conditions.

- There is an association between admission rates and deprivation, with higher rates of emergency admission for people in areas with higher levels of deprivation.

Epilepsy in children and young people

- The highest rate of epilepsy admissions among children and young people are for 0-4 year olds, with significantly fewer admissions for 10-14 year olds than younger age groups.

- A higher rate of admissions was observed in other and black ethnic groups than white and Asian groups. An association was again observed between non-elective admissions and deprivation.

Comorbidities

- Comorbidities play a significant role in the care needs of people with LTNCs, with over four times the number of admissions where a neurological condition is a mentioned in the diagnosis code compared with admissions where the LTNC is the primary diagnosis.

Prescribing

- Merton CCG has a lower spend on drugs for epilepsy and PD per 10,000 people than England.

- While the volume of prescribing for both epilepsy and PD has risen between 2011/12 and 2013/14, the cost of prescribing has declined overall, with a slight increase in 2013/14.

Prevalence

There is little data available on the local incidence and prevalence of LTNCs. Epilepsy data is recorded as part of the GP Quality and Outcomes Framework (QOF), however local estimates for other neurological conditions must be derived from national research. Table 2 summarises this data for Merton. As this is not an exhaustive list of all neurological conditions, the resulting total will be a conservative estimate of the true number of people with LTNCs in Merton.

Table 2. Estimated incidence and prevalence of neurological conditions in Merton

Group	Condition	National incidence per 100,000	National prevalence per 100,000	Expected incidence in Merton	Expected prevalence in Merton
Intermittent	Epilepsy	80	500	165	1031
	Migraine	400	15,000	825	30932
	Cluster headache	4	100	8	206
	Paroxysmal hemicrania	N/k	10		21
	Chronic migraine	N/k	3,000		6186
	Chronic tension-type headache	N/k	2,000		4124
Progressive	Parkinson's disease	17	200	35	412
	Motor neurone disease	2	7	4	14
	Multiple sclerosis	4	144	8	297
	Dystonia (primary idiopathic)	n/k	65	n/k	134
	Huntington's disease	n/k	13.5	n/k	28
	Essential tremor	n/k	850	n/k	1753
	Muscular dystrophy	n/k	50	n/k	103
Stable with changing needs	Cerebral palsy	n/k	186	n/k	384
	CNS infections	n/k	7	n/k	14
Sudden onset	Traumatic brain injury	100-150	228	206-309	470
Total expected number of people with a neurological condition in Merton					46, 095
Total expected number of people with a neurological condition in Merton excluding migraine and headaches					4,626

Source: The Neurological Alliance[8] and London Neuroscience SCN[9]

Due to variations in the rates of each LTNC in different population groups, these estimates must be treated with caution. There are a greater number of children and young people in Merton and fewer people aged 50 and above compared to the national population, therefore the overall prevalence of neurological conditions is likely to differ from that suggested by national estimates, with variations between conditions.

Epilepsy Prevalence

More is known locally about the prevalence of epilepsy as this forms part of the GP Quality and Outcomes Framework (QOF). Comparing Merton with geographical and statistical neighbours, Merton has a comparatively low prevalence of epilepsy, with significantly lower rates than most geographical neighbours and than England as a whole.

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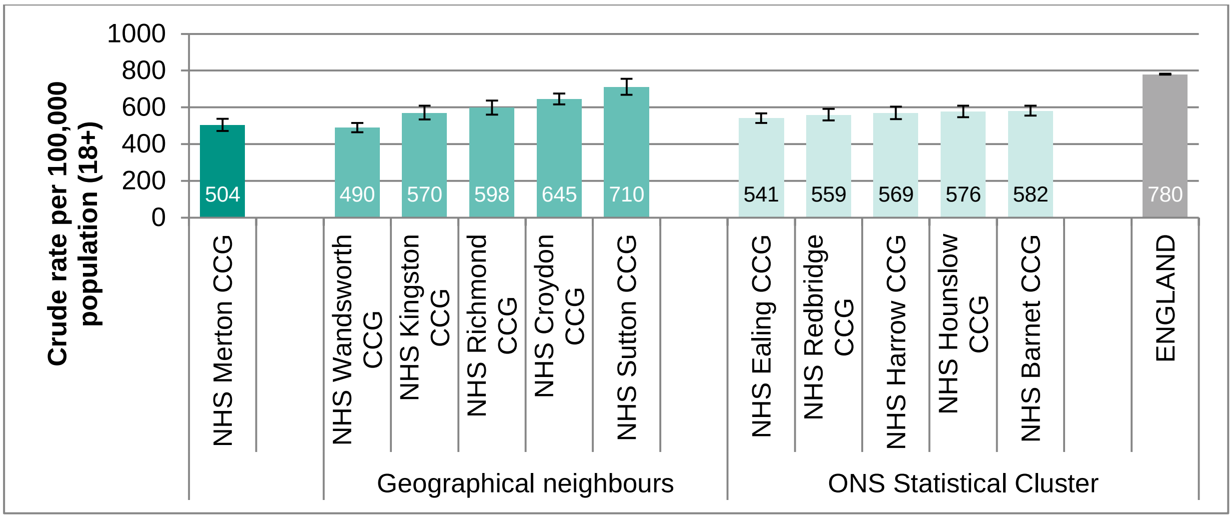
[8] The Neurological Alliance (2003) Neuro numbers. London: The Neurological Alliance

[9] London Neuroscience SCN (2014) CCG Neurology Profiles

Fig 2. Recorded prevalence of epilepsy (18 years+), Merton CCG and comparators, 2012/13, with 95% confidence intervals *, **



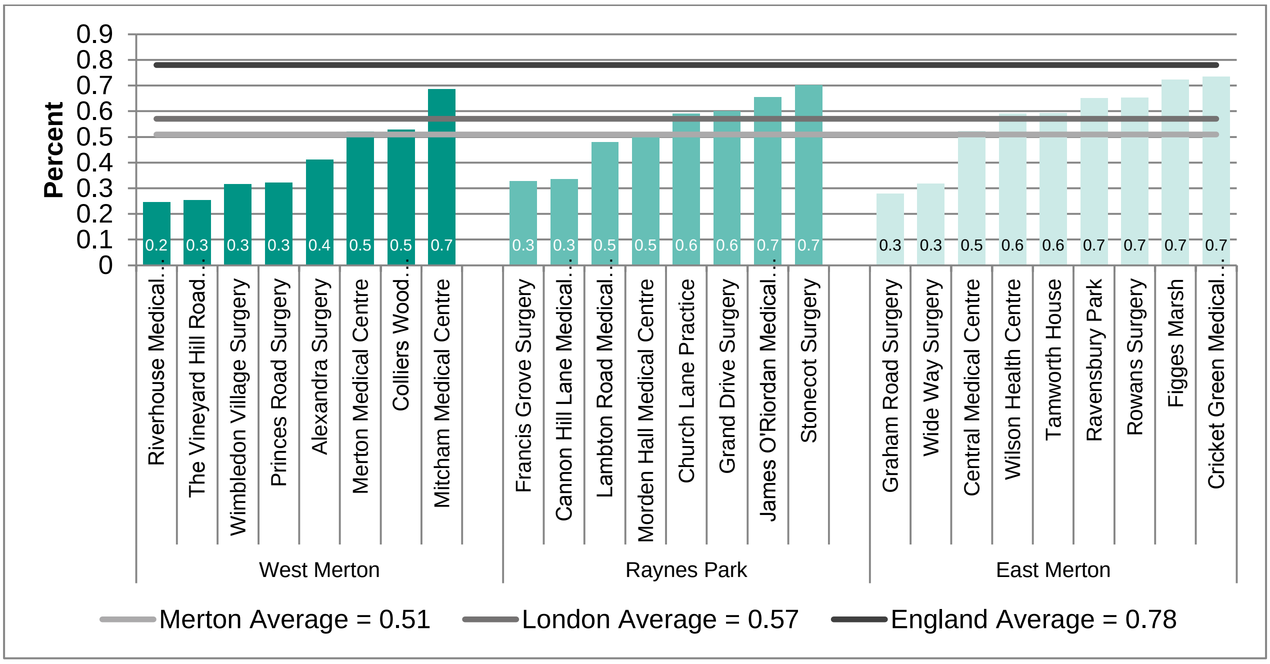
Source: Public Health England Neurology Profiles

* 95% **Confidence Intervals** (CI) indicate the precision with which the percentages are calculated. They also indicate the range of values in which there is a 95% likelihood that the true value for the patient population lies - the narrower the range, the more precise the calculation. The intervals are the widest for the smaller sample sizes. These are shown by the vertical lines at the top of the bar graphs. When the percentages are compared, if the CI intervals do not overlap this represents a statistically significant difference. Source: NHS Information Centre, HSCIC https://indicators.ic.nhs.uk/webview/

***London value not available*

Prevalence rates vary between Merton practices from 0.25% to 0.73%, with an average of 0.51% across the CCG. This is below the England average of 0.78% and equates to between 9 and 94 patients per practice.

Fig 3. Epilepsy prevalence (18+) by GP practice and locality in Merton, 2013-14



Source: Quality and Outcomes Framework, Health and Social Care Information Centre

Practices in the East Merton locality generally have a higher prevalence than other localities. With higher levels of deprivation in East Merton, this reflects the known association between epilepsy and deprivation. Table 3 shows the distribution across the three GP localities in Merton.

Table 3. Numbers of people aged 18 and above diagnosed with epilepsy by GP locality in Merton, 2013-14

GP Locality	Numbers with a recorded diagnosis of epilepsy (18 yrs+)
East Merton	375
Raynes Park	457
West Merton	281

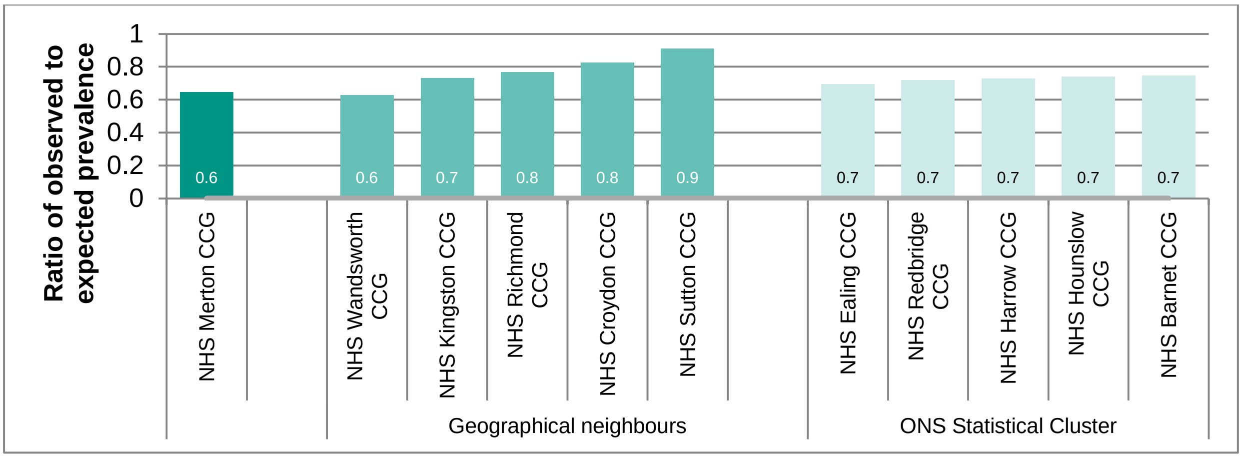
Source: Quality and Outcomes Framework, Health and Social Care Information Centre

Observed vs expected prevalence

Using the national prevalence rate for epilepsy in people aged 18 years and over it is possible to calculate the expected number of cases for Merton and comparator CCGs, and for each individual GP practice. The ratio of observed to expected prevalence then gives an indication of levels of diagnosis. A value below 1 indicates that fewer cases are diagnosed than would be expected according to national prevalence rates. A value above 1 indicates that a greater number of cases are diagnosed than would be expected.

Merton CCG has a lower ratio of observed to expected prevalence than all statistical comparator CCGs. At a ratio of 0.6, Merton CCG also has the lowest ratio of all South West London CCGs, with Wandsworth CCG being the only comparator with the same ratio. This is potentially suggestive of a level of under-diagnosis.

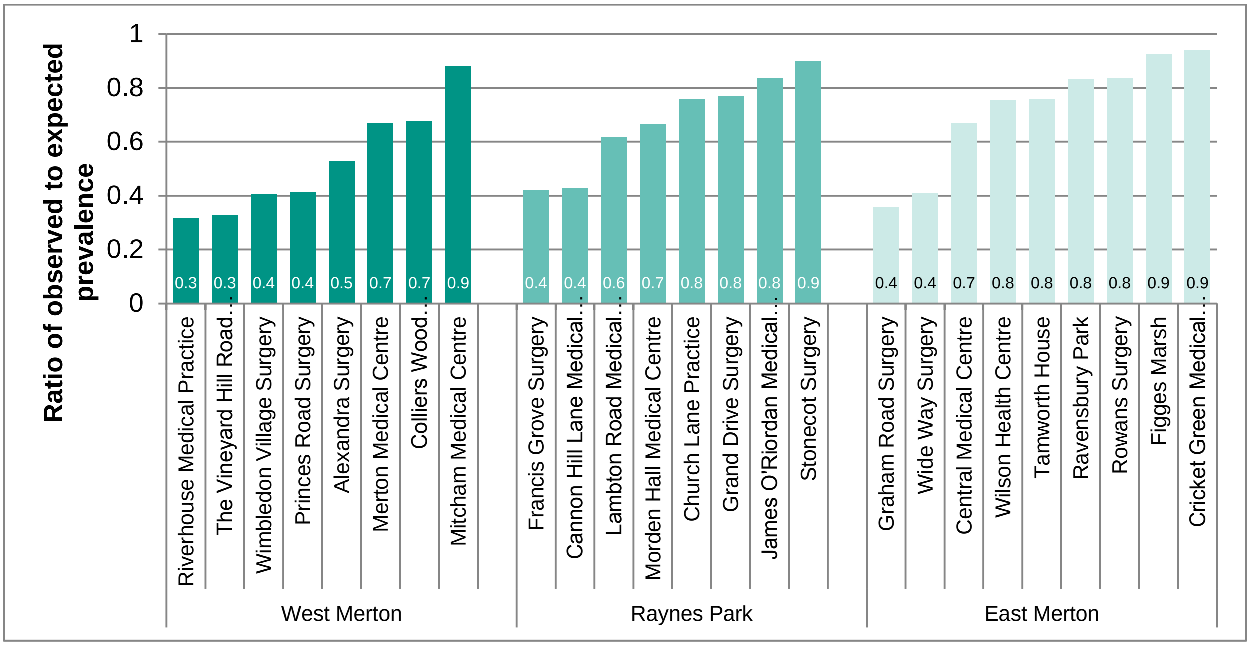
Fig 4. Ratio of observed to expected prevalence of epilepsy (18+) in Merton CCG and comparators, QOF 2013-14



Source: Quality and Outcomes Framework, Health and Social Care Information Centre

The ratio of observed to expected prevalence varies significantly between practices in Merton, with practices in East Merton generally having a higher ratio than the other localities. West Merton generally has much lower levels of diagnosis, with all but one practice below the Merton average. This suggests a level of under-diagnosis across the borough, but particularly in West Merton, however this may be reflective of the differing prevalence in areas with different levels of socio-economic deprivation.

Fig 5. Ratio of observed to expected prevalence of epilepsy (18 years and over) in Merton GP practices, QOF 2013-14



Source: Quality and Outcomes Framework, Health and Social Care Information Centre

Mortality data

Examination of Primary Care Mortality Database records gives an indication of the number of deaths associated with neurological conditions in Merton. The data indicates a very low level of mortality associated with the selected conditions over the five years to December 2014. This reflects the fact that people often live for many years with a LTNC following diagnosis, and the LTNC itself is often not the cause of death. Neurological conditions consequently cause far greater morbidity than they do mortality.

Table 4. Number of deaths for which selected neurological conditions are recorded as a cause of death in Merton, 2010-2014

Neurological condition	**Number of associated deaths**
PD	55
Epilepsy	18
MND	18
MS	10

Source: Primary Care Mortality Database

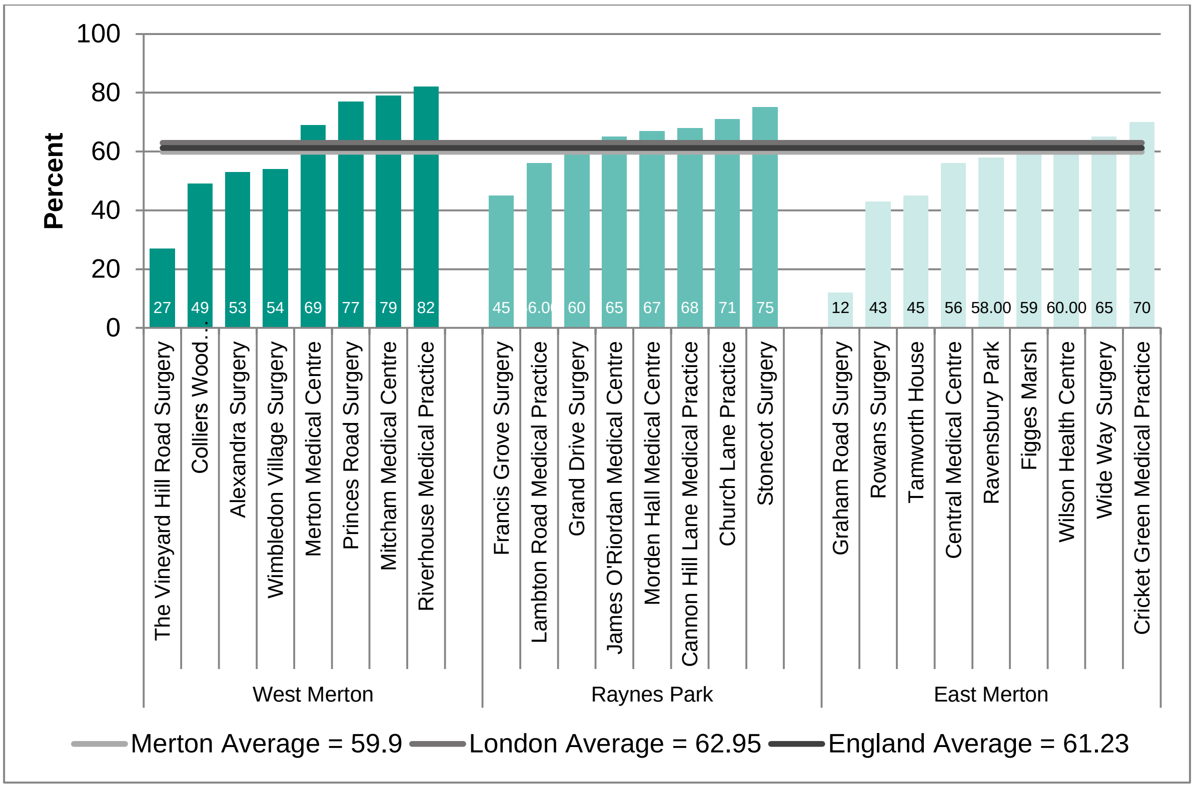
Primary Care

Further QOF indicators allow evaluation of primary care for individuals with epilepsy.

Seizure control

Measures of seizure control give some indication as to the effectiveness of the epilepsy management strategy, although it is acknowledged that factors outside the GP's control can also influence levels of seizure control. Fig 6 demonstrates that The Vineyard Hill Road Surgery and Graham Road Surgery have particularly low levels of epilepsy patients on drug treatment who have a record of being seizure free in the last 12 months. These practices also have the highest exception rates for epilepsy indicators at 50.0 and 82.4 respectively.

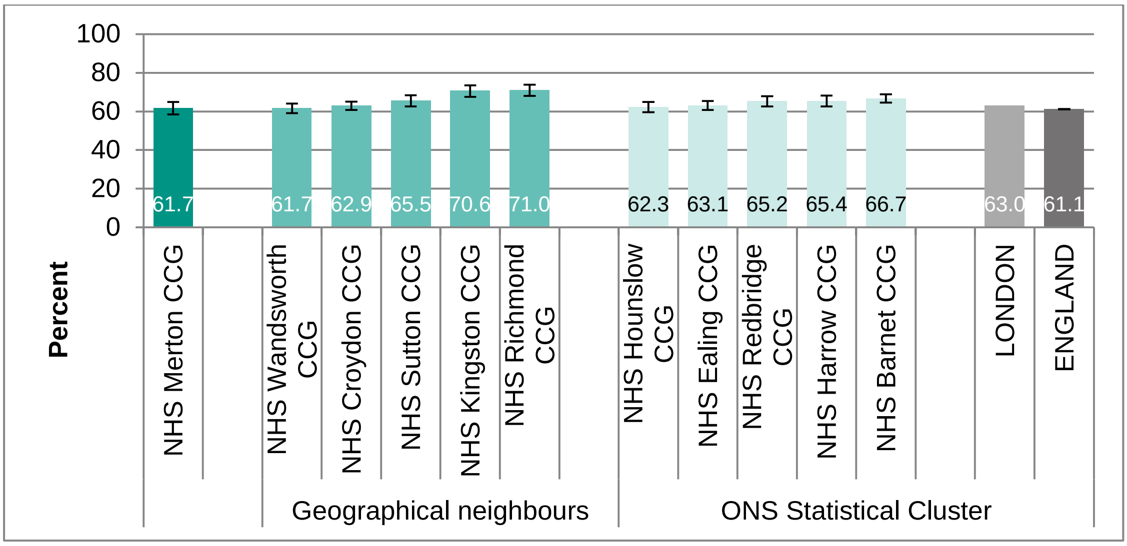
Fig 6. EP002: Epilepsy patients (18+) on drug treatment and seizure free for the last 12 months in Merton by GP practice and locality, 2013-14



Source: Quality and Outcomes Framework, Health and Social Care Information Centre

Merton has the lowest proportion of seizure free patients recorded of all geographical and statistical neighbours, equal to Wandsworth at 61.7%. This is significantly lower than Kingston and Richmond upon Thames, however Merton CCG is slightly above the national average.

Fig 7. EP002: Proportion of individuals aged 18 years and over receiving drug treatment for epilepsy who have been seizure free in the last 12 months, Merton and comparators, 2013/14, with 95% confidence intervals*



Source: Public Health England Neurology Profiles

* 95% **Confidence Intervals** (CI) indicate the precision with which the percentages are calculated. They also indicate the range of values in which there is a 95% likelihood that the true value for the patient population lies - the narrower the range, the more precise the calculation. The intervals are the widest for the smaller sample sizes. These are shown by the vertical lines at the top of the bar graphs. When the percentages are compared, if the CI intervals do not overlap this represents a statistically significant difference. Source: NHS Information Centre, HSCIC https://indicators.ic.nhs.uk/webview/

Women of childbearing age

It is important that women of reproductive age who are receiving antiepileptic drugs (AEDs) are given appropriate advice regarding contraception, conception and pregnancy as ssociations have been demonstrated between AEDs taken during pregnancy and an increased risk of major congenital malformations.[10]

Fig 8 displays the results of this indicator for Merton practices, demonstrating significant variation in achievement. While the Merton average (73%) is higher than both the London (69%) and England (57%) averages, five practices are at a level of 50% or below.

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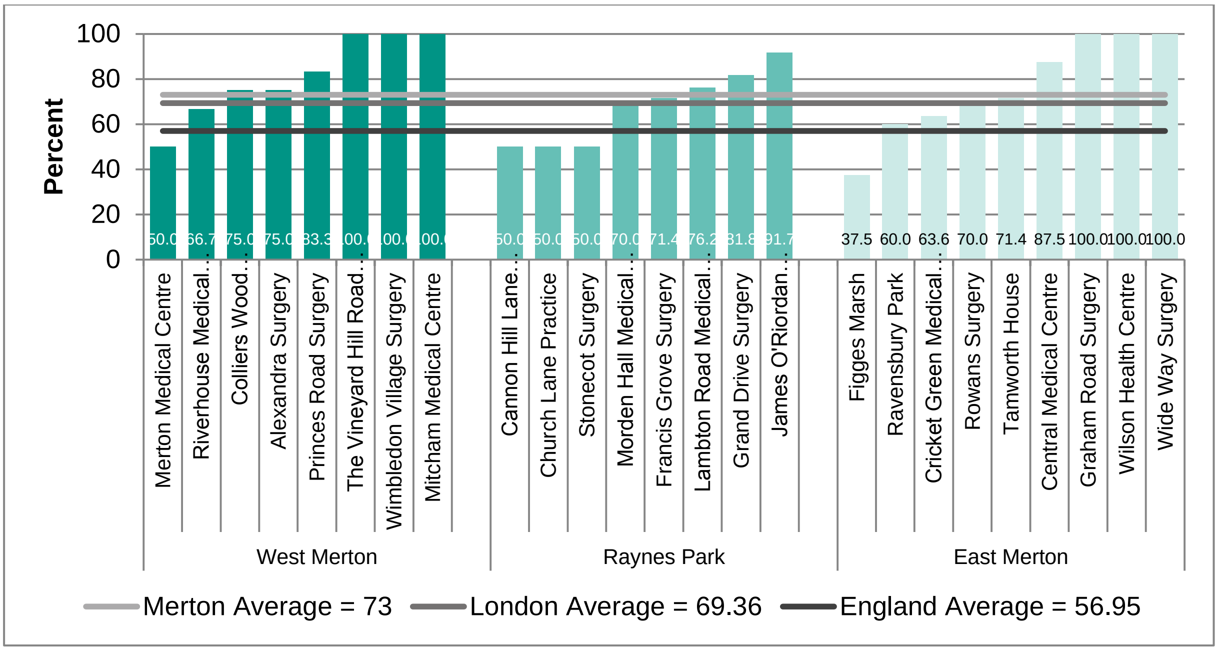
[10] Public Health England Neurology Profiles: QOF rationale

Fig 8. EP003: Female epilepsy patients, 18-54 yrs old, with contraception, conception and pregnancy record in the last 12 months in Merton, by GP practice and locality, 2013-14

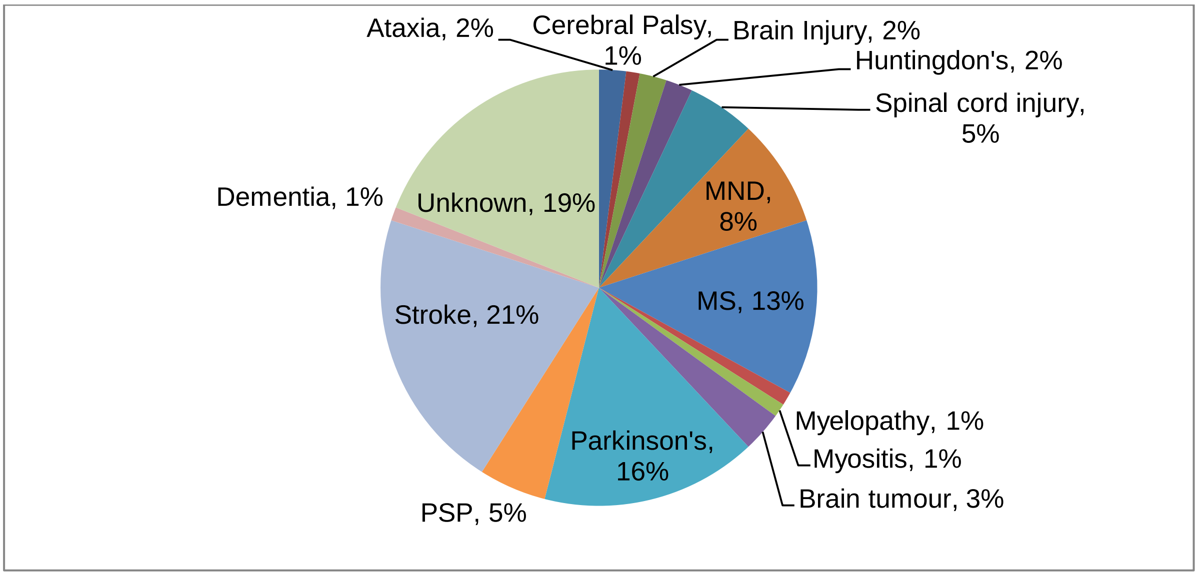


Source: Quality and Outcomes Framework, Health and Social Care Information Centre

Community care

Data from Sutton and Merton Community Services (SMCS) demonstrates the range of conditions seen among patients who access services provided by the Community Neurotherapy Team. As at May 2015, 21% of the caseload represented patients with stroke, 16% Parkinson's disease and 13% MS.

Fig 9. Merton caseload of the Community Neurotherapy Team by condition as at 01/05/2015



Source: SMCS

A large number of other people with LTNCs access general community services, however routine information is not collected on the conditions of those accessing services.

Secondary and tertiary care

Numbers of admissions for LTNCs

Data presented by the London Neuroscience SCN (Table 5) indicates that in total, there were 1,727 hospital admission with a primary diagnosis of a neurological condition in Merton in 2012/13. This represents a rate of 793 admissions per 100,000 population, slightly above the London rate of 721 per 100,000.

The rate of admissions where neurological conditions are a mention in the diagnosis code are significantly higher than admissions for a primary diagnosis of a neurological condition. This is similar to the pattern across London, indicating a much greater level of need for care when people with LTNCs are admitted for reasons other than their neurological condition.

A third comparative figure displays the number of admissions categorised under the Payment by Results Neurology Programme Budget Category. This represents admissions coded not only by diagnosis code but also by the treatment received. This figure therefore provides a more accurate indication of the need for care due to neurological conditions, whether or not they are the primary reason for admission. These figures indicate a rate of 1,350 per 100,000, representing some of the lowest admission rates across CCGs in London and much below that of the London rate of 1,904 per 100,000.

Table 5. Merton CCG total neurology admissions, by primary diagnosis, mention and PbR Budget Category, benchmarked against other London, 2012/13

	Merton		**London**
	Number of admissions	**Rate of admissions per 100,000**	**Rate of admissions per 100,000**
Primary diagnosis	1,727	793	721
Mention	4,416	2,028	2,025
Payment by Results Programme Budget Category	2,940	1,350	1,904

Source: London Neuroscience SCN

Admission type

Fig 10 demonstrates a trend in decreasing numbers of neurology admissions in Merton year on year since 2009-10. This decrease is solely due to a reduction in the numbers of emergency admissions. Fig 11 represents the consequent convergence of the proportion of emergency and elective admissions. This shows that the reduction in emergency admission in Merton has been more marked between 2011-12 and 2012-13 than across London as a whole.

Fig 10. Neurology admission per 100,000, Merton CCG*

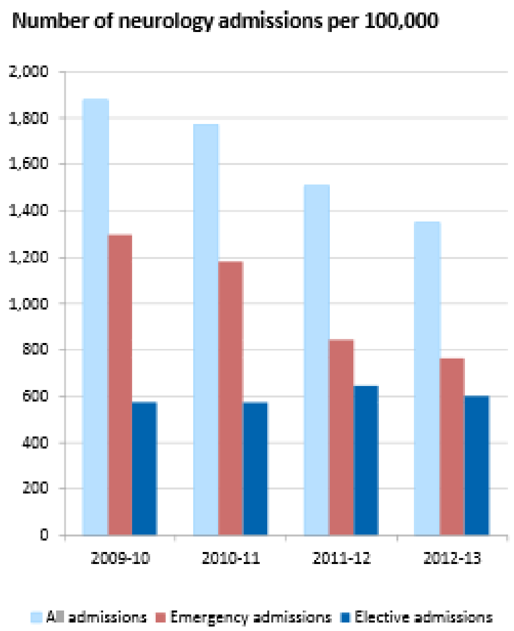
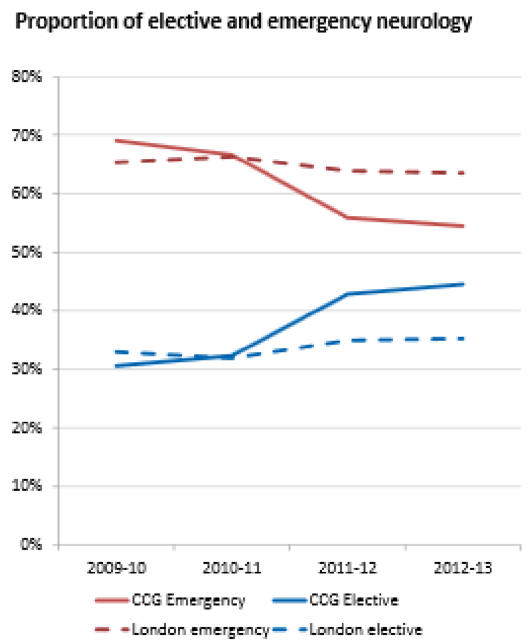


Fig 11. Proportion of neurology admissions by type, Merton CCG and London*



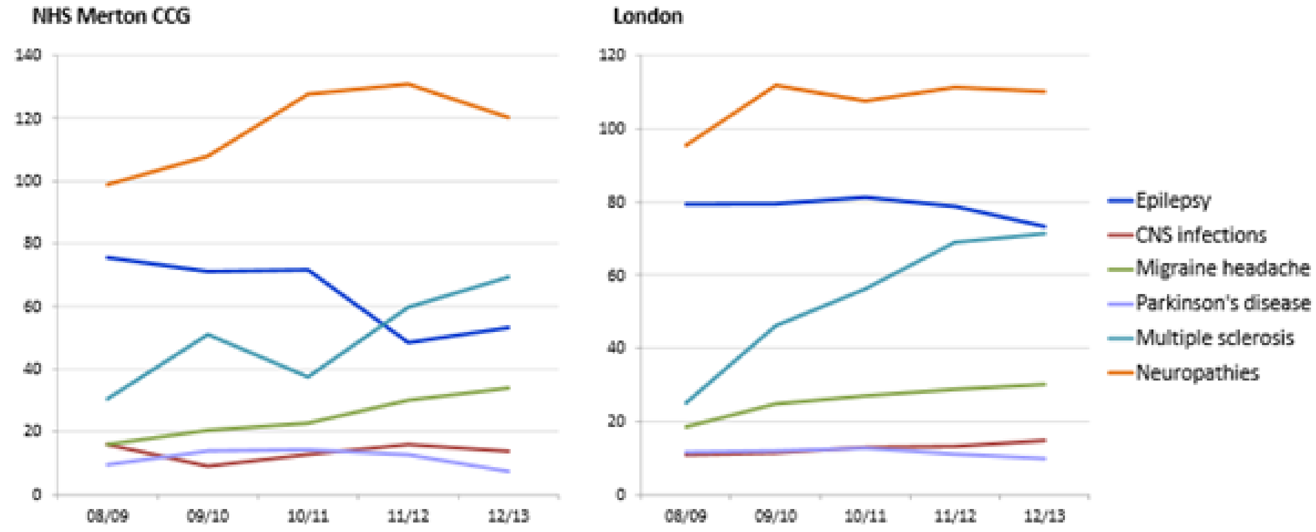
**Neurology Programme Budget admissions*

Source: London Neuroscience SCN

Admissions by condition

When admissions are analysed by condition, a more nuanced picture emerges with large differences in admission rates for different conditions. Neuropathies have the highest number of admissions for any group of conditions in Merton CCG. While admissions for epilepsy have begun to reduce across London since 2010/11, they have reduced more dramatically in Merton, dropping below 60 per 100,000 in 2011/12 and 2012/13. Admissions for Multiple Sclerosis have seen a marked increase since 2008/09 across London. This is known to be due to an increase in the availability of disease-modifying therapy.

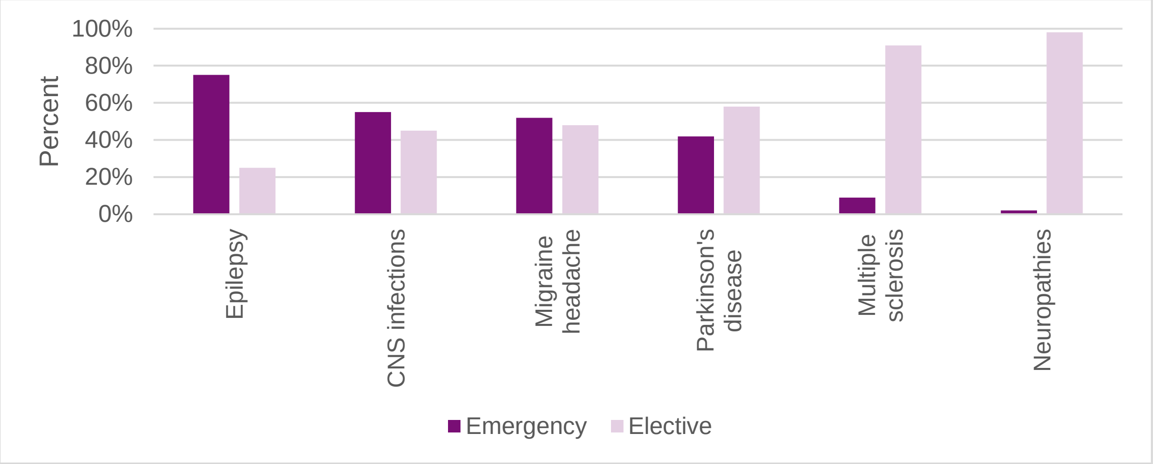
Fig 12. Rate of admissions per 100,000 population for selected LTNCs in Merton CCG and London, 2008/9-2012/13.



Source: London Neuroscience SCN

Data analysing the rates of emergency and elective admissions demonstrates that epilepsy had the greatest proportion of emergency admissions as a proportion of total admissions in 2012/13, while MS and neuropathies have much greater proportions of elective admissions.

Fig 13. Proportion of admissions by admission type for selected neurological conditions in Merton, 2012/13

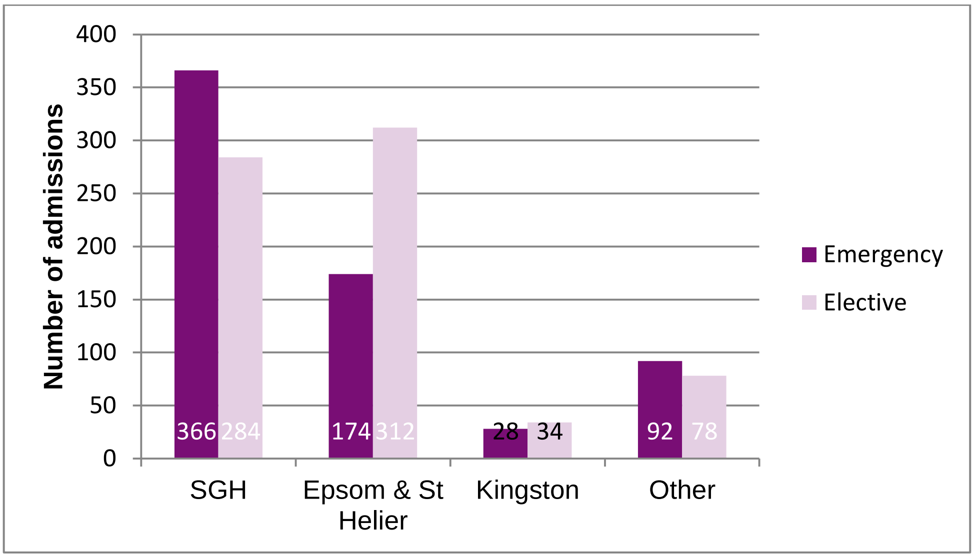


Source: London Neuroscience SCN

Admissions by provider

Disaggregating admissions by provider, St George's Healthcare NHS Trust (SGH) and Epsom and St Helier University Hospitals NHS Trust (ESH) are the main providers of secondary and tertiary neurology services for Merton patients. ESH received 44% of all Merton elective neurology admissions, while SGH received the majority of emergency admissions.

Fig 14. Total number of admissions by provider and admission type, 11/12-13/14



Source: SUS data

Emergency admissions

SUS data indicates that 48% of admissions for a primary diagnosis of the selected LTNCs were emergency admissions, however when neuropathies are removed from the analysis, this figure rises to 77%.

Merton is found to have significantly lower rates of emergency admission for epilepsy than Sutton, Croydon and Ealing as well as England overall (Fig 15). Low numbers of admissions for a number of other conditions mean that differences between CCGs are not found to be statistically significant, therefore while Merton appears to have a higher rate of emergency admissions for MS and inflammatory disorders than comparators (Fig 16), it is not possible to draw firm conclusions from this.

Fig 15. Emergency admissions to hospital with a primary diagnosis of epilepsy (18+ yrs), Merton and comparators, 2012/13, with 95% confidence intervals*

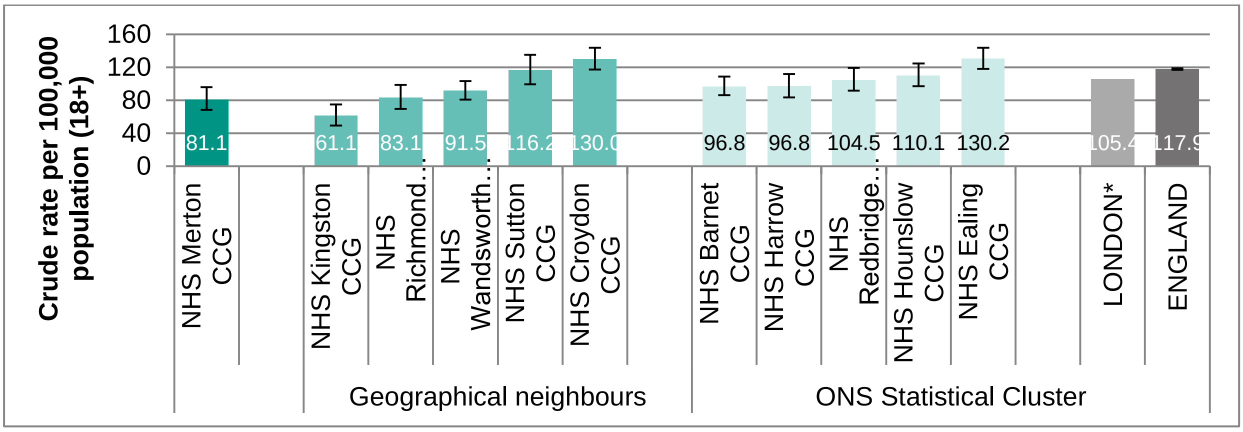
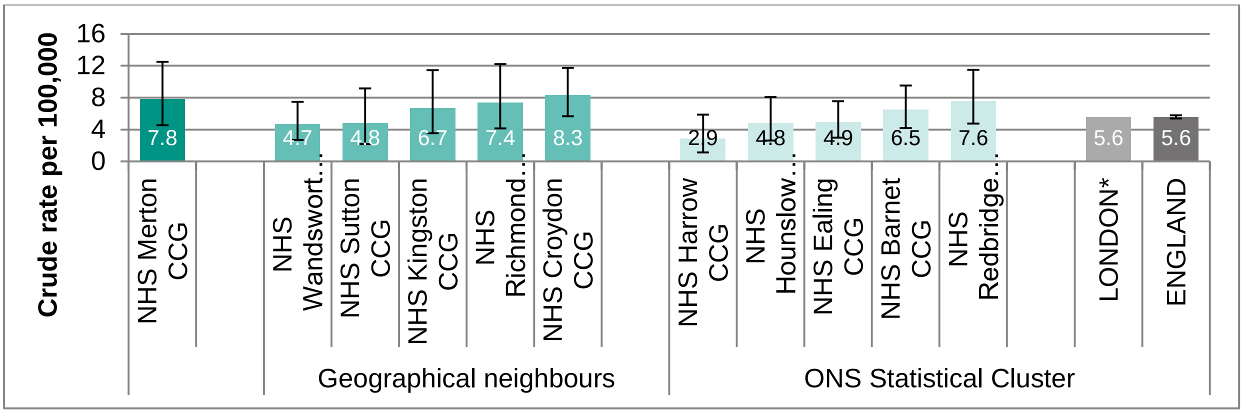


Fig 16. Emergency admissions with a primary diagnosis of Multiple Sclerosis and inflammatory disorders, Merton and comparators, 2012/13, with 95% confidence intervals*



Source: Public Health England Neurology Profiles

* 95% **Confidence Intervals** (CI) indicate the precision with which the percentages are calculated. They also indicate the range of values in which there is a 95% likelihood that the true value for the patient population lies - the narrower the range, the more precise the calculation. The intervals are the widest for the smaller sample sizes. These are shown by the vertical lines at the top of the bar graphs. When the percentages are compared, if the CI intervals do not overlap this represents a statistically significant difference. Source: NHS Information Centre, HSCIC https://indicators.ic.nhs.uk/webview/

**Estimated values for London*

Data for the year 2013/14 indicates a total of 188 avoidable emergency admissions for convulsions and epilepsy, classified as admissions for ambulatory care sensitive conditions where community and case management can prevent admission to secondary care. Table 6 demonstrates the breakdown of these admissions by condition category and age group. Among 0-19 year olds in the acute group, 71% of admissions were of 0-4 year olds.

Table 6. Avoidable emergency admissions for convulsions and epilepsy in Merton by condition category and age group, 2013/14

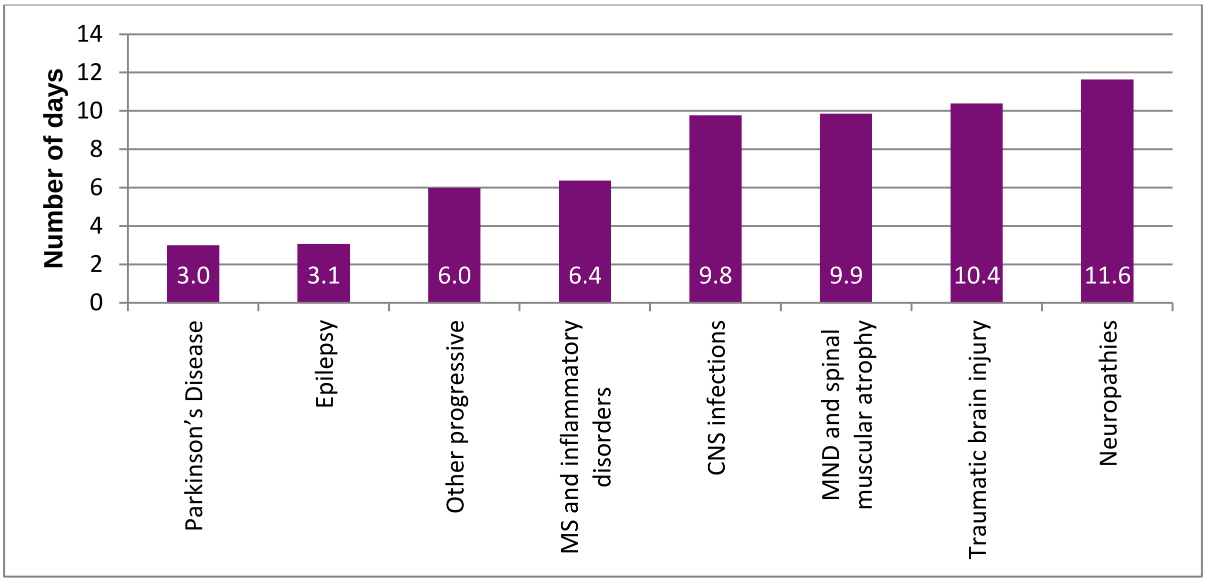
	Acute conditions	Chronic conditions
0-19	51	15
20-64	26	48
65+	20	13

Source: SUS data

Emergency bed use

Mean length of stay for emergency admissions varies by condition. The longest length of stay is for emergency admissions due to neuropathies and traumatic brain injury, both with mean lengths of stay greater than 10 days. The shortest length of stay for emergency admissions are for Parkinson's disease and Epilepsy, at 3.0 and 3.1 days respectively.

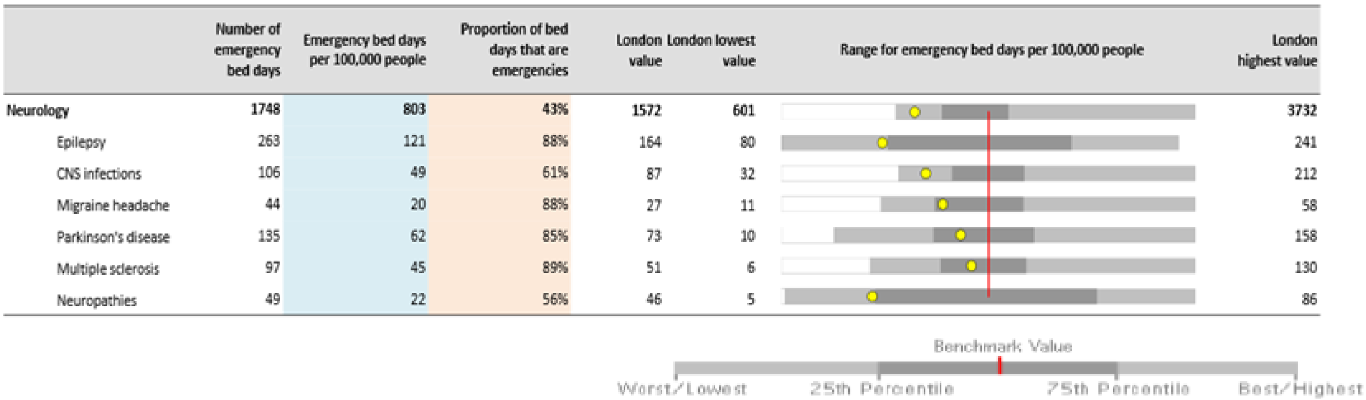
Fig 17. Mean length of stay for emergency admissions for selected neurological conditions, 11/12-13/14



Source: SUS data

Emergency bed days represented 43% of total neurology bed days in Merton in 2012/13. The highest number of emergency bed days were for epilepsy (263 bed days), followed by Parkinson's disease (135 bed days). While both conditions have a low mean length of stay, these figures are indicative of the high number of emergency admissions for both epilepsy and Parkinson's. Nevertheless rates of emergency bed days per 100,000 people for all reported conditions in Merton are below the London benchmark, with rates for epilepsy and neuropathies being below the 25th percentile.

Fig 18. Use of bed days following emergency admissions in Merton (PbR Neurology Budget Category), 2012/13



	Number of emergency bed days	Emergency bed days per 100,000 people	Proportion of bed days that are emergencies	London value	London lowest value	Range for emergency bed days per 100,000 people	London highest value
Neurology	1748	803	43%	1572	601		3732
Epilepsy	263	121	88%	164	80		241
CNS infections	106	49	61%	87	32		212
Migraine headache	44	20	88%	27	11		58
Parkinson's disease	135	62	85%	73	10		158
Multiple sclerosis	97	45	89%	51	6		130
Neuropathies	49	22	56%	46	5		86

Source: London Neuroscience SCN

Inpatient management of LTNCs

For all conditions examined, below 50% of neurology admissions in Merton are managed by a consultant neurologist. The London Neuroscience SCN argue that the low proportion of neurology patients being managed by consultant neurologists across London is likely to be having a negative impact on patient care. Nevertheless benchmarking Merton against other

London CCGs, Merton is above the average value for all conditions except CNS infections and above the 75th percentile for epilepsy, migraine headache and Parkinson's disease.

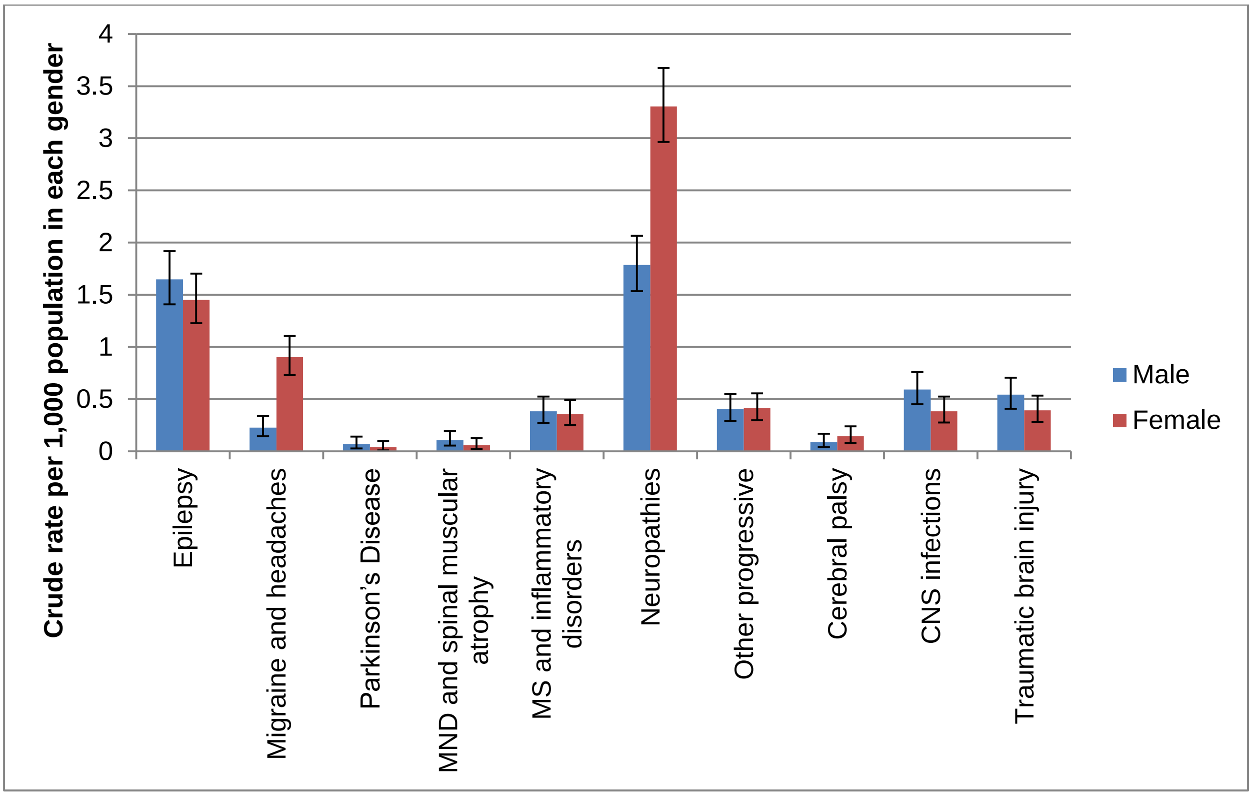
Inequalities

Gender

The prevalence of different neurological conditions varies by gender, with some conditions such as MND and Parkinson's being more prevalent in men, and others such as MS seeing a higher prevalence among women.

57% of admissions for the selected groups of conditions between April 2011 and March 2014 were for females. Fig 19 details the rate of admissions by gender for each group of conditions. The only conditions for which there is a statistically significant difference in admissions are migraine and headaches and neuropathies, both of which see significantly higher rates of admissions in females.

Fig 19. Crude rate of admissions for selected neurological conditions in Merton by gender, 11/12-13/14, with 95% confidence intervals*



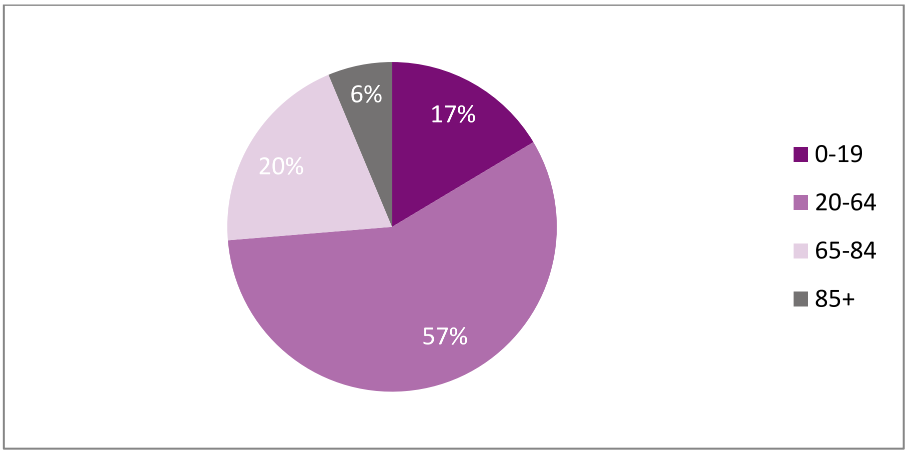
Source: SUS data and GLA 2013 round demographic projections

* 95% **Confidence Intervals** (CI) indicate the precision with which the percentages are calculated. They also indicate the range of values in which there is a 95% likelihood that the true value for the patient population lies - the narrower the range, the more precise the calculation. The intervals are the widest for the smaller sample sizes. These are shown by the vertical lines at the top of the bar graphs. When the percentages are compared, if the CI intervals do not overlap this represents a statistically significant difference. Source: NHS Information Centre, HSCIC
https://indicators.ic.nhs.uk/webview/

Age

Overall, 57% of admissions are in working age people between 20 and 64 years old. This has significant implications for the management of LTNCs and the ability of people to remain as independent as possible, with individuals likely to be faced with challenges relating to employment and implications for their family and potential dependents.

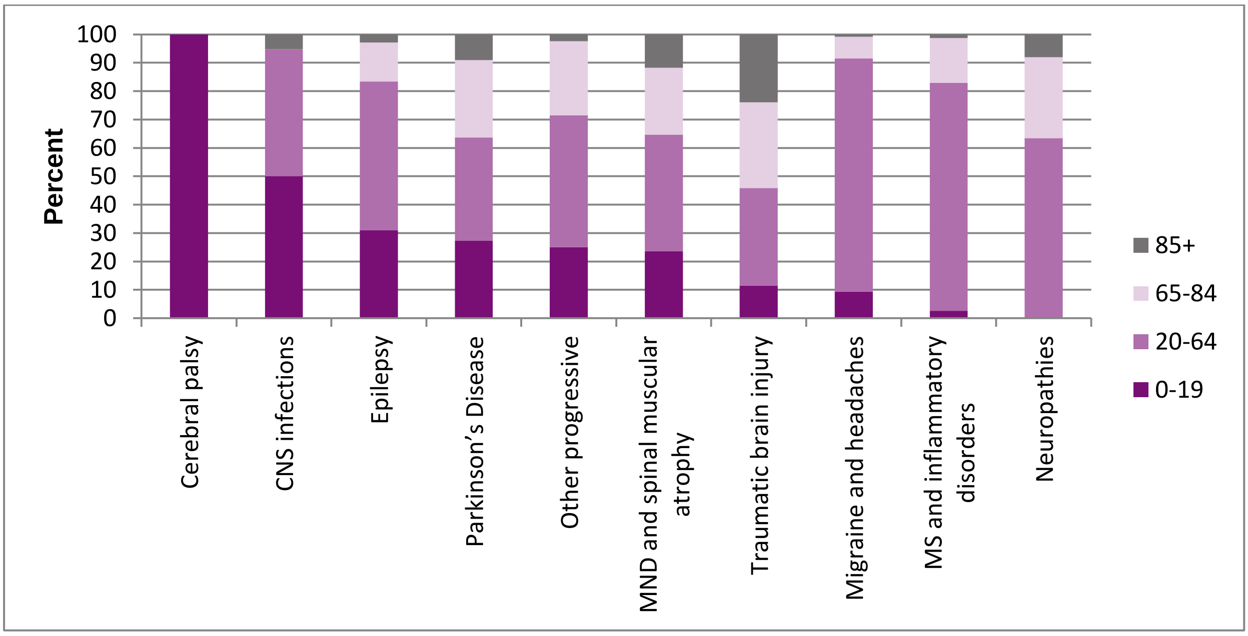
Fig 20. Proportion of admissions for selected neurological conditions in Merton by age group, 11/12-13/14



Source: SUS data

With the exception of cerebral palsy, admissions for all conditions are spread across a wide range of ages. This indicates some of the complexity inherent in care for individuals for LTNCs. Regarding cerebral palsy, it is likely that the observed concentration in the 0-19 age group is due to the fact that admissions in adults with cerebral palsy are coded more descriptively by the presenting condition, rather than as cerebral palsy itself.

Fig 21. Proportion of admissions for selected neurological conditions in Merton by age group and condition, 11/12-13/14

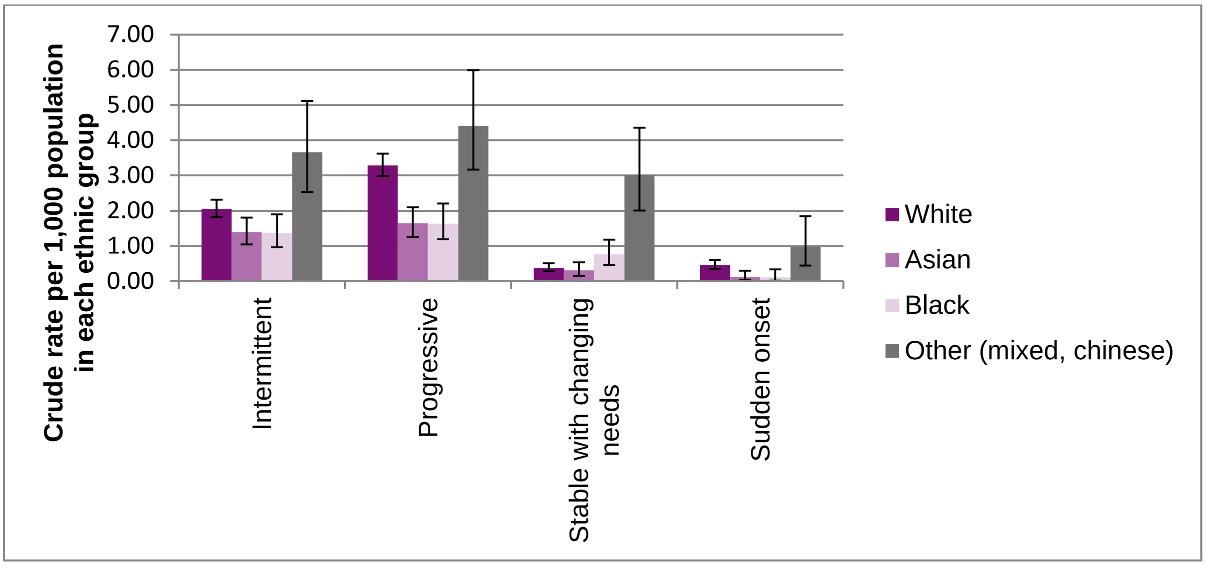


Source: SUS data

Ethnicity

Significantly higher rates of admissions are seen for individuals in the ‘other’ category for all groups of condition except sudden onset conditions. Those from a white background also have a significantly higher rate of admissions than Asian or Black groups for intermittent and progressive conditions. Ethnicity was not known or not stated for 14% of admissions.

Fig 22. Crude rate of admissions for selected neurological conditions in Merton by condition group and ethnicity, 11/12-13/14, with 95% confidence intervals*



Source: SUS data and GLA Ethnic Group: 2013 round capped Strategic Housing Land Availability Assessment-based population projections

* 95% **Confidence Intervals** (CI) indicate the precision with which the percentages are calculated. They also indicate the range of values in which there is a 95% likelihood that the true value for the patient population lies - the narrower the range, the more precise the calculation. The intervals are the widest for the smaller sample sizes. These are shown by the vertical lines at the top of the bar graphs. When the percentages are compared, if the CI intervals do not overlap this represents a statistically significant difference. Source: NHS Information Centre, HSCIC https://indicators.ic.nhs.uk/webview/

Locality

Practices in the East Merton locality have a substantial proportion of admissions for cerebral palsy, CNS infections, epilepsy, neuropathies and traumatic brain injury. This is likely to be due to the age profile of the borough, with a younger profile of residents in the East compared to the West.[11]

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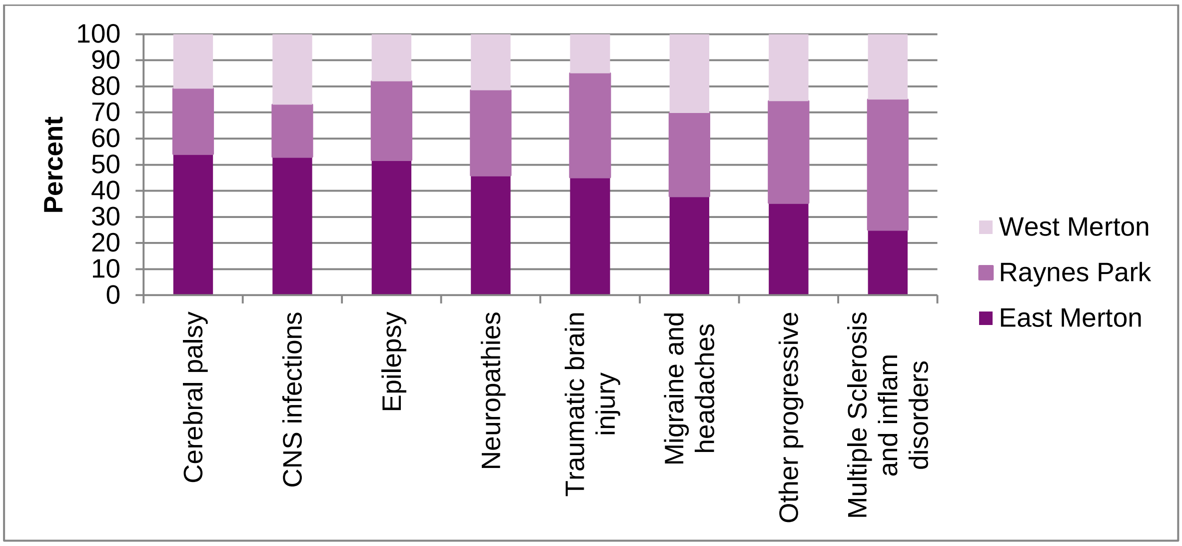
[11] Merton Joint Strategic Needs Assessment http://www.merton.gov.uk/health-social-care/publichealth/jsna.htm

Fig 23. Proportion of admissions for selected LTNCs in Merton by GP locality, 11/12-13/14

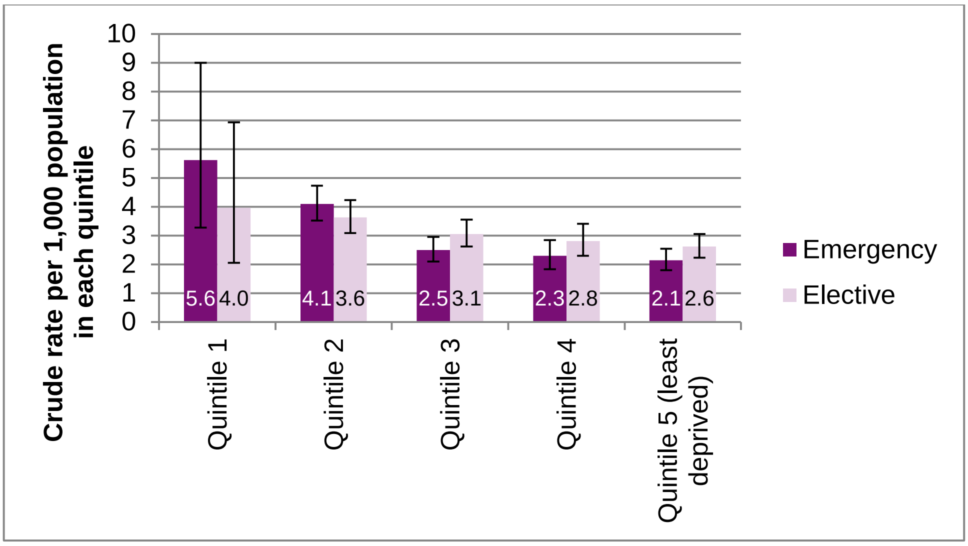


Source: SUS data

Deprivation

Assessing admissions by deprivation quintile, a trend can be seen in the rate of emergency admission by deprivation with significantly higher rates of emergency admissions for individuals in Index of Multiple Deprivation (IMD) Quintiles 1 and 2 than less deprived quintiles. There is also a significantly lower rate of elective admissions for LTNCs in IMD quintile 5 than quintile 2.

Fig 24. Crude rate of admissions for selected neurological conditions in Merton by deprivation quintile, 11/12-13/14, with 95% confidence intervals*



Source: SUS data and Index of Multiple Deprivation

* 95% **Confidence Intervals** (CI) indicate the precision with which the percentages are calculated. They also indicate the range of values in which there is a 95% likelihood that the true value for the patient population lies - the narrower the range, the more precise the calculation. The intervals are the widest for the smaller sample sizes. These are shown by the vertical lines at the top of the bar graphs. When the percentages are compared, if the CI intervals do not overlap this represents a statistically significant difference. Source: NHS Information Centre, HSCIC https://indicators.ic.nhs.uk/webview/

This indicates inequalities in service use within neurology, most notably for acute care, suggesting that people from more affluent areas are more likely to have increased levels of management of their LTNC than those from deprived areas.

Epilepsy in children and young people

While this review has taken a broad approach looking at all age ranges, almost half of the admissions identified by SUS data for the age group 0-19 were for a diagnosis of epilepsy (44%). Consequently this section examines the profile of admissions for epilepsy in children and young people.

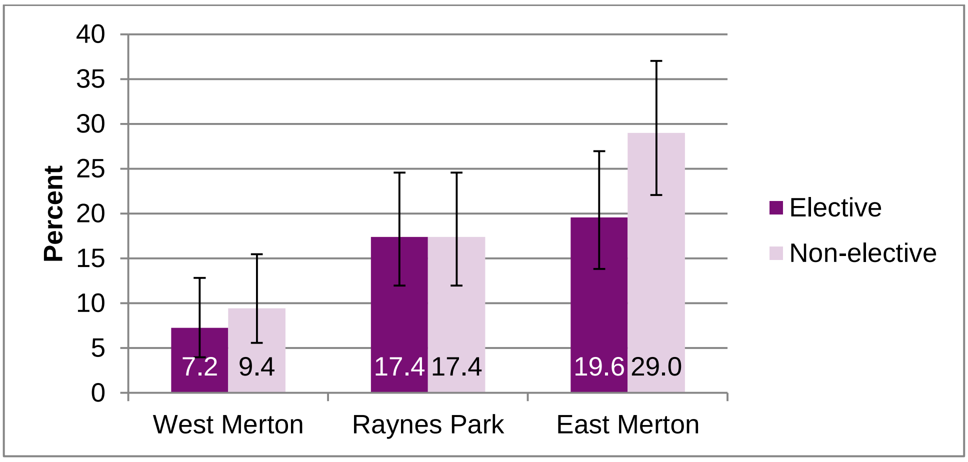
Provider

Unlike neurology admissions broadly, the majority of elective and non-elective admissions for epilepsy in 0-19 year olds are seen at Epsom and St Helier University Hospitals. 44% of elective admissions go to Epsom and St Helier, with just over a quarter going to St George's (26%) and a further fifth to Great Ormond Street Hospital (21%). 51% of emergency admissions go to Epsom and St Helier, with 38% going to St George's Hospital.

Type of admission and locality

The difference in the proportion of emergency and elective admissions is not as great as that seen in the population as a whole, with 45% of admissions for a primary diagnosis of epilepsy in 0-19 year olds being elective admissions. A higher proportion of admissions are from GPs in the East Merton locality, likely reflecting the higher proportion of young people living in the east of the borough.

Fig 25. Proportion of admissions for a primary diagnosis of epilepsy in 0-19 year olds in Merton by GP locality, 11/12-13/14, with 95% confidence intervals*



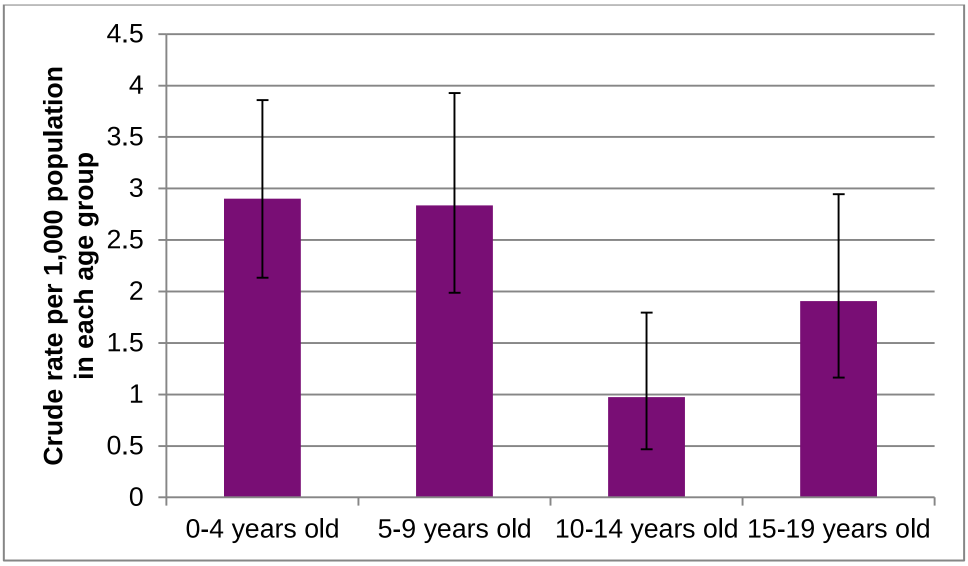
Source: SUS data

* 95% **Confidence Intervals** (CI) indicate the precision with which the percentages are calculated. They also indicate the range of values in which there is a 95% likelihood that the true value for the patient population lies - the narrower the range, the more precise the calculation. The intervals are the widest for the smaller sample sizes. These are shown by the vertical lines at the top of the bar graphs. When the percentages are compared, if the CI intervals do not overlap this represents a statistically significant difference. Source: NHS Information Centre, HSCIC https://indicators.ic.nhs.uk/webview/

Age and gender

In children and young people, the highest rate of admissions are among 0-4 year olds, followed closely by 5-9 year olds. There are significantly fewer admissions in 10-14 olds than either of the younger groups.

Fig 26. Crude rate of admissions for a primary diagnosis of epilepsy in 0-19 yr olds in Merton by age group, 11/12-13/14, with 95% confidence intervals*



Source: SUS data and GLA round capped Ethnic group Strategic Housing Land Availability Assessment-based population projections

* 95% **Confidence Intervals** (CI) indicate the precision with which the percentages are calculated. They also indicate the range of values in which there is a 95% likelihood that the true value for the patient population lies - the narrower the range, the more precise the calculation. The intervals are the widest for the smaller sample sizes. These are shown by the vertical lines at the top of the bar graphs. When the percentages are compared, if the CI intervals do not overlap this represents a statistically significant difference. Source: NHS Information Centre, HSCIC https://indicators.ic.nhs.uk/webview/

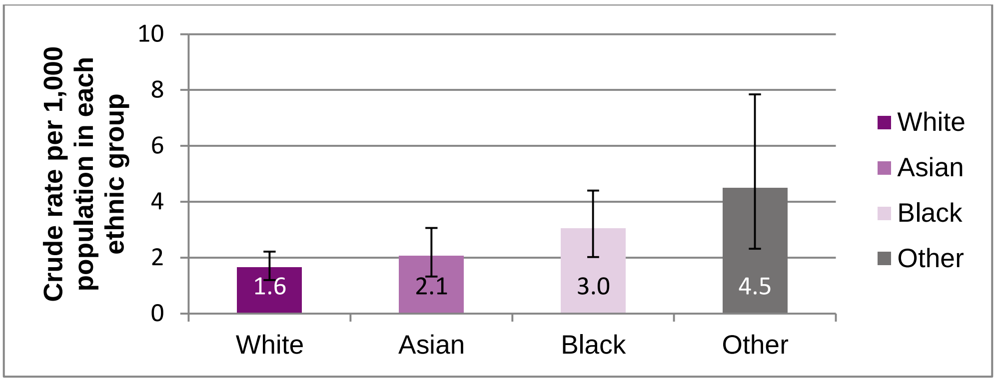
When gender is taken into account, approximately equal proportions of admissions are seen for males (52%) and females (48%), however there are a higher rate of admissions for females in younger age groups than older age groups, and a higher rate of adolescent males admitted than females.

Ethnicity

A high proportion of admissions for epilepsy in children and young people is seen among black and minority ethnic groups, with only 35% of admissions for children and young people from a white background.

While white and Asian populations have similar rates of admission, black populations have an admission rate of 3.0 per 1,000 and those from other ethnic minorities have a rate of 4.5 per 1,000. Admissions from ‘other’ backgrounds are significantly higher than those from white backgrounds. As with the population as a whole, 14% of all epilepsy admissions in 0-19 year olds were not stated or not known.

Fig 27. Crude rate of admissions in 0-19 yr olds with a primary diagnosis of epilepsy in Merton by ethnicity, 11/12-13/14, with 95% confidence intervals*



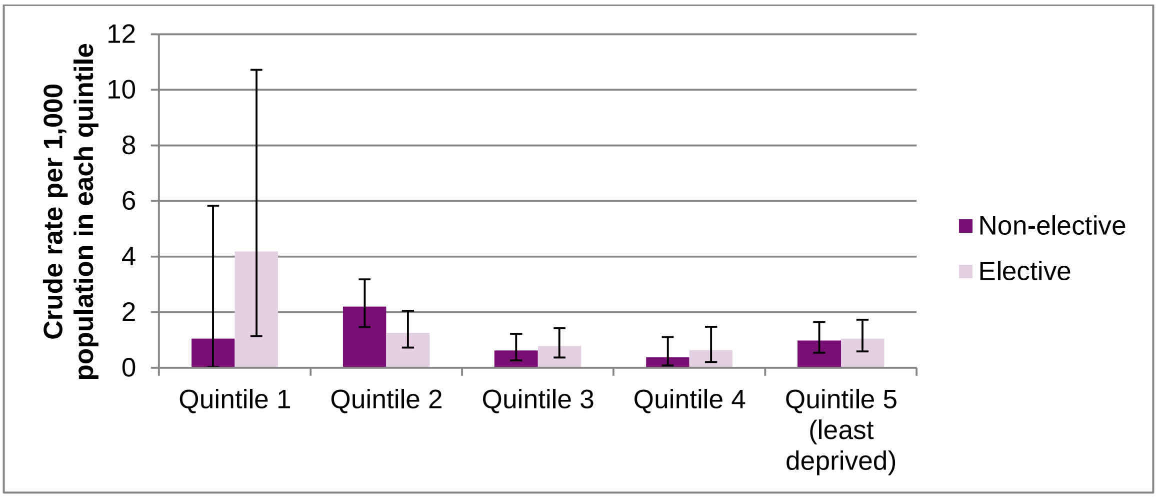
Source: SUS data and Greater London Authority (Ethnic Group: 2013 round capped Strategic Housing Land Availability Assessment-based population projections)

* 95% **Confidence Intervals** (CI) indicate the precision with which the percentages are calculated. They also indicate the range of values in which there is a 95% likelihood that the true value for the patient population lies - the narrower the range, the more precise the calculation. The intervals are the widest for the smaller sample sizes. These are shown by the vertical lines at the top of the bar graphs. When the percentages are compared, if the CI intervals do not overlap this represents a statistically significant difference. Source: NHS Information Centre, HSCIC https://indicators.ic.nhs.uk/webview/

Admissions by deprivation

The association between deprivation and admissions is demonstrated again in the picture of epilepsy admissions for 0-19 year olds, with significantly higher rates of non-elective admissions for epilepsy for IMD Quintile 2 compared to IMD 3 and 4.

Fig 28. Crude rate of admissions for a primary diagnosis of epilepsy in 0-19 yr olds in Merton by IMD quintile, 11/12-13/14, with 95% confidence intervals*



Source: SUS data and Index of Multiple Deprivation

Comorbidities

A significant amount of emergency care for people with LTNCs is for admissions related to a comorbidity rather than admissions directly relating to their neurological condition. Earlier data illustrated the high number of admissions where neurological conditions were a mention in the diagnosis code compared to numbers where they are recorded as the primary diagnosis. Further data below demonstrates this trend for emergency admissions.

Table 7. Number of emergency admissions in Merton where neurological conditions are a primary diagnosis or mention, 2012/13

Condition	**Number of emergency admissions in Merton for selected neurological conditions, 2012/13**	
	Primary diagnosis	**Mention**
Epilepsy	139	416
Headache and migraine	50	111
MS and inflammatory disorders	17	90
Peripheral nerve disorders	6	95
Neuromuscular disease	9	43
CNS infections	17	37
Parkinson’s disease	8	221
Total	**246**	**1013**

Source: Public Health England Neurology Profiles

Merton tends to have similar rates of admissions to comparators where neurological conditions are a mention in the diagnosis code. The only significant differences are in rates of admissions where epilepsy and peripheral nerve disorders are mentioned, with Merton having significantly lower rates than England.

Common comorbidities

The London Neuroscience SCN analysed additional data on the main comorbidities where neurological conditions were a secondary diagnosis. Admission numbers for each condition were too small to present a reliable analysis at a smaller geographic level, therefore the analysis was performed at London level.

Falls are frequently seen in patients with Parkinson’s, as are urinary tract infections, which are also the most common comorbidity for patients with MS. Urinary tract infections also feature among the most common comorbidities for patients with epilepsy, with dental caries being by far the most common comorbidity for these patients.

Table 8. Common comorbidities in London for selected neurological conditions (number of patients with the comorbidity condition)

Epilepsy	Dental caries (181) Unspecified acute lower respiratory tract infection (107) Urinary tract infection (96) Syncope and collapse (81) Cerebral palsy (73)
Parkinson’s disease	Tendency to fall (176) Urinary tract infection (100) Cataract (67) Constipation (44) Acute lower respiratory tract infection (43)

Multiple sclerosis	Urinary tract infection (128) Epilepsy and convulsions (40) Unspecified acute lower respiratory tract infection (30) Fitting and adjustment of urinary device (26) Adjustment and management of infusion pump (25)
Headaches and migraine	Mental disorders and diseases of the nervous system complicating pregnancy, childbirth and the puerperium (50) Epilepsy and convulsions (41) Chest pain, unspecified (22) Transient ischaemic attack (22) Syncope and collapse (18)
Cerebral palsy	Epilepsy and convulsions (187) Acute lower respiratory tract infection (41) Dental caries (39) Management of infusion pump (30) Sleep disorders (19)

Source: London Neuroscience SCN

The importance of recognising and addressing the neurological needs of patients when admitted for other conditions is paramount, particularly in conditions such as Parkinson’s disease where the timings of drug regimes are important in avoiding deterioration while in hospital.

Social care data

Use of social care services by people with LTNCs is difficult to quantify, as service use is defined by need rather than condition. For the first time, data has been collected in 2014/15 in Merton on the medical diagnoses of people who access social services. Not all fields in the new data system are mandatory, therefore collection of data on numbers of service users with LTNCs may be patchy and incomplete, nevertheless it is promising that the facilities are now in place to record this information.

Unfortunately the data for 2014/15 was not available for Merton at the time of writing, however it is hoped that going forward, this will enable a fuller assessment of service use by individuals with neurological needs.

In the absence of this data, The Neurological Alliance estimate that a quarter of people aged between 16 and 64 with a chronic disability and a third of people living in residential care have a LTNC.[12] Using data from the National Adult Social Care Intelligence Service, local estimates can be made that suggest that in 2013/14, 296 social care clients in Merton are likely to have a neurological condition, comprising 73 clients aged 18 to 64 receiving services due to physical disability and 223 clients supported in residential or nursing care.

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[12] The Neurological Alliance (2003) Neuro numbers. London: The Neurological Alliance

Prescribing data

Data on primary care prescribing gives an indication of the level of NHS spending on drug treatment for LTNCs.

Epilepsy prescribing in Merton was substantially lower than the national value in the first to quarters of 2012/13, costing £15,227 less per 10,000 of the population. This is likely to be due to the low observed prevalence of epilepsy in Merton. Rates of prescribing for Parkinson's and movement disorder/tremor and dystonia are much lower than national figures, both in terms of number of items and cost.

Table 9. NHS Prescribing data for selected neurological conditions 2012-13 Qtrs 1 & 2 per 10,000 population

Condition	Merton CCG		England		Difference from national figure
	Total items (Rx)	Total cost (Nic*)	Total items (Rx)	Total cost (Nic*)	
CNS infections	6	£144	4	£101	£43
Epilepsy	1,123	£25,442	1,786	£40,669	-£15,227
Migraine headache	190.13	£3,727	319	£3,655	£72
PD and movement disorder/tremor	326	£6,751	404	£9,740	-£2,990
Dystonia	60	£363	113	£787	-£424

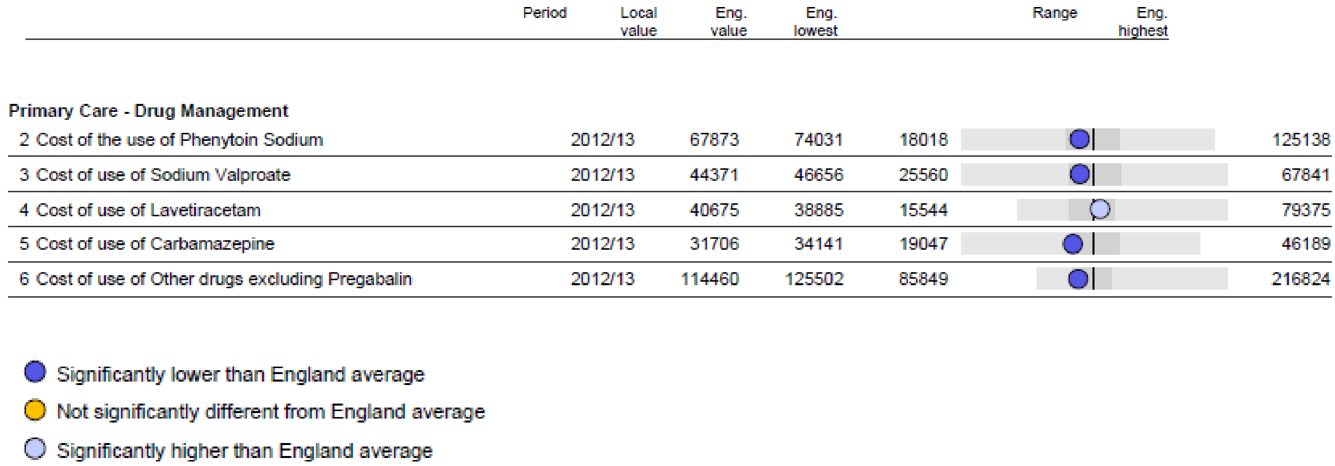
**Net ingredient cost*

Source: HSCIC (2014)

Caveats should be noted in this data due to the use of some drugs in the treatment of other conditions. Drugs for LTNCs in Merton are also predominantly prescribed under shared care agreements, whereby treatment is initiated in hospitals and continued in primary care, therefore the available data does not capture all NHS prescribing costs.

While the data above is influenced by prevalence, data for epilepsy is adjusted for the number of known cases of epilepsy in a population. Fig 29 indicates a comparatively low spend on anti-epileptic drugs in Merton compared to neighbours and London as a whole, with the cost of all drugs being below the England average except for the cost of Levetiracetam.

Fig 29. Primary care prescribing data for epilepsy, Merton CCG benchmarked against England average, 2012/13



	Period	Local value	Eng. value	Eng. lowest	Range	Eng. highest
Primary Care - Drug Management						
2 Cost of the use of Phenytoin Sodium	2012/13	67873	74031	18018	●	125138
3 Cost of use of Sodium Valproate	2012/13	44371	46656	25560	●	67841
4 Cost of use of Lavetiracetam	2012/13	40675	38885	15544	○	79375
5 Cost of use of Carbamazepine	2012/13	31706	34141	19047	●	46189
6 Cost of use of Other drugs excluding Pregabalin	2012/13	114460	125502	85849	●	216824

● Significantly lower than England average

● Not significantly different from England average

○ Significantly higher than England average

Source: Public Health England Neurology Profiles

Further ePACT data was obtained locally demonstrates trends in prescribing for epilepsy and Parkinson’s disease. The list of drugs included in the analysis was reduced from that analysed in the published data in an attempt to address the caveats noted above and remove hospital-only drugs. The lists for the published and local data can be found in Appendix 3 and 4.

Table 10 indicates that there is a higher volume of prescribing for the selected drugs for both epilepsy and Parkinson’s in Raynes Park, with the lowest volume of prescribing for both in East Merton. This is despite a higher number of people aged 18 and over recorded to have epilepsy in the East Merton locality than the West Merton locality.

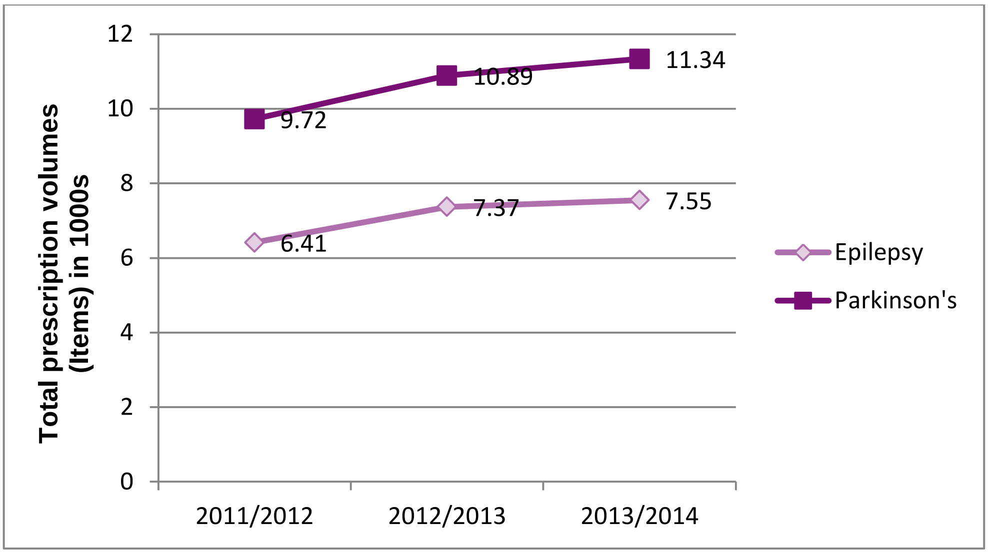
Table 10. Merton CCG primary care prescribing data for epilepsy and Parkinson’s disease by GP locality, 11/12-13/14

Condition	GP Locality Group	Total Items Rx	Total quantity x items	Total Cost
Epilepsy	East Merton	4,782	3,95,433	£71,640.55
	Raynes Park	10,413	719,983	£146,790.52
	West Merton	6,162	543,731	£132,503.04
	Total	***21,357***	***1,659,147***	***£350,934***
Parkinson’s disease	East Merton	7,726	575,782	£102,234.39
	Raynes Park	13,806	874,271	£171,223.24
	West Merton	10,412	703,116	£166,152.56
	Total	***31,944***	***2,153,169***	***£439,610***

Source: ePACT via CCG

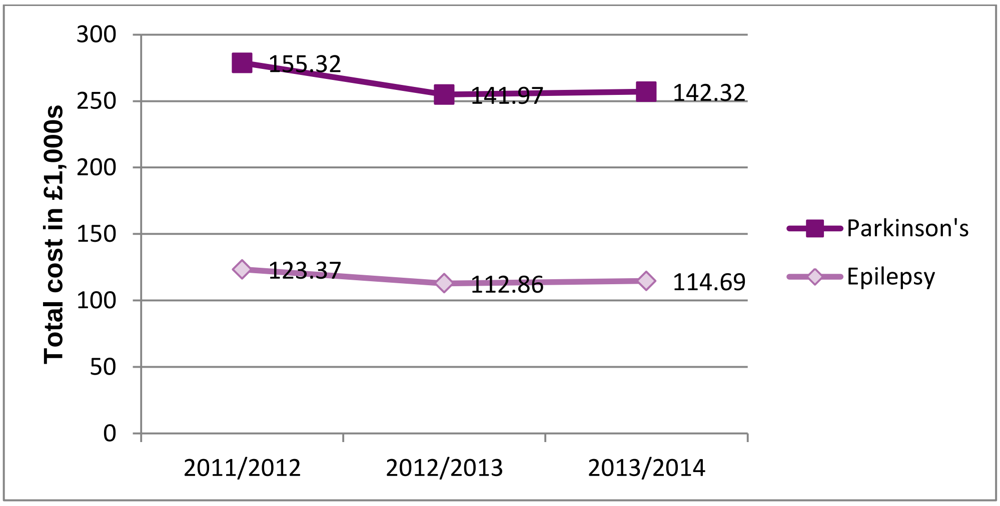
The total volume of prescriptions for both conditions has steadily risen over the three years for which data was obtained (Fig 30), however despite this increase in volume, there has been a slight reduction in the overall cost of prescriptions since 2011/12 (Fig 31). It is likely that these fluctuations are a result of reductions in the costs of older drugs combined with the entry of newer drugs into the market.

Fig 30. Merton CCG total primary care prescription volumes for Parkinson's and epilepsy by financial year, 11/12-13/14



Source: ePACT via CCG

Fig 31. Merton CCG total primary care prescription costs in 1000s per year, 11/12-13/14



Source: ePACT via CCG

What is the pattern of neurology spend and outcomes in Merton?

Key Points:

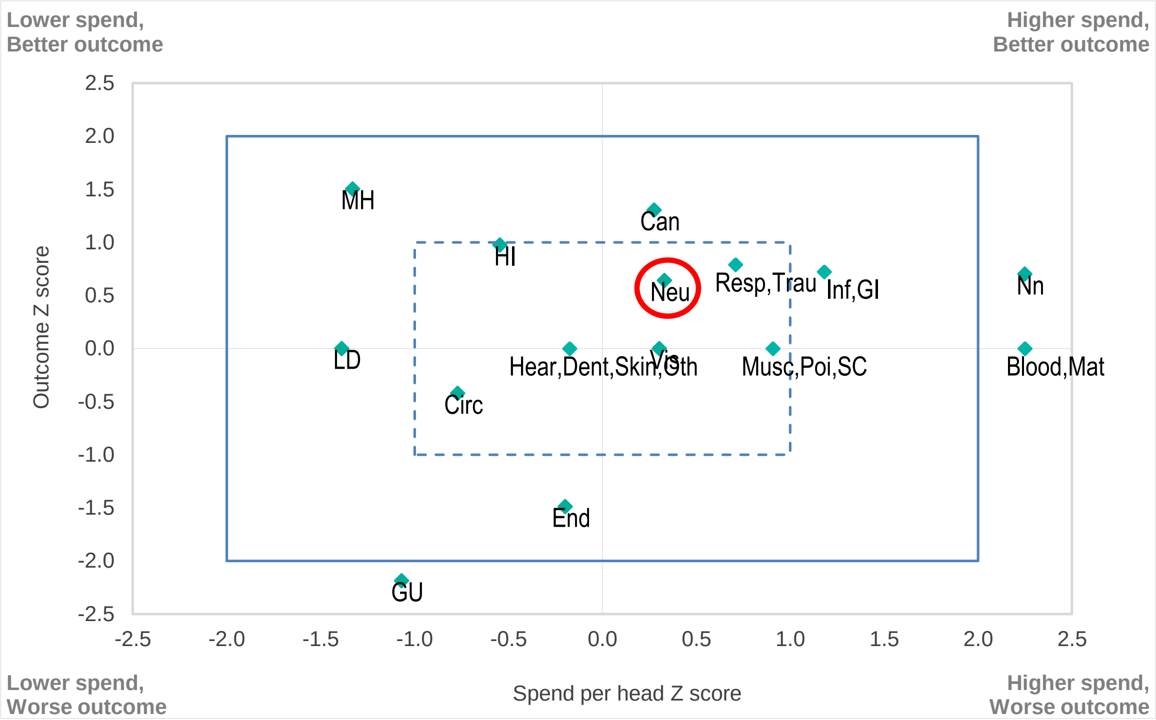
- The SPOT tool indicates that Merton CCG has a slightly higher spend on Neurology for marginally better outcomes. The spend per capita is the 10th highest nationally, at £88 per head.
- The highest spend was on inpatient non-elective care, representing 37% of the total neurology budget.
- Merton CCG currently spend a much lower proportion of the neurology programme budget on community and integrated care than the national average, and a greater proportion on scheduled outpatient care.

Spend and outcomes data can be assessed to indicate which areas of care account for the majority of neurology spend and how these relate to the outcomes being achieved locally.

Spend and Outcomes Tool (SPOT)

The Spend and Outcomes Tool (SPOT) is produced by Public Health England, benchmarking spend and outcomes across a range of business areas. The 2014 SPOT report for Merton[13] is displayed below.

Fig 32. Spend and Outcomes Tool for Merton CCG, 2014



Source: Public Health England

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[13] PHE (2015) Spend and Outcomes Tool http://www.yhpho.org.uk/default.aspx?RID=49488

Interpretation; The z-scores on the chart indicate the distance of the value from the mean, with a positive z-score indicating a value higher than the mean, and a negative z-score indicating a value lower than the mean. Where a programme lies outside the solid line, further investigation is required. Programmes lying outside the dotted line may also warrant further exploration.

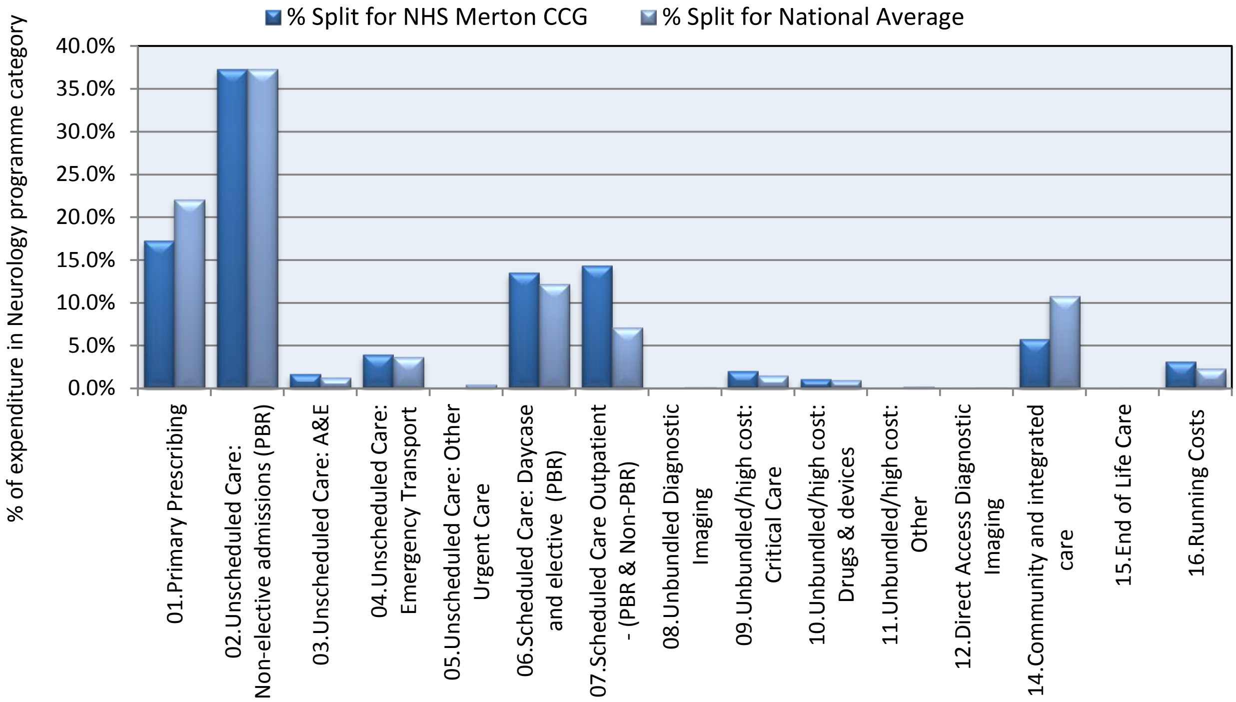
Benchmarked against comparators, Merton has the 10th highest national spend on the Neurology Programme Budget at £88 per head, compared with a national spend of £84 per head. Under 75 mortality from epilepsy is lower than the national, London and ONS cluster values, and Merton is a better outlier for the register of patients on drug treatment for epilepsy.

Spend by care setting and condition

NHS England publish benchmarking data for Programme Budget spend, enabling comparison of spend by care setting with other CCGs and the national average.[14]

The highest proportion of spend in neurology was on non-elective inpatient care, representing 37% of the total spend. Merton CCG spent a significantly lower proportion than the national average on community and integrated care, at 5.8% compared with 10.8%, but a greater proportion on scheduled outpatient care, at 14.3% compared with 7.1%.

Fig 33. Proportion of neurology budget spend by care setting, Merton CCG and England, 2013/14



Source: NHS England

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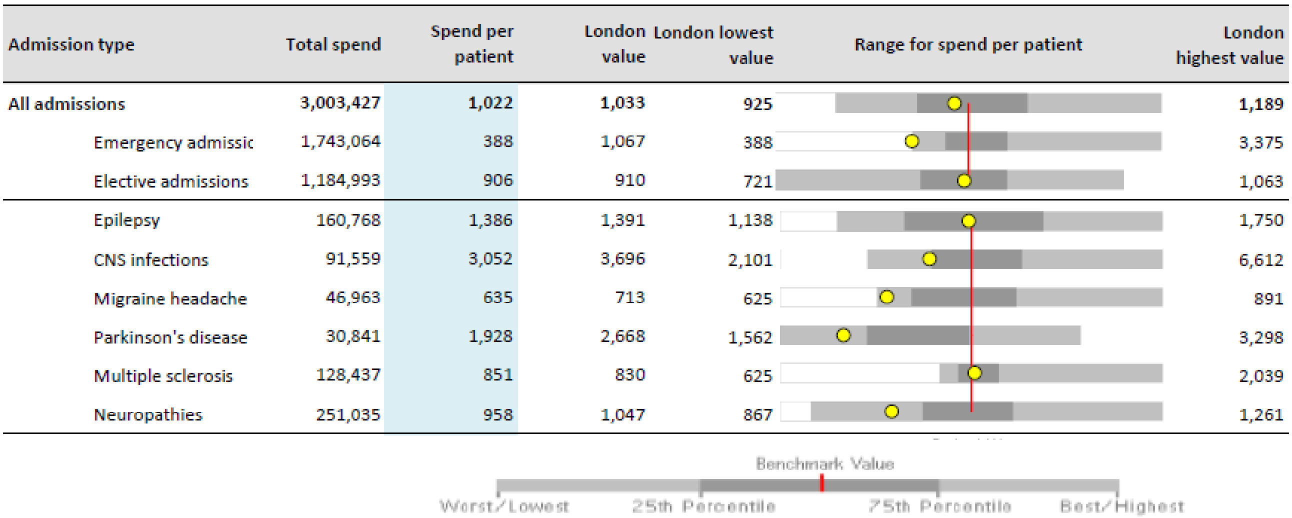
[14] NHS England (2015) Programme Budgeting tool https://www.england.nhs.uk/resources/resources-for-ccgs/prog-budgeting/

An analysis of 2012/13 spend by type of admission and specific condition demonstrates a higher level of total spend on emergency admissions than elective admissions, but the lowest spend across all London CCGs on emergency admissions per patient (£388). Spend per patient is highest for admissions due to CNS infections, followed by Parkinson's disease and epilepsy.

Fig 34. Spend by admission type and condition in Merton CCG, 2012/13



Admission type	Total spend	Spend per patient	London value	London lowest value	Range for spend per patient	London highest value
All admissions	**3,003,427**	**1,022**	**1,033**	**925**		**1,189**
Emergency admissic	1,743,064	388	1,067	388		3,375
Elective admissions	1,184,993	906	910	721		1,063
Epilepsy	160,768	1,386	1,391	1,138		1,750
CNS infections	91,559	3,052	3,696	2,101		6,612
Migraine headache	46,963	635	713	625		891
Parkinson's disease	30,841	1,928	2,668	1,562		3,298
Multiple sclerosis	128,437	851	830	625		2,039
Neuropathies	251,035	958	1,047	867		1,261

Source: London Neuroscience SCN

Service user survey

Key Points:

- Results of a local and national service user survey provide insight into the experience of people in Merton living with LTNCs.
- Respondents reported a substantial impact of their condition on their daily activities, with approximately one third of respondents reporting a lengthy diagnosis process with multiple visits to the GP prior to referral and diagnosis.
- Less than a fifth of respondents reported being offered a care plan to help manage their condition, suggesting a lack of personalised care planning for people with LTNCs.
- Most respondents valued the care and treatment they receive, with 85% reporting at least some benefit to their condition. A wide variety of professionals were reported to be involved in respondents' care, with hospital doctors, GPs and specialist nurses being most commonly involved on a regular basis. There were mixed views as to whether respondents felt these professionals worked well together.
- Almost three quarters of respondents in Merton reported delays in access to care and treatment, while only 43% of respondents reported being asked by a health professional about their emotional wellbeing since their diagnosis.
- Key priorities identified by respondents related predominantly to service access, communication between professionals and with the service user themselves and a holistic approach to care, addressing the broader needs of the individual.

Results from the local service user survey are presented in this section alongside the London responses to the national pilot survey.[15] While the local sample was small, trends generally follow those seen across London, suggesting a reasonably accurate representation of the experiences of people living with LTNCs in Merton.

Impact of the condition

The majority of respondents reported that their neurological condition has a significant impact on their daily lives, either causing frequent problems that restrict daily activities or constant problems that confine them most or all of the time.

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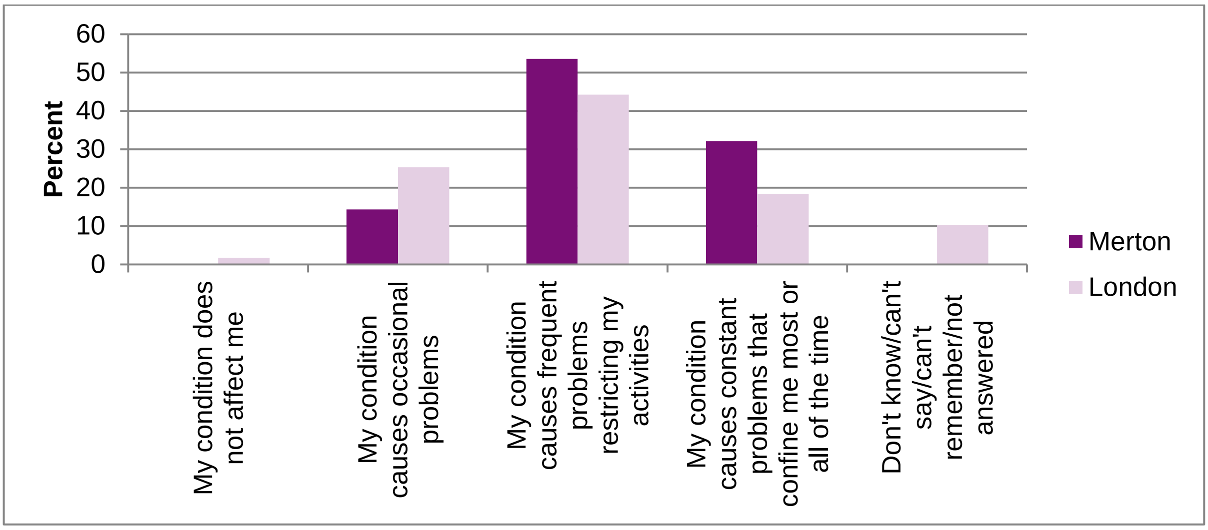
[15] The Neurological Alliance (2015) The invisible patient: revealing the state of neurology services. http://www.neural.org.uk/store/assets/files/495/original/Invisible_patients_-_revealing_the_state_of_neurology_services_final_14_January_2015_.pdf

Fig 35. How affected are you by your neurological condition?



Over three quarter of respondent to both surveys receive the majority of care for their condition in one of three locations; the home, a local primary care clinic or a hospital clinic.

Diagnosis

While a high proportion of respondents only saw their GP once or twice before being referred to a neurological specialist, approximately a third of respondents saw their GP on more than two occasions (Fig 36). Further to this, approximately a third of respondents waited more than twelve months from when they first noticed their symptoms to see a neurological specialist (Fig 37). This is likely to reflect the difficulties in diagnosing LTNCs, however it highlights a need for increased awareness of the presentation of these conditions among primary care professionals as well as the general public.

Fig 36. Before you were told you needed to see a neurological specialist about your condition, how many times did you see your GP about the health problems caused by your condition?

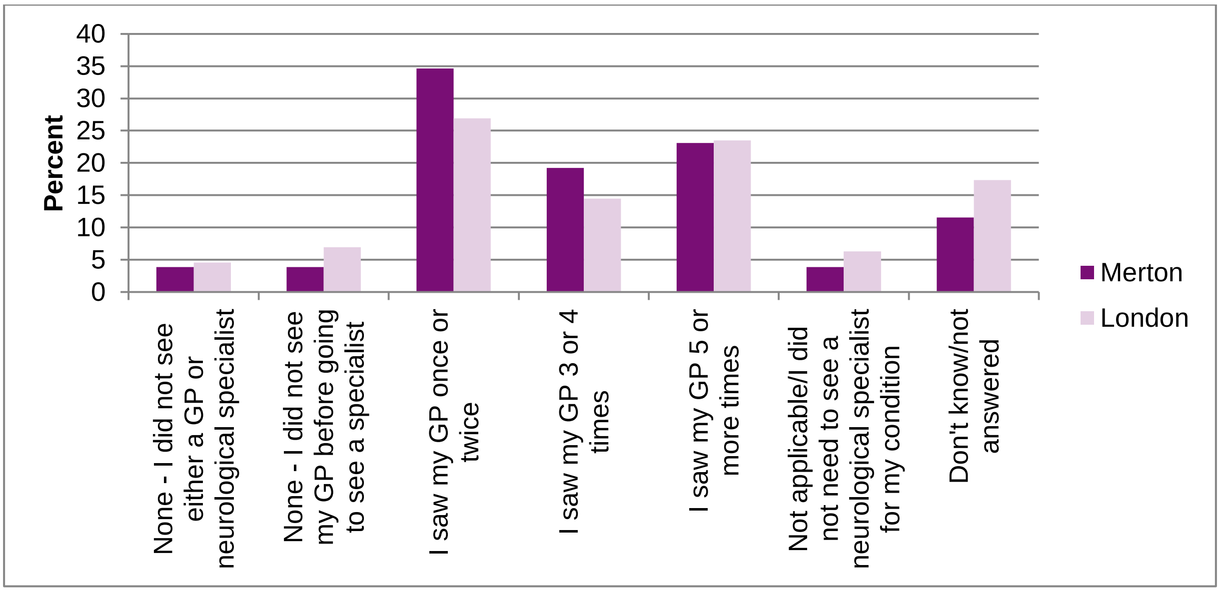
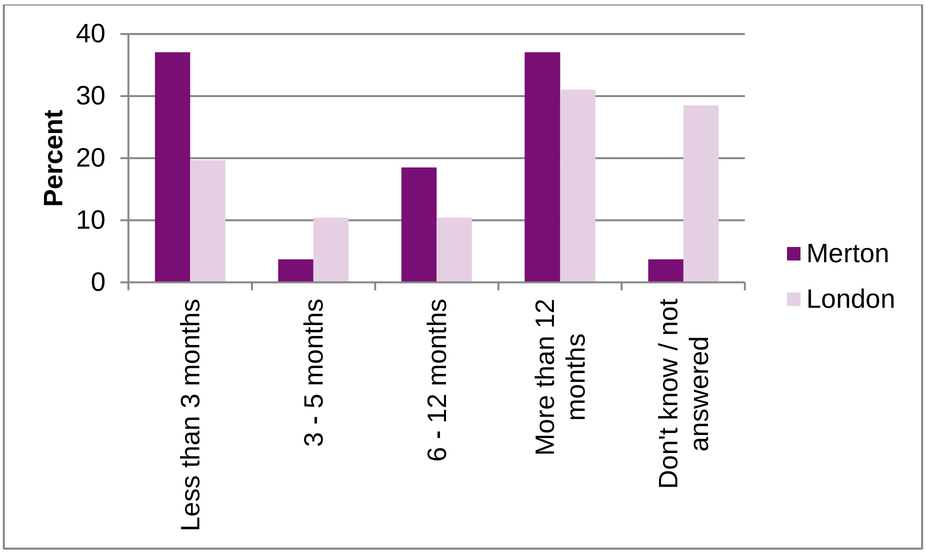


Fig 37. How long was it from when you first noticed your symptoms until you first saw a neurological specialist?



Responses further showed that diagnoses were predominantly confirmed by a hospital doctor (Merton = 82%, London = 56%).

Provision of information

There were varying levels of satisfaction in the local survey as to the information received. Relatively high levels of dissatisfaction were reported with regards to the provision of information about the neurological condition itself (**46% dissatisfied or very dissatisfied**), and information about additional sources of support such as patient support groups and financial advice (**42% dissatisfied or very dissatisfied**). Responses as to information about treatment options and a single point of contact did not show a clear trend.

Care planning

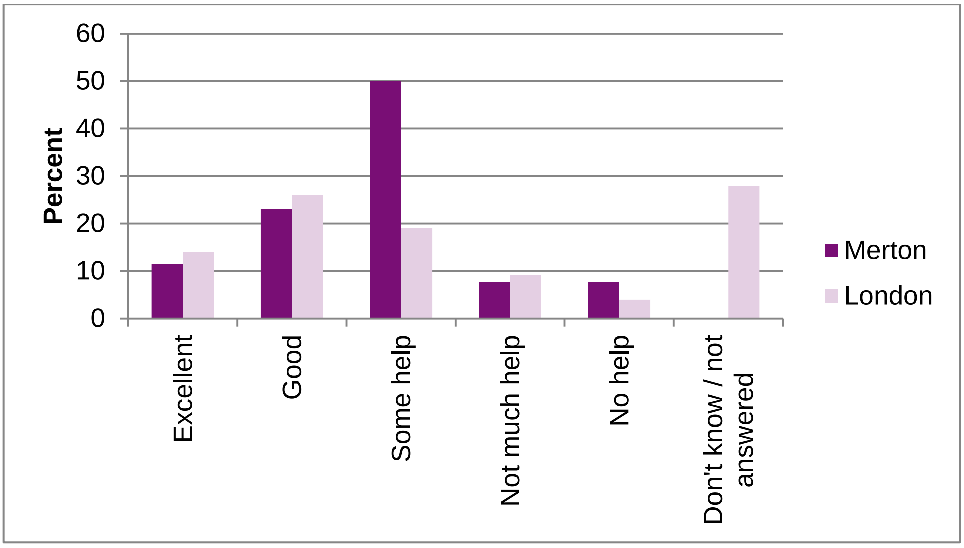
Over half of respondents had not been offered a care plan to help manage their condition. While some respondents were unsure, **only 15% of respondents in Merton and 18% of respondents in London reported being offered a care plan**. This is despite personalised care plans being recognised as a vital tool to assist in the management of LTNCs.

Most respondents felt that they were involved either fully or to some extent in choices about their care and treatment, however a minority of respondents (Merton = 26%, London = 15%) felt that their views were often not, or never, taken into account.

Ongoing care and treatment

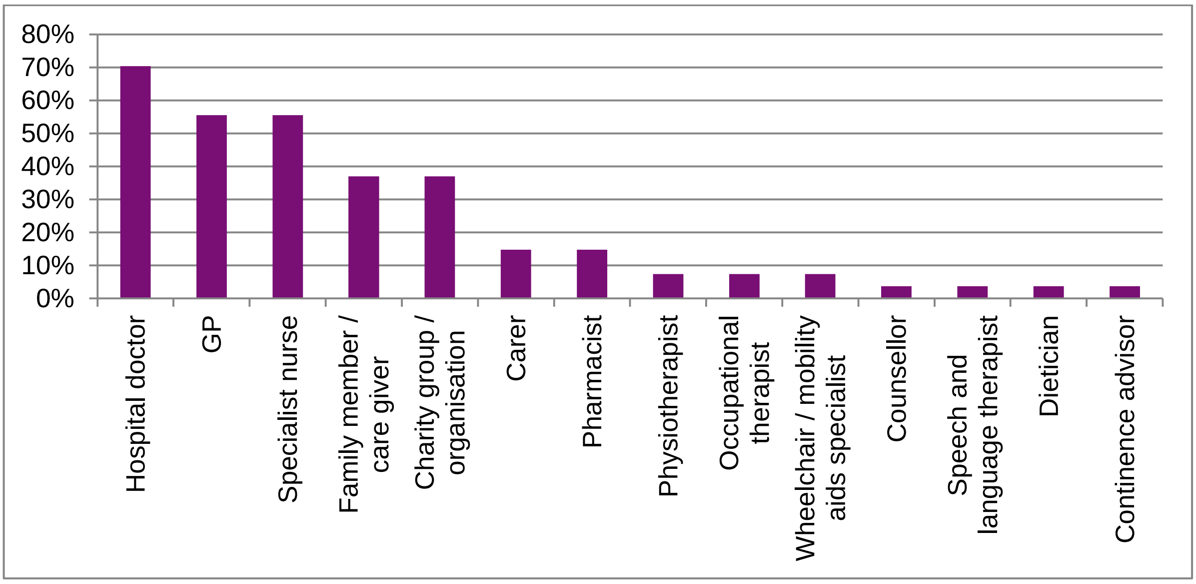
85% of respondents in Merton viewed the care and treatment they received positvely, reporting that it had some degree of impact on their condition (Fig 38).

Fig 38. Overall, how do you rate the care and treatment you have received for your neurological condition?



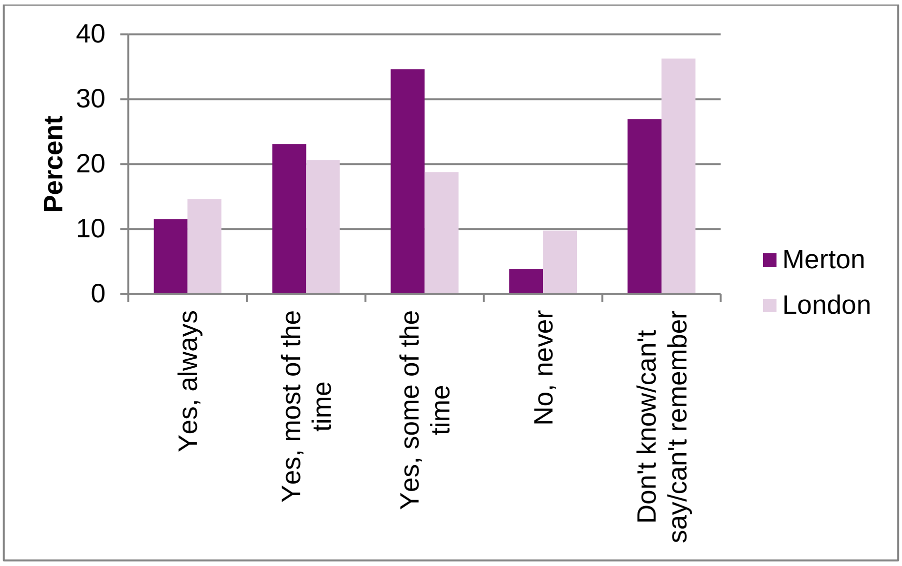
Many respondents reported coming into contact with multiple health and social care professionals, with 60% of Merton respondents having contact with 2 or more professionals in an average year. These professionals commonly included hospital doctors, GPs and specialist nurses, with over a third of respondents also citing a family member or care giver and charity group as playing a regular role in the management of their LTNC. A number of other professionals were cited as being regularly involved in the care by a small number of respondents, illustrating the plurality of the response required to support people with LTNCs.

Fig 39. Which of the following do you regularly have contact with to help manage your condition?



When asked whether the range of people providing care work well together, both the local and London surveys had a high level of respondents who were uncertain about this question (Fig 40). Of those who did respond, the majority felt that there was at least some degree of collaborative working. This would suggest that while individuals do not experience active difficulties with communication between professionals and agencies, many do not know whether this occurs.

Fig 40. Do the different people treating and caring for you work well together to give you the best possible care?



Concerningly, almost three quarters of respondents in Merton reported experiencing problems or delays in accessing care and treatment (**Merton = 73%, London = 41%**). This high proportion may be due to selection bias and a small sample size locally, with individuals who have experienced difficulties being more likely to participate in the survey. Nevertheless both figures suggest that these difficulties are a common experience of people living with LTNCs.

An additional question was asked in the local survey about an assessment of an individual’s emotional wellbeing. **Only 46% of respondents reported to have been asked by a health professional about their emotional wellbing** since being diagnosed with a neurological condition. Given the significant impact of most neurological conditions, either in the present or future, this figure demonstrates a gap in the assessment of mental health needs for people with LTNCs.

Respondents to the local survey were also asked what they felt was the single most important priority was for health and social care services for people with neurological conditions. Responses are displayed below under themed headings, pointing to gaps in access to appropriate services, communication with the indivdual themselves and between professionals and a holistic approach to care.

Access

“A more responsive GP service”
“Availability of Parkinson’s Nurse when necessary”
“Provision of therapy that has maximum benefit to the patient”
“More rehabilitation places”
“(Access to) specialist MS nurses”
“Waiting times for appointments/referrals/treatment (currently) too long”

Communication

“Communication between the doctor, pharmacy and specialist”
“Keep in contact. Regular communication does not exist”

“To get all professionals who are involved with (the) patient to communicate with each other - this does not happen now and is left to (the) spouse to coordinate between everybody”

Holistic support

“Emotional wellbeing support of people living with the long term impact of a neurological condition”

“Recognition that we are a whole person and not just a disease…we may have other issues and they all overlap”

Qualitative work

Key Points:

A number of prominent themes emerged from interviews with carers and wider stakeholders.

These included;

- High value placed on the role of specialist nurses in supporting the management of LTNCs.
- Variation in access to the range of services required by people with LTNCs, including therapies, equipment and social services.
- Concerns over the extent to which neurological needs are met when individuals access other types of care.
- A need for greater mental health support for people who are diagnosed with LTNCs to assist with the difficulties in coming to terms with limitations in ability and functioning.
- The potential for more systematic coordination of care across agencies, enabling more comprehensive support to be given, in particular to those with complex needs.

Interviews with carers

Many people who have LTNCs require a high level of care, therefore families and friends who provide this care play a significant role in meeting the needs of this population. It is important that the needs of carers are taken into consideration when planning services as the care they provide is often fundamental to the long term management of these conditions.

Four themes emerged from the telephone interviews with carers. These are summarised below.

Experience of caring

Informants discussed their experience of caring during the interviews and the associated support available to them.

- Some expressed a desire to cope as much as possible on their own, however others spoke of the need for support due to their own health issues and an inability to provide all of the care their family member required.
- The significant burden of caring, both physical and emotional, was discussed, with caring often being very hands on and time intensive, with little rest. The feelings of isolation and loneliness that can result from this were consequently raised, alongside the onus placed on informal carers to provide a significant amount of care.
- Informants greatly appreciated local support groups and noted that, where they could be accessed, respite care packages were invaluable in enabling carers to cope.

Access to services

Informants discussed access to health and social care, reporting differing experiences as to the ease with which appropriate services could be accessed.

- The value of occupational and physiotherapy services was emphasised by informants, however while some experienced prompt access, others experienced a long wait and expressed disappointment at short nature of the service.
- Some informants reported that specialist nursing support had ended without them being aware of the reason why.
- Variability was also reported in access to social care assessments, equipment and adaptations. Prompt access experienced by some contrasted with significant difficulties found by others, with one respondent reporting a lack of flexibility with social care appointments and a very lengthy process accessing equipment.

Overall, it was felt that the systems could be overwhelming and often difficult to negotiate, with varying levels of communication between professionals and a lack of consistently joined-up working.

Neurological needs when accessing other types of care

Informants raised concerns as to the lack of specialist care when those they care for are admitted to hospital or other care settings. There was universal agreement that sufficient support is lacking, with nurses and carers tending to be inexperienced in dealing with LTNCs and lacking in relevant knowledge as to the specific needs that accompany them. Consequently carers reported witnessing a deterioration in their family member's neurological condition as a result of episodes in hospital.

Specific challenges of LTNCs

Challenges were identified by informants in the diagnosis and care of people with LTNCs, including difficulties in identifying LTNCs due to their range of symptoms and relative low profile in comparison with conditions such as dementia. Several informants spoke of the significant emotional reaction experienced by those who are diagnosed with neurological conditions, including denial and ensuing frustration and anger at the limitations imposed on their abilities. The need for the mental health needs of people with LTNCs to be better addressed was subsequently identified as important by informants.

Wider stakeholder interviews

Five overarching themes and a further nine sub-themes were identified through interviews with a wide range of professional stakeholders.

Identification of LTNCs

The difficulties in diagnosing LTNCs were discussed by a number of informants, who noted differing levels of awareness of conditions among clinicians.

- There was general agreement that recognition of LTNCs was relatively poor compared to stroke, with subsequent care pathways undefined.
- MS and MND were perceived to be better known than Parkinson's, however the vague symptoms of some LTNCs and the lack of tests to confirm diagnoses were understood to contribute to the often lengthy process of diagnosis.
- Waiting times for non-urgent neurology referrals were thought to increase the risk of admissions due to factors such as falls.
- Informants acknowledged that while early access to specialists can help to slow the progress of some conditions, early recognition is not always preferable.

Access to appropriate services

Ongoing community rehabilitation and therapy

Specialist community neurotherapy services were praised by informants, with close links generally reported with clinicians and nursing staff. Additional therapy services provided by domicillary therapists, general community rehabilitation teams (HARI) and the reablement team were also noted to be useful in optimising function.

Access to services was generally perceived to be good, however a number of informants raised the issue of service capacity, particularly for occupational and physiotherapy support.

Access to wider services

Variable access was reported to many other services.

- The interval between referral and access to social services was understood to contribute to unnecessary admissions on occasions.
- Comprehensive access to respite care was perceived to be lacking.
- Problems with funding for vocational rehabilitation were reported by several informants, in addition to a lack of vocational rehab in the community.
- Access to inpatient neurorehabilitation was generally believed to be poor, with too few places in local centres to match demand.
- Access to equipment and adaptations was reported to be variable, based largely on the route through which they are accessed. There was general agreement that while equipment could be accessed almost immediately through the reablement team, individuals referred routinely to social services often faced long waiting times. It was also felt that no clear process existed for accessing equipment due to a health need.
- Palliative care needs were reported to be met well by local services, however access was raised as an issue due to limited capacity. Seeking earlier input of palliative care teams was suggested as potentially beneficial to some groups of patients.

Management of admissions

Admission avoidance

Informants stressed the need for flexible and responsive services that adapt to patients' needs, particularly where those needs are unpredictable, as with epilepsy and MS. The need for prompt access to advice from specialist staff was emphasized, as was the role for better training of community health staff in issues that may lead to multiple admissions, such as urinary tract infections and spasticity in MS.

Neurological support when patients are admitted for other reasons

Concerns were again raised almost universally as to the extent to which an individual’s neurological needs are met when they receive care for other reasons. While the neurology teams tend to be aware of planned admissions, the importance of picking up neurology patients on general wards following an unplanned admission was highlighted. This relies heavily on communication from ward staff, which was reported to be very variable.

Ongoing management of care

Care coordination

Informants noted the move towards more integrated care, nevertheless the split still existing between health and social care was felt to be a significant influence on coordination of care.

- Responsibility for care coordination was felt to be uncertain and communication between agencies variable. The establishment of integrated care pathways for common conditions was seen as an opportunity to address these issues.
- GPs were noted to take on the role of ‘go to’ person for the care needs of people with LTNCs. While some believed this to work well, others thought that there should be a key worker or care coordinator to fulfil this role, especially in the case of individuals with less common conditions and those with complex needs.
- The importance of transitional care for young people between paediatric and adult services was raised as an issue by a number of respondents who felt that this was currently lacking, particularly with regards epilepsy and cerebral palsy.
- Pharmacists in Merton were perceived by respondents to play an active role in the management of Parkinson’s, with opportunities to make more of this role in other conditions such as epilepsy noted.
- Levels of current care planning were reported to be disease-dependent and dependent on the timing of a diagnosis and the extent of an individual’s needs. Those with a new diagnosis were thought to receive good health and social care support, while those with an old diagnosis or no rehabilitation potential were thought receive more patchy support.

Importance of CNS roles

The role played by specialist nurses was discussed in almost all interviews, with universal value placed on these roles.

- A number of gaps were noted in the provision of specialist nursing services, in particular the lack of a hospital-based PD nurse and an epilepsy nurse at St Helier Hospital.
- Most informants felt that specialist nurses should have a degree of input in hospital settings due both to the need for input and support for the nurse themselves as well as the need for the nurses to see patients who have been admitted.

- Respondents noted the potential for specialist roles to be carried out by therapists as well as nurses.

Support for daily living

Information and practical support

Informants discussed the information and support available to help people manage their condition.

- The significant role played by active local voluntary sector groups was consistently highlighted, with acknowledgement of the onus now placed on the voluntary sector to take on much of this role.
- A number of other methods of support were mentioned, including a new group being set up at St George's Hospital for people with a new diagnosis of Parkinson's disease to provide education and support in the early stages.
- Some informants felt that while the medical side of LTNCs is dealt with comprehensively, information is lacking on wider issues such as nutrition, employment support, benefit entitlements and relationships matters. This was felt to be particularly true for younger people diagnosed with a LTNC.
- It was suggested that greater importance should also be placed on the needs of carers when people with LTNCs come into contact with services, using this opportunity to assess the wider social circumstances and signpost to relevant support. A need was also reported for better respite care.

Mental health needs

Many informants expressed concern over the level of mental health support for individuals with LTNC. While neuropsychiatry services are available and informants reported good access for those with significant psychiatric needs, low level counselling in the community was believed to be lacking. Improved access to psychological support services was understood to be important going forward.

Impact on the wider family

Informants spoke of the wide-reaching impact of many LTNCs on the whole family, of particular significance among cultures where stigma is often associated with these conditions. It was also acknowledged that many people with LTNCs are cared for by elderly partners who have health issues themselves. There was consequently felt to be a large role to play in offering families support to overcome the anxieties associated with the practicalities and emotional impact of LTNCs and the stigma associated with them.

Local service provision

Key Points:

- Commissioning structures for neurological services are complex, with responsibilities for healthcare commissioning being split between NHS England Specialised Commissioning and local CCGs.
- A wide variety of services are provided locally to address the needs of individuals with LTNCs. These include specialist and general inpatient and outpatient care, specialist nursing support, community rehabilitation and an active voluntary sector for specific conditions. In addition, palliative care, end of life care and social services support can be accessed by people with a neurological condition.
- There is an established path for epilepsy patients in place with a two year open review following diagnosis. Concrete pathways are not in place for other LTNCs, however informal pathways are followed which reflect best practice guidelines.
- A recent audit was conducted by the London Neuroscience SCN to establish a baseline for the quality of current neurological services across London. Some gaps were identified locally in the provision of specialist nursing care and written protocols relating to patient pathways.

Commissioning responsibilities

The provision of neurological services is complex, with commissioning arrangements split between Clinical Commissioning Groups (CCGs) and specialised commissioning through NHS England.

Table 11 sets out the commissioning responsibilities for current neurology services.

Table 11. Neuroscience services: structure and commissioning responsibilities

Service	**Services provided**	**Commissioning Responsibility**
Regional Neuroscience Centre	Neuroscience and neurosurgery services including specialist diagnostics and treatments for rare or complex neurological conditions. These centres receive referrals from other neurological providers for specialist services and provide general neurological services to local populations	NHS England specialised commissioning and CCGs.
Specialist Neurological Centres	Similar services to regional centres but without neurosurgical services	NHS England specialised commissioning and CCGs.
Acute General Hospitals	General neurological services for the local population, referring rare and complex patients to regional or specialist hospitals	CCGs.

Specialised rehabilitation	Specialist neurorehabilitation provided in hospital settings on inpatient and day patient bases	NHS England specialised commissioners
Community rehabilitation	Neurotherapy and general therapy and rehabilitation services for the local population delivered in the community	CCGs
General practice	Primary care	NHS England
Social care	Range of services based on care needs rather than neurological condition	Local Authority

Source: NHS Commissioning Board [16]

NHS England is responsible for commissioning all adult specialist neurosciences services provided by adult neurosciences and neurology centres. This includes all such services delivered on an outreach basis in local District General Hospitals as part of a provider network. A list of the services covered under is specialised commissioning is set out below: [17]

- All neurosurgery activity
- All interventional procedures within neuroradiology
- Inpatient neurology
- Specialist diagnostics (including neurophysiology, neuroradiology)
- Associated services (neuropsychology, neuropsychiatry, neurorehabilitation, neuro-critical care)
- Neurology outpatients (but not first GP to neurology consult, only when an inter-specialty referral has been made or care is multidisciplinary)
- Immunoglobulins

CCGs commission neurology inpatient and outpatient services provided at local hospitals and neuro-rehabilitation by local multidisciplinary teams. From April 2015, outpatient neurology referrals made by GPs to Adult Neurosciences Centres and Adult Neurology Centres will no longer be commissioned by NHS England but will be the responsibility of the CCG.[18] A patient only becomes the responsibility of NHS England on confirmation of a firm diagnosis.

Specialist neuroscience services for children and young people are also commissioned by NHS England. This includes all services provided by Specialist Paediatric Neurosciences Centres, whether they are inpatient, day case or outpatient services or those delivered as outreach services.[19] Nevertheless many neurological conditions in children and young people are managed by secondary care providers, other specialist services or community based paediatricians. These include 'simple' headaches, febrile seizures, the majority of epilepsy cases and meningitis.

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[16] NHS Commissioning Board (2012) Manual for prescribed specialised services. http://www.england.nhs.uk/wp-content/uploads/2012/12/pss-manual.pdf

[17] London Neuroscience SCN (2014) Quality and Safety Audit. London Neuroscience SCN

[18] NHS England (2014) Commissioning Intentions 2015/16 for Prescribed Specialised Services

[19] NHS Commissioning Board (2012) Manual for prescribed specialised services. http://www.england.nhs.uk/wp-content/uploads/2012/12/pss-manual.pdf

The complexity of these commissioning structures heightens the importance of close working between all commissioning agencies, including local authorities, to ensure the whole patient pathway is covered.

Local services

Secondary and tertiary care

The **Atkinson Morley Regional Neurosciences Centre**, part of St George's Healthcare NHS Trust, is the specialist neuroscience centre for the region, providing a full range of tertiary neurosurgery and neuroscience services for patients across South West London.

Acute and outpatient care is provided at St George's Hospital in addition to local District General Hospitals including Epsom and St Helier University Hospital and Kingston Hospital NHS Trust. The neurophysiology department at Epsom and St Helier also offers an investigative or diagnostic service to patients referred by consultant and local GPs.

There are a number of **specialist nurse posts** based in the local hospitals. St George's Healthcare NHS Trust employs epilepsy specialist nurses, Parkinson's disease nurses and MS nurses, while St Helier has MS nurse input via an outreach model. These nurses predominantly conduct outpatient work, in addition to home visiting and input into inpatients, linking with a wide range of other services.

Specialist neurorehabilitation is provided at **Wolfson Neurorehabilitation Unit**, part of St George's Healthcare NHS Trust. This service is aimed at patients who require intensive therapy following acquired neurological conditions resulting in physical or psychological disabilities. A Vocational Rehabilitation Programme is also provided, offering a tailored approach to help neurological patients back into employment. Clients must be; over 16, independent in personal care, have completed all medical investigations and neuro-rehabilitation and demonstrate a clear commitment to returning to work.

Community care

Community Neurorehabilitation services are provided by the **Community Neurotherapy Team (CNTT),** part of Sutton and Merton Community Services (SMCS). The team works across Sutton and Merton providing specialist, multidisciplinary rehabilitation and care in the community for people aged 18 years and over with neurological conditions. The team comprises occupational therapists, physiotherapists, speech and language therapists and rehabilitation assistants. Individuals with progressive, life-limiting conditions remain on the priority caseload and can self-refer if their condition deteriorates.

Merton CCG co-commission a **Parkinson's Nurse Specialist** from SMCS who works across Sutton and Merton providing community care to people with a confirmed diagnosis of Parkinson's. Patients from St Helier Hospital are picked up by this service as there is currently no PD nurse based in the hospital.

Two community neurorehabilitation hospitals are found locally; The Cedars Unit at Tolworth Hospital, run by Your Healthcare CIC, and the Royal Hospital for Neurodisability, Queen Mary's Hospital, Roehampton. Both accept referrals from the NHS to provide rehabilitation and long term care to people with complex neurological disabilities.

SMCS provide a number of other additional services that can be accessed by individuals with neurological conditions. These include;

- Community Physiotherapy for adults
- Community Speech and Language Therapy for adults
- Paediatric Physiotherapy
- Paediatric Speech and Language Therapy
- Paediatric Occupational Therapy
- Children and Family Respite Service

Additional services

Merton CCG fund **Continuing Care** services that can benefits adults and children with neurological conditions, offering a package of care for individuals who have on going healthcare needs outside of hospital. Equipment requests may also be funded on an ad-hoc basis.

Adult Social Care

London Borough of Merton provide a variety of social care services that can be accessed by individuals who have additional support needs due to physical disability, mental health need, learning disability or visual impairment. These include;

- The **Merton Reablement Team**; this team comprises occupational therapists, social workers, carers and reablement staff who provide support for up to six weeks to promote and maintain independent living following a significant change in their ability.
- The **Occupational Therapy** service; further facilitating independent living through adaptations to the living environment and appropriate equipment.
- **Social work teams**, including the Merton Adult Access Team and Assessment and Support Planning Teams; providing assessment and signposting, managing referrals to social care and assessing eligibility for services including personal assistants and home care.
- The Hospital Social Work Teams based in St George's Hospital and St Helier Hospital; facilitating safe and appropriate discharges when clients are admitted to hospital.
- **All Saints Day Centre** in South Wimbledon; providing activities and outreach for disabled adults, including support with returning to work and workplace adaptations.
- **MASCOT Telecare;** providing year round support through an alarm system to further support independent living in an individual's own home.

Children's Social Care

The **Special Educational Needs and Disabilities Integrated Service (SENDIS)** provide a range of services through education, social care and health professionals to support children, young people and their families with multiple needs. Services delivered include Early Support, Educational Psychology, Language and Learning Support, Merton Autism Outreach Service and Short Breaks (previously respite care).

Palliative Care

Palliative care services are provided in the acute trusts and in St Raphael's Hospice in Sutton. St Raphael's offers specialist medical and nursing care for people with serious illnesses, providing services free of charge in a 14 bed unit or through the Hospice at Home service. A small proportion of funding is received from the Merton and Sutton CCGs, with the hospice relying heavily on fundraising and donations.

End of life care

End of life care in Merton is provided by a range of professionals in a number of settings. Merton CCG commission a community End of Life Nursing Service that provides specific support to nursing homes in addition to support and education for community nurses and local GP practices. An End of Life Fast Track Discharge Service is also commissioned that speeds up discharge from hospital for people in the last days of life.

Voluntary sector services

The voluntary sector plays a very active role in supporting individuals with LTNCs in Merton.

- **Parkinson's UK Merton** offer information and support to local people with Parkinson's and their families and carers, organising regular events and social activities. South West London Younger Parkinson's Network also offers an active support service to younger people with PD.
- The Merton Branch of the **MS Society** offers support and information to people in Merton living with MS. They also hold monthly meetings in addition to weekly physiotherapy classes that can be accessed at a small cost.
- The **Motor Neurone Disease Association** have a **South London Group** that provides support for people affected by MND. An Association Visitor offers regular contact and support, providing advice and signposting. Funding is also offered through the association for specialist equipment and services.
- The **Epilepsy Society** and **Epilepsy Action** are national organisations working to support people affected by epilepsy both through the provision of information and advice as well as research and awareness raising campaigns. They have close links with local epilepsy services, with a volunteer attending the weekly outpatient clinic at St George's Hospital.
- **Headway South West London** provides support, information and services to people with a brain injury, their families and carers and professionals.

In addition to disease-specific organisations, **Carers Support Merton** provides valuable support to carers of people with LTNCs including support groups, information, advice and advocacy. **Crossroads Care South Thames** also offers individual home-based respite care services, providing a few hours of respite on a regular basis to those who care for people with disabilities, with referrals accepted from organisations that provide funding including NHS, GP surgeries and social care.

Patient Pathways

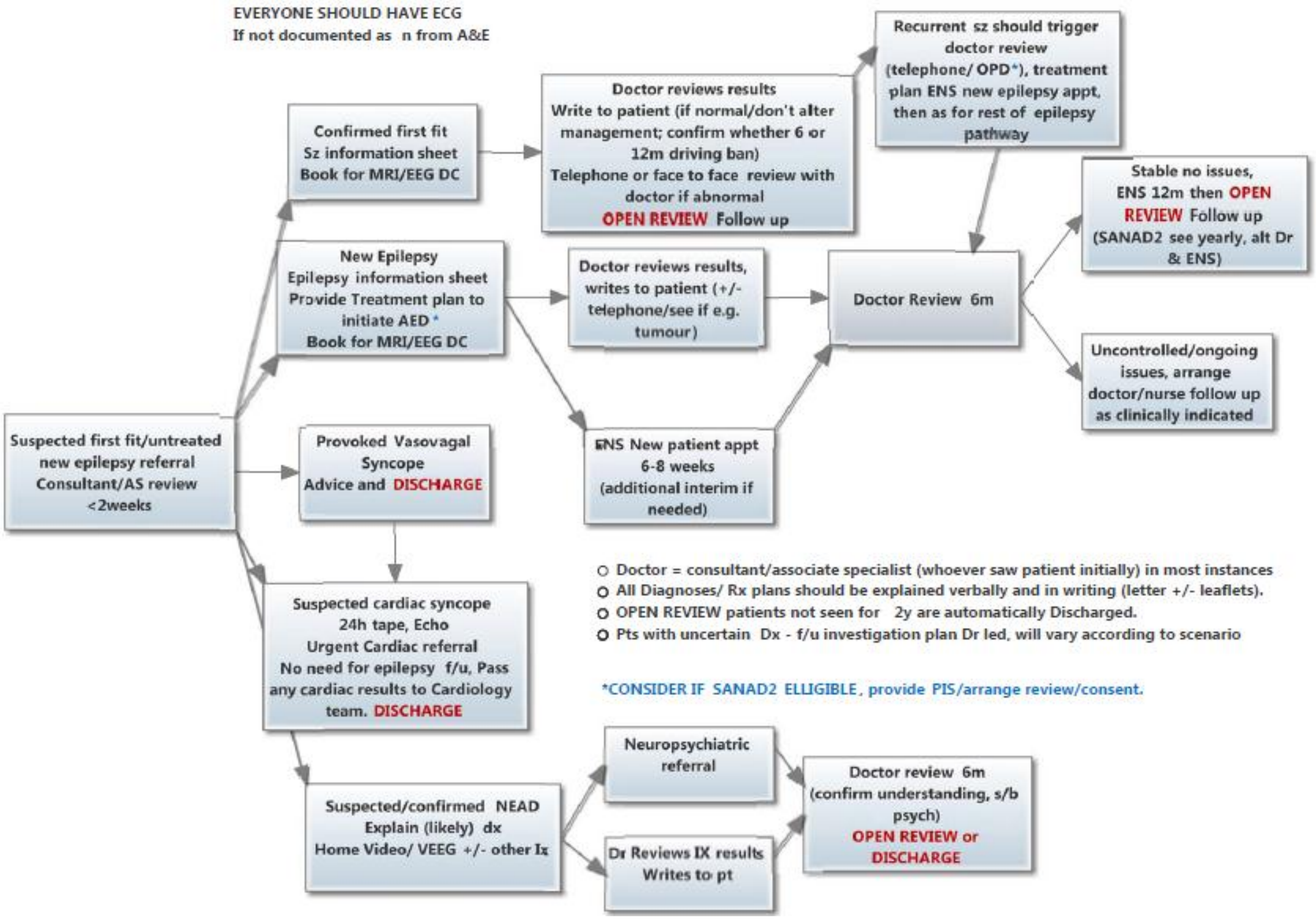
Patients will generally present to their GP in the first instance, who on suspicion of a neurological condition will refer directly to a specialist neurology consultant for testing and diagnosis. Patients are then likely to follow a varied pathway depending on the condition they present with, its severity and their range of needs.

Epilepsy is the only condition with a specific pathway in place. The open review pathway means that following a first fit, patients are able to self-refer directly to a consultant within a two year period (**Fig 41**). This pathway was introduced following identification of a number of difficulties with the traditional model of fixed appointments for follow up, including high DNA rates, a high incidence of mental health problems and the unpredictable nature and timing of advice and support. This pathway is noted to work particularly well for refractory patients with good support networks as they are empowered to make decisions and take a proactive role in managing their care.

Discussions are currently underway to define clear prescribing practices for epilepsy in Merton. This work, ongoing across the South West London area, looks to clarify the role of hospital specialists and GPs in individualised treatment planning and the prescribing of AEDs for patients over the age of 16.

Various pathways based on NICE guidelines are followed for other neurological conditions, with referral from GP to neurology consultant on suspicion of a neurological condition. A number of pathways have been developed by the Community Neurotherapy Team (CNTT) in conjunction with clinicians that consider the patient journey and collaborative working, pointing to the stages at which escalation is required. The pathway in **Fig 42** represents a hypothetical pathway for patients with progressive neurological conditions in Merton based on information provided by the CNTT and discussions with clinicians.

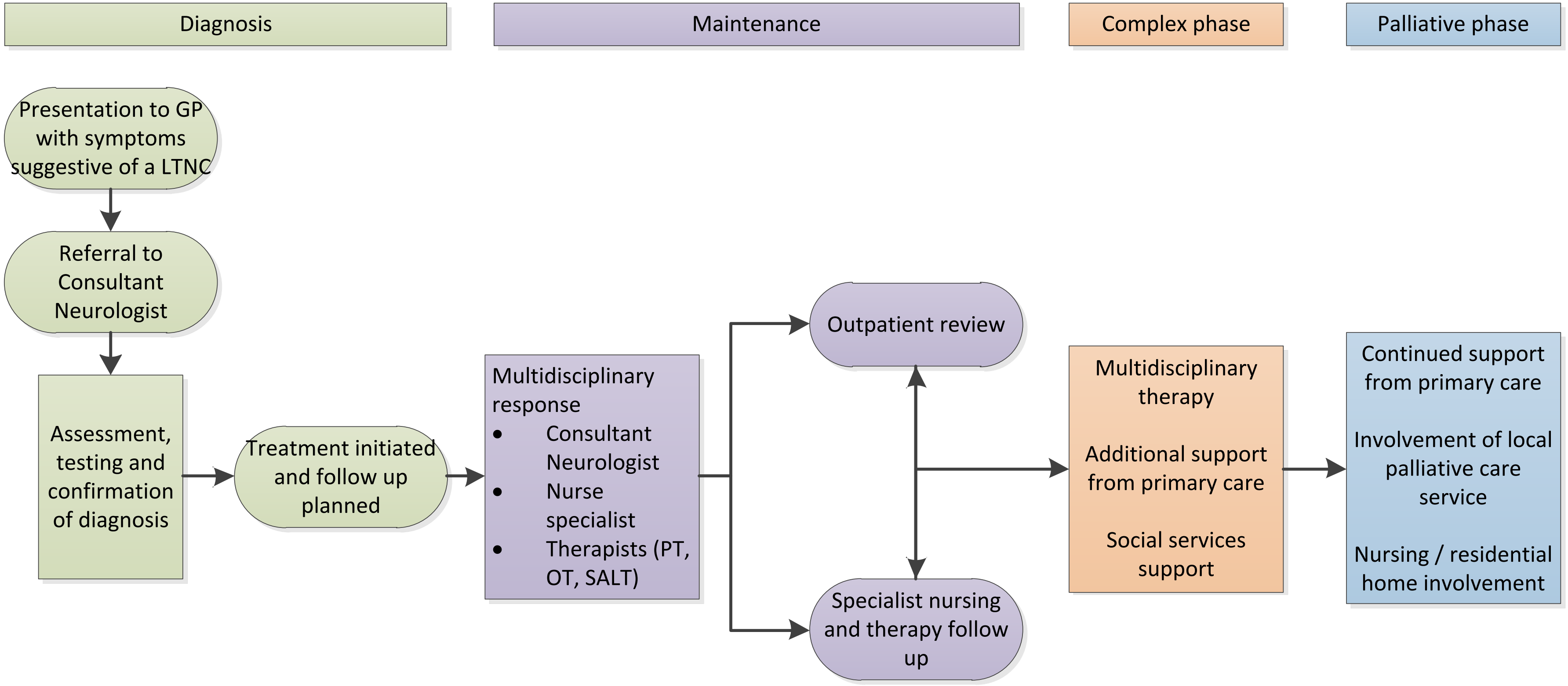
Fig 41. Epilepsy suspected first seizure pathway, St George’s Healthcare NHS Trust



○ Doctor = consultant/associate specialist (whoever saw patient initially) in most instances
○ All Diagnoses/ Rx plans should be explained verbally and in writing (letter +/- leaflets).
○ OPEN REVIEW patients not seen for 2y are automatically Discharged.
○ Pts with uncertain Dx - f/u investigation plan Dr led, will vary according to scenario

*CONSIDER IF SANAD2 ELLIGIBLE, provide PIS/arrange review/consent.

Figure 42. Hypothetical pathway for progressive LTNCs in Merton



London Organisational Audit of care providers

Secondary and tertiary services

A 2013 audit of secondary and tertiary providers of neurological services in London identified gaps in specialist nursing provision in Merton, particularly regarding MND nurse specialists.

The London Neuroscience SCN completed the audit in order to provide a baseline picture of hospital based neurology services across London to inform service development and standard setting.[20]

While St George's Healthcare NHS Trust (SGH) compared favourably with other regional centres in most aspects of the audit, of note was the lack of a MND specialist nurse.

St Helier Hospital also had many strengths, particularly in the information and support services provided to patients. However in common with other acute general hospitals, there were a number of gaps identified. These included the provision of specialist nursing care, with no epilepsy or MND nurse specialists, and agreed protocols for certain areas of the neurology pathway. The level of training and advice provided by specialist staff for general nursing staff and staff in other care settings was not known.

Community rehabilitation services

A shorter report was also compiled on community rehabilitation services.[21] No information was returned for Sutton and Merton Community Services, however the audit found significant variation in access to services nationally. Over half of services have no access to neuro-psychology and the 83% do not include a social worker. Further to this, only 33% services carried out coordinated care planning with social services teams.

Strengths were apparent in standards of patient-centred care, with most services providing a named individual responsible for managing an individual's care, and over half of services offering personalised care plans that were held by the patient and regularly reviewed by the team.

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[20] London Neuroscience SCN (2014) London organisational audit of secondary and tertiary neurological care providers. http://www.slcsn.nhs.uk/scn/neuro/ldn-neuro-scn-audit-112014.pdf

[21] London Neuroscience SCN (2014) Organisational audit of specialist community neurorehabilitation services

Best practice in the management of LTNCs

Key Points:

- NICE Clinical Guidelines provide guidelines on evidence-based practice for the treatment and management of a number of neurological conditions.
- The 2005 National Service Framework for Long Term Conditions set out eleven quality requirements for LTNCs from diagnosis through to palliative care, however recent reviews find limited evidence towards the achievement of these requirements.
- Literature evaluating current service provision and models of care for people with LTNCs identifies a number of shortfalls in current provision including a lack of integration across health and social care services, limited access to ongoing therapy and variations in access to additional support such as specialist nursing care and vocational rehabilitation.
- In the context of a lack of robust evidence on the effectiveness of service models and models of care coordination, a number of reports make recommendations to commissioners to improve service provision in these areas.

There are a large number of NICE guidelines and resources relevant to neurological conditions. These include clinical guidelines, quality standards, interventional practice guidance, commissioning guidelines and advice. These can be found at: https://www.nice.org.uk/guidancemenu/conditions-and-diseases/neurological-conditions

NICE Clinical Guideline CG35: Parkinson’s disease: Diagnosis and management in primary and secondary care, July 2011

https://www.nice.org.uk/guidance/cg35

This guideline covers a number of areas relating to the diagnosis and management of Parkinson’s disease, including methods of communicating information, medicines that can be used to control symptoms, alternative methods of symptom management, care for people with Parkinson’ whose mental health is affected and end of life care.

NICE Clinical Guideline CG 137: The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care, Jan 2012

https://www.nice.org.uk/guidance/cg137

The importance of urgent specialist assessment for people with suspected seizures is emphasised in this guideline, along with recommendations addressing the need for a personalised drug strategy and regular review.

NICE Clinical Guideline CG186: Multiple Sclerosis: management of multiple sclerosis in primary and secondary care, Oct 2014

https://www.nice.org.uk/guidance/cg186

This guideline covers the diagnosis of MS, provision of appropriate information and support, coordination of care and management both of symptoms and of modifiable risk factors for relapse or progression of MS.

NICE Clinical Guideline CG105: Motor neurone disease: The use of non-invasive ventilation in the management of motor neurone disease, June 2010

https://www.nice.org.uk/guidance/cg105

This guideline provides advice on the use of non-invasive ventilation for people with motor neurone disease. It was most recently reviewed in November 2014, at which point a decision was made to develop a full guideline on the assessment and management of motor neurone disease, amalgamating and replacing the current guideline. The anticipated publication date is February 2016.

NICE CG150: Headaches: Diagnosis and management of headaches in young people and adults, Sept 2012

https://www.nice.org.uk/guidance/cg150

This guideline discusses the diagnosis and management of tension-type headache, migraine, cluster headache and medication overuse headache in young people and adults. The guideline sets out a table detailing the features of each headache type and recommends the use of a headache diary to aid with assessment, with subsequent suggestions for drug therapy to treat the different headache types.

A clinical guideline for cerebral palsy is currently under development, due for publication in 2016.

A number of other guidelines address issues of relevance to neurological conditions including faecal incontinence, urinary incontinence.

The National Service Framework for Long Term Conditions

Due to an increasing recognition of the complexity of neurological conditions and the level of support required across both health and social care services, neurological conditions formed the focus of the 2005 National Service Framework (NSF) for Long Term Conditions. [22] The Framework identified a number of difficulties faced by people with long term conditions. These included lengthy diagnosis, a lack of information on the condition itself and the services available and inconsistent access to health and social services.

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[22] Department of Health (2005) The National Service Framework for Long-Term Conditions. London: DH

The NSF consequently set out 11 quality requirements for the management of LTNCs, setting out a target of full implementation by 2015. These quality requirements recognise the need to provide appropriate support to individuals living with conditions for which there is currently no cure, reducing the impact of these conditions by facilitating access to high quality services that help people to manage their symptoms and maintain as much independence as possible.

Fig 43. Quality requirements of the National Service Framework for Long Term Conditions

Quality requirement 1: A person centred service
People with longterm neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

Quality requirement 2: Early recognition, prompt diagnosis and treatment
People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.

Quality requirement 3: Emergency and acute management
People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.

Quality requirement 4: Early and specialist rehabilitation
People with longterm neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist settings to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support.

Quality requirement 5: Community rehabilitation and support
People with longterm neurological conditions living at home[ii] are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.

Quality requirement 6: Vocational rehabilitation
People with longterm neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities.

Quality requirement 7: Providing equipment and accommodation
People with longterm neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently, help them with their care, maintain their health and improve their quality of life.

Quality requirement 8: Providing personal care and support
Health and social care services work together to provide care and support to enable people with longterm neurological conditions to achieve maximum choice about living independently at home.

Quality requirement 9: Palliative care
People in the later stages of longterm neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.

Quality requirement 10: Supporting family and carers
Carers of people with longterm neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.

Quality requirement 11: Caring for people with neurological conditions in hospital or other health and social care settings
People with longterm neurological conditions are to have their specific neurological needs met while receiving treatment or care for other reasons in any health or social care setting.

A report by the National Audit Office in 2011[23] found that, despite significant increases in health and social care spending on neurological conditions, poor progress had been made in implementing the framework. This was in part due to the lack of any formal targets. Data limitations restricted the conclusions that could be drawn, however it was identified that while access to health services had improved and emergency bed days reduced, quality of care indicators had worsened since publication of the framework, with high levels of emergency admissions and readmissions.

A number of additional reports have further examined best practice in the management of LTNCs, identifying shortfalls in the provision of care for people with LTNCs in England and providing guidance for commissioners to address these deficiencies.

Comprehensive care across service boundaries

A 2008 report published by the Royal College of Physicians, in conjunction with the National Council for Palliative Care and the British Society for Rehabilitation Medicine, identified the key roles fundamental to a comprehensive system of care for neurological conditions.[24] The report highlighted the interface between the different phases of disease progression, from diagnosis and active treatment, rehabilitation for the management of symptoms, and palliative care.

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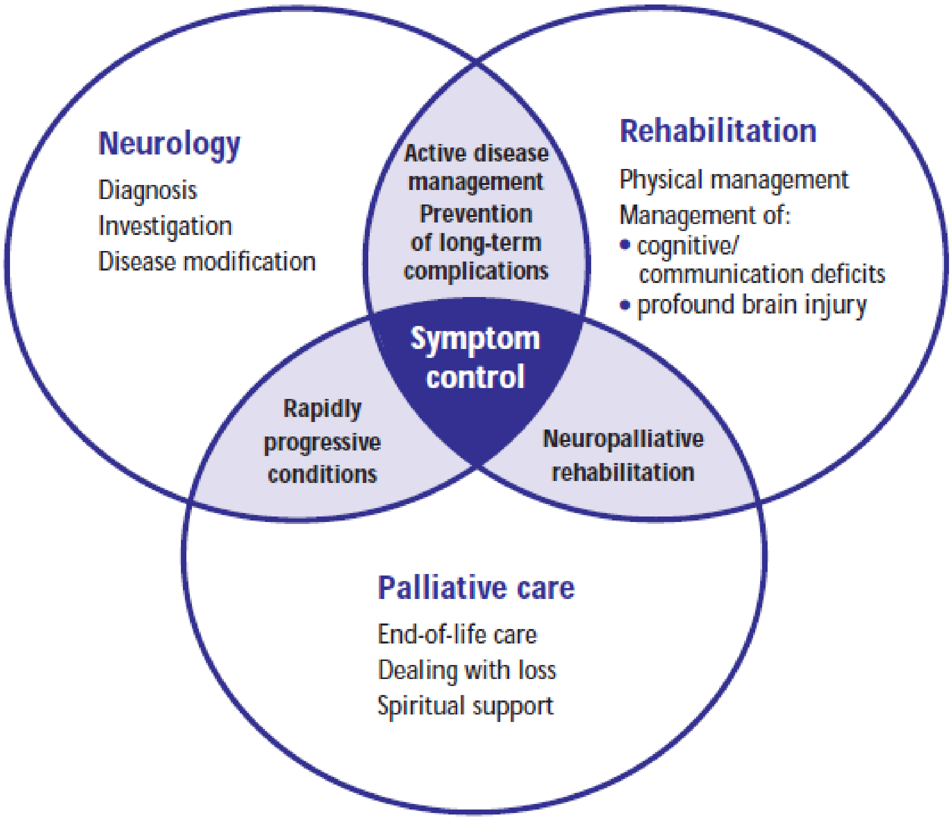
[23] National Audit Office (2011) Services for people with neurological conditions. London: DH

[24] Royal College of Physicians, National Council for Palliative Care, British Society of Rehabilitation Medicine (2008) Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care. Concise Guidance to Good Practice series, No 10. London: RCP

Fig 44. Key roles of neurology, rehabilitation and palliative care services in supporting people with LTNCs



Source: RCP (2008)

The specific roles identified in each of the service areas are set out in Table 12.

Table 12. Detailed roles of neurology, rehabilitation and palliative care in supporting people with LTNCs

Neurology	Rehabilitation	Palliative care
• Investigation and diagnosis • Information • Ongoing specialist advice • Disease modifying treatments • Neurological interventions • Practical advice from specialist nurses	• Ongoing medical management • Practical holistic support and disability management • Coordinated multidisciplinary team interventions (including OT, PT, SLT, psychology) • Aids and equipment • Care planning and support • Communication and psychosocial support • Medico-legal issues	• Multi-professional management of distressing symptoms • Support for end of life decisions and advance care planning • Support of the dying person and their family • Bereavement counseling • Advisory/liaison service

Source: RCP (2008)

The importance of considering palliative care at an early stage is crucial to facilitating the management of symptoms and enabling people's wishes to be met in the later stages of the condition. This phase extends beyond an individual's death to include support for family and carers and bereavement counselling. Individuals currently have the right to refuse life-sustaining medical treatment, with the ability to make legally binding advance decisions in the event that someone's capacity to consent may be affected in the future. Beyond this, there is currently debate nationally on the role of euthanasia and assisted suicide. This debate has been prompted by several high profile cases in the media, with a Private Member's Bill on Assisted Dying being put forward by Lord Falconer in 2014.[25] Assisted suicide remains illegal in the UK, in contrast to a number of European countries including Holand and Switzerland, however support has been signalled by a number of MPs and it is likely, with the general election now passed, the debate will be reopened in due course.

Gaps in service provision

Patchy service provision was found across the country by a recent report commissioned by the Department of Health, with inequities in access due to geography and condition type. [26] While treatment and early rehabilitation appeared to be satisfactory, continuity and coordination of ongoing care was found to be much weaker. The report emphasised the crucial role of Community Neurorehabilitation Teams and specialist nurses. Nevertheless it was noted that due to the time limited nature of many therapy services, continuity of care was often lost. Voluntary organisations were also frequently found to be leading in the establishment of specialist nurse services.

A model was suggested for future services reflecting four areas of need for people with LTNCs, set out in Fig 45.

The report concluded by making recommendations in the three outcome areas identified in this model. These included community neurorehabilitation teams having a core role in care coordination and continuity, the use of individual budgets in order to ensure that individuals receive personalised services, and improved access to vocational rehabilitation and employment support services to allow full participation and contribution to society.

Recent engagement with clinicians and wider professionals identified similar gaps, including a lack of local pathways between secondary, tertiary and community care, and a lack of capacity in community neurorehabilitation services. [27]

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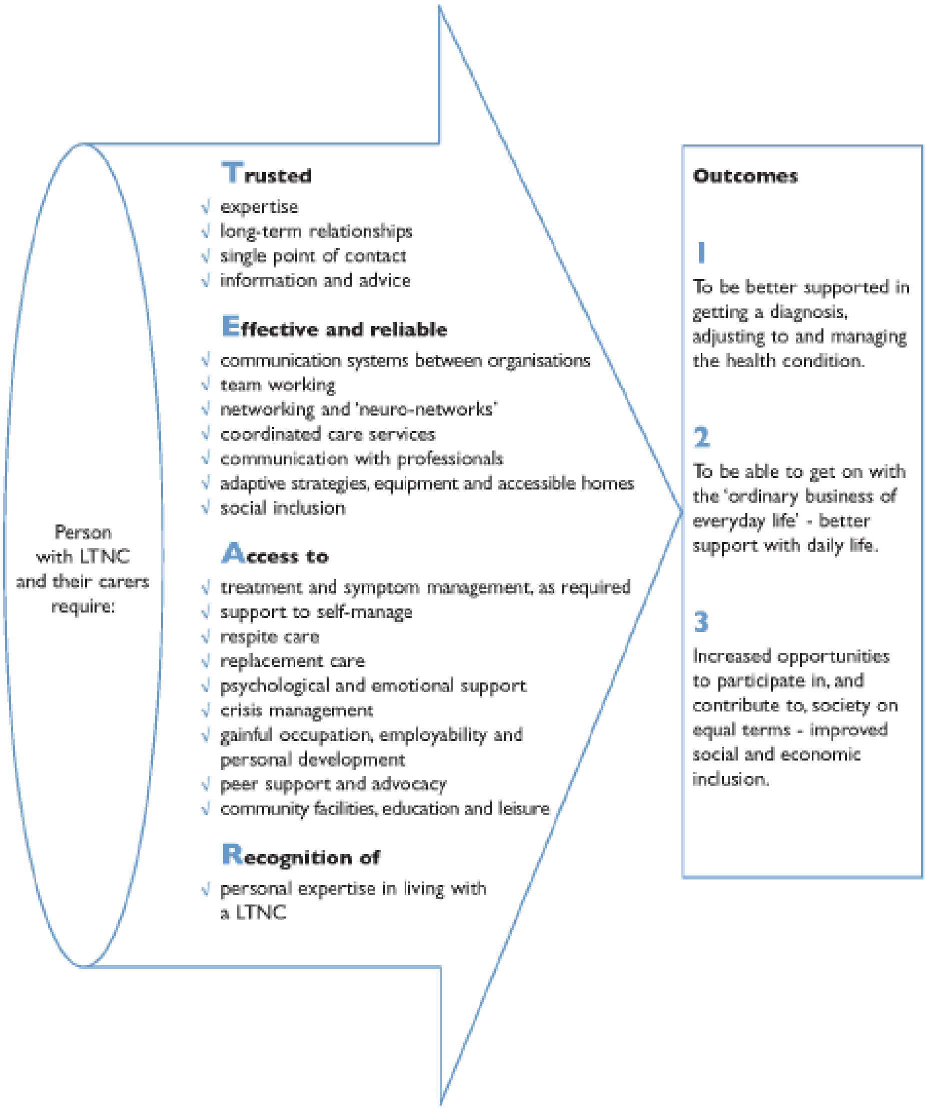
[25] Assisted Dying Bill 2014-14 http://www.publications.parliament.uk/pa/bills/lbill/2014-2015/0006/15006.pdf

[26] Winchcombe M (2012) A life more ordinary – findings from the Long-term Neurological Conditions Research Initiative. Accessed online at http://www.ltnc.org.uk/download_files/final%20reports/ALMO_for_web.pdf on 03/03/2015

[27] London Neuroscience SCN (2013) Driving the neuroscience agenda in London – summary of 1 July feedback https://www.networks.nhs.uk/nhs-networks/.../**neuro-summary**-v13.pdf

Fig 45. The TEAR Model for future services



Source: A Life More Ordinary (2012)

Care coordination

Gaps have been identified in the coordination of care across health, social care and other services. As such, there has been increased interest in the role of models of multi-disciplinary care for people with LTNCs. Nevertheless a lack of evidence-based models for the provision of multi-disciplinary care has been consistently highlighted, particularly regarding the lack of evidence on long-term outcomes.[28] [29] [30]

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[28] Van der Marck M & Bloem B (2014) How to organize multispecialty care for patients with Parkinson's disease. Parkinsonism & Related Disorders 20(S1) S167-S173

[29] Prizer LP & Browner N (2012) The integrative care of Parkinson's disease: a systematic review. Journal of Parkinson's Disease 2(2) 79-86

[30] Gage H et al (2014) Specialist rehabilitation for people with Parkinson's disease in the community: a randomised controlled trial. NIHR Journals Library

Further to this, much of the existing evidence is limited to qualitative research. While a systematic review found neurology nurse specialists to contributed to all elements of continuity of care through specialist knowledge of the neurological condition and a comprehensive knowledge of local services, this evidence is limited to case studies.[31]

Relatively little is therefore known about effective methods for care coordination, with a current lack of outcome measures to assess the cost-effectiveness of services and gaps in research into different models of care.[32] In the absence of this evidence, approaches that facilitate communication across agencies, such as networks of care and proactive team management are recommended to commissioners, which advocates for the use of key workers in community teams to act as a single point of contact.[33]

Ongoing management

Research relating to ongoing management of LTNCs identified concerns among clinicians as to standards of care when PD patients are admitted to hospital. The potential for PD nurse specialists to see all PD inpatients, flagging of Parkinson's admissions and a Parkinson's outreach service were seen as the most likely of service developments to improve care.[34]

A further article reviewed current evidence on the use of self-management programmes for people with LTNCs, finding evidence on existing programmes to be limited. There was some evidence that group interventions have had positive outcomes for patients, including self-efficacy and social connection, with cost-savings in comparison to individual interventions. However the review also cites studies demonstrating negative outcomes for patients following self-management education for progressive conditions, thought to be due to an increased awareness of future deterioration.[35] Nevertheless toolkits to help patients self-manage their conditions are recommended, including information for both patients and clinicians about social care and other services to help navigate the neurological pathway.[36]

Specialist nurses

There is a growing body of literature on the wider benefits of specialist nursing roles, both in terms of care coordination and with regards to patient outcomes. Nevertheless this research is again limited to small studies and qualitative work. [37] [38] [39] These studies have found the benefits of such roles to range from higher patient satisfaction, rapid access to competent

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[31] Aspinal F et al (2012) Promoting continuity of care for people with long-term neurological conditions: the role of the neurology nurse specialist. Journal of Advanced Nursing 68(10):2309-19

[32] Langton Heweer R (2013) Neurology on the move? Clinical Medicine 13(5) 440-442

[33] RCP (2011) Local adult neurology services for the next decade. London: RCP

[34] Skelly R et al (2015) Hospitalization in Parkinson's disease: a survey of UK neurologists, geriatricians and Parkinson's disease nurse specialists. Parkinsonism Related Disorders 21(3): 277-81

[35] Chaplin H, Hazan J & Wilson P (2012) Self-management for people with long-term neurological conditions. British Journal of Community Nursing. 17(6):250-4, 256-7

[36] RCP (2011) Local adult neurology services for the next decade. London: RCP

[37] Bourke D et al (2012) The appointment of a Huntington's disease nurse specialist has reduced admission rate and improved admission quality. Journal of Huntington's disease. 1(1) 27-30

[38] Hellqvist C & Bertero C (2015) Support by Parkinson's disease specialist nurses to Parkinson's disease patients and their spouses. Applied Nursing Research 28(2) 86-91

[39] Kirton JA et al (2012) Care of patients with neurological conditions: the impact of a Generic Neurology Nursing Service development on patients and their carers. Journal of Clinical Nursing 21(1-2):207-15

and individually tailored support, and continuity of contact and emotional support for patients and their families.

Further published literature is limited to discussions on the role of specialist nurses and their contribution to care. This literature emphasises the value of the nurses crossing hospital and primary care settings and involving patients and carers in the planning and delivery of care.[40] [41] The MS Trust has published a summary of the use and value of MS nurses across the UK, providing case studies of their use and the potential cost savings associated. These include the avoidance of emergency admissions and a reduction in the number of outpatient appointments, however the document notes the difficulties in creating an economic model for the use of MS nurse posts due to lack of information on activity levels and costs, proposing methods by which nurse performance and value can be measured going forward. [42]

Commissioning priorities

In view of current evidence, commissioning priorities identified by the London Neuroscience SCN for 2014/16 comprise the following;[43]

1. Increasing the priority of service developments and pathways for patients with neurological conditions
2. Including patients with long term neurological conditions who are at high risk of unplanned care in local integrated care developments
3. Developing pathways with local providers that give responsive access to expertise where needed but also support the management of common neurological conditions by primary care
4. Commissioning appropriate capacity for community rehabilitation
5. Ensuring appropriate emergency access for patients with serious neurological conditions to facilities with appropriate expertise
6. Commissioning services that meet both the availability and timeliness of disease modifying drugs
7. Providing a comprehensive range of palliative care services: to control symptoms, offer pain relief and meet the needs for personal, social, psychological and spiritual support

As part of the work carried out by the network, the feasibility of implementation of an integrated case management and support system for neurological conditions that covers both health and social care is being considered. A multiple sclerosis care pathway is currently being tested in North West London against the integrated model originally designed for over 75s and diabetes, with the long-term view that the development of such pathways will facilitate more coordinated care across agency boundaries.

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[40] Embrey N (2014) Multiple sclerosis: managing a complex neurological disease. Nurs Standards. 29(11):49-58

[41] Strickland K & baguley F (2015) The role of the community nurse in care provision for people with multiple sclerosis. British Journal of Community Nursing

[42] Mynors G, Perman S & Morse M (2012) Defining the value of MS Specialist Nurses. London: MS Trust

[43] London Strategic Clinical Networks: Recommended commissioning priorities – 2014/16 http://www.slcsn.nhs.uk/scn/comms/general/scn-recommended-commiss-priorities-022014.pdf

What are the gaps in Merton?

Table 13 maps the outcomes identified in the TEAR model and best practice against current service provision in Merton. Taking this into consideration and evaluating all of the evidence gathered, including information from stakeholders, a number of gaps have subsequently been identified in Merton in relation to LTNCs. These are set out beneath the table.

Table 13. Merton service provision mapped against best practice

TEAR Outcome	Best practice[44]	Merton provision
To be better supported in getting a diagnosis, adjusting to and managing the health condition	Specialist nurse roles [45]	PD nurse provision at St George's and through SMCS MS nurse provision in place No provision of MND nurse No epilepsy nurse at St Helier Hospital
	Individualised care planning	Variable, with a minority of individuals reporting being offered a personalised care plan
	Ongoing access to community neurotherapy and CNTTs to act as one of the core healthcare components that ensures continuity	Patients with life-limiting conditions remain on the priority caseload of the CNTT, however stakeholders and service users report some difficulties in access to services
To be able to get on with the 'ordinary business' of everyday life	Single point of contact	Condition-dependent - GPs fulfill the role where there is no specialist nurse or contact with the CNTT
	Support to self manage	Merton's Expert Patients Programme is open to patients with any long-term condition
	Personalised services including the option to use a personal budget	Personal budgets not currently used for LTNCs in Merton
	Psychological and emotional support [46]	No neuropsychologist in CNTT. Psychosocial support consistently reported by stakeholders and service users as a gap
Increased opportunities to participate in, and contribute to, society on equal terms – improved social and economic inclusion	Employability and personal development	Vocational rehabilitation offered, however access perceived by stakeholders to be limited with further support required for those not meeting eligibility for this service
	Peer support and advocacy	Strong voluntary sector support for individuals with LTNCs

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[44] Taken from TEAR model unless otherwise stated

[45] Specifically recommended for MS, MND and epilepsy in NICE guidelines. PD guidelines state that patients should have regular access to specialist nursing care, which may be provided by a PD nurse specialist

[46] Discussed in NICE guidelines and outlined in guidance from the RCP (see Table 12, p81)

1 Primary care

1.1 Variation is observed in the primary care management of epilepsy in Merton, with QOF measures indicating considerable variation between practices.

1.2 Merton is slightly below the London and England average for epilepsy patients (18+) on drug treatment who have been seizure free for the last 12 months, with two practices demonstrating particularly low rates.

1.3 Merton CCG does well overall for the proportion of female epilepsy patients 18-54 years old with a record of contraception, conception and pregnancy advice in the last 12 months, however five practices have proportions of 50% or less.

1.4 Variation is also demonstrated between practices in the recorded prevalence of epilepsy, ranging from 0.25% to 0.73%. All practices have a lower observed prevalence compared with that which would be expected based on national prevalence.

1.5 The service user survey indicated that the process of diagnosis is often lengthy, with feedback from service providers and primary care staff suggesting that limited awareness of the presentation of neurological conditions contributes to delays in diagnosis and access to specialist care. While this was understood by stakeholders to reflect inherent difficulties in diagnosis, the historic focus on stroke and dementia at the expense of other conditions was believed to be a factor in this.

2 Community care

2.1 Patients with cerebral palsy and traumatic brain injury appear to be under-represented in the Community Neurotherapy Team caseload when accounting for estimated prevalence, with anecdotal evidence of few referrals for these condition groups. This may indicate a lower need for services, however it may also indicate that individuals with these conditions are ‘slipping through the net’ between primary, secondary and community care.

2.2 Capacity in community services was reported by stakeholders to be limited at times. While these services were highly valued, capacity issues were understood to limit the ability of individuals to access on going care. This finding was also reported in the service user survey, where a high number of individuals had experienced problems or delays in accessing care and treatment. Access to on going physiotherapy, occupational therapy and speech and language therapy is highlighted in best practice guidelines as important in reducing the impact of LTNCs on an individual’s life.

2.3 There is a perceived lack of knowledge among non-specialist community care staff about the needs of people with neurological conditions. Professional stakeholders reported this to be a gap that contributed to unnecessary admissions.

3 Secondary and tertiary care

3.1 A high proportion of emergency admissions and emergency bed days relate to particular neurological conditions. Notable are epilepsy and Parkinson’s disease.

While Merton CCG has performed well in comparison to London regarding reductions in emergency neurology admissions, there remains scope for further reductions.

3.2 Provision of specialist nursing support is patchy, with variation between hospitals. Most notably, there is currently no MND specialist nurse role in local hospitals and no epilepsy nurse at St Helier Hospital. NICE guidelines recommend that specialist nurses form part of the multi-disciplinary team coordinating the on going treatment and management of these patients.

3.3 Feedback from service providers and carers suggests a gap in the knowledge of general hospital staff in the management of neurological conditions. This was reported as a concern of both professionals and carers, contributing to deteriorations in people’s conditions when admitted to hospital for other reasons.

4 Inequalities

4.1 ***Ethnicity***: There are high rates of total admissions of people from ‘Other’ ethnic backgrounds for intermittent, progressive and stable neurological conditions and for epilepsy in 0-19 year olds.

4.2 ***Deprivation***: There are higher rates of emergency admissions for neurological conditions for people living in more deprived areas. This pattern is reflected for epilepsy admissions in children and young people. There is also a significantly lower rate of elective admissions from Index of Multiple Deprivation (IMD) quintile 5 (least deprived) than from IMD 2.

5 Planning and continuity of care

5.1 The service user survey and stakeholder engagement exercise suggest that comprehensive care planning currently only occurs in some cases. Best practice guidelines advocate the use of individualised care plans to address a person’s comprehensive health and social care needs, however it appears that these are not yet being used routinely for all LTNCs in Merton. While examples of good practice in collaborative working exist in Merton, such as the links provided by specialist nurses to a range of support services, it appears that there is scope for more integrated working between health and social care agencies in the management of care for people with LTNCs.

6 Further gaps expressed by stakeholders

A number of other gaps were identified by stakeholders in the consultations.

- Limited access to lower level mental health and psychosocial support for people with LTNCs was reported. Given the impact of LTNCs on the lives of individuals and their families, the provision of appropriate support in this regard is crucial to enabling people to live as independently as possible.
- There was a perception that vocational rehabilitation and support is lacking for those not meeting the eligibility criteria for current services. This is a particular concern given the high proportion people in Merton with LTNCs who are of working age.

- Access to equipment was reported to be variable, with a general pattern of good access through reablement services but long waits when the need is less urgent. There also appears to be no set process for accessing equipment where there is a specific health need.
- There was general agreement that the needs of carers are not being as comprehensively addressed as they should be.
- The difference in level of service provision from paediatric to adult services was understood to have the potential to cause significant difficulties if not managed well, particularly for young people with epilepsy and cerebral palsy.

7 Data gaps

7.1 As with most areas of the country, Merton has very little information on the numbers of people living with LTNCs in the local area. This makes service planning inherently challenging as the full extent of the needs cannot be fully understood.

Health and social care recommendations

Key Points:

A number of recommendations are made in view of the evidence presented.
Recommendations are made in six areas;

- Primary care
- Community care
- Secondary care
- Inequalities
- Planning and continuity of care
- Addressing wider needs
- Data collection

In light of the gaps identified in this needs assessment, the following recommendations have been developed, to inform decisions made by commissioners and service providers.

1 Primary care

1.1 Provide opportunities for the up skilling of GPs with regards to more common LTNCs including epilepsy and Parkinson's. This would serve to support the diagnosis process and is particularly important in view of the role played by GPs in the on going management of epilepsy.

2 Community care

2.1 Review the capacity of community rehabilitation services in order to establish whether sufficient capacity exists to enable comprehensive access to on going therapy.

2.2 Facilitate training for the general community services workforce in order to increase awareness of the needs of people with LTNCs to help in the avoidance of hospital admissions.

3 Secondary care

3.1 Consider the local provision and capacity of specialist nursing support for people with LTNCs, considering in particular diseases or geographical areas where support is not currently provided.

3.2 Facilitate training for secondary care staff to increase knowledge of LTNCs so that appropriate support can be provided to patients with neurological conditions when admitted to hospital and other care settings.

4 Inequalities

4.1 Targeted action should be considered with ethnic minority populations and those in more deprived areas to increase knowledge of LTNCs, support access to services and facilitate appropriate management strategies. This would need to be linked with primary care management and training (Recommendation 1.1) and include strategies to raise awareness of LTNCs among these communities, for example through the use of health champions.

5 Planning and continuity of care

5.1 Ensure that everyone diagnosed with a LTNC has access to a key worker and a comprehensive individualised care plan that can be shared between agencies and supports on going coordination of their care.

5.2 Ensure that integrated local pathways across primary, secondary, community and social care exist, addressing relevant support needs for people with neurological conditions. These pathways should enhance communication and ensure strong links between health and social care agencies. Any work on this should link into the work being done by the London Neuroscience Strategic Clinical Network.

5.3 Encourage patients to play an active role in the management of their condition, increasing the opportunities and resources available to support self-management.

6 Addressing wider needs

6.1 Increase opportunities to access mental health and psychosocial support in the community, considering appropriate input from neuropsychologists.

6.2 Review the availability of vocational rehabilitation and general employment support for the large numbers of people with LTNCs in Merton who are of working age.

6.3 Consider the processes through which individuals can access funding for specialist equipment, bearing in mind the potential for individual budgets to give people greater control and choice over the care and support they receive.

6.4 Review what is available for young people with LTNCs through the transition period into adult services to ensure they are appropriately supported.

6.5 Consider mechanisms to ensure that the needs of carers are more comprehensively assessed, with appropriate support provided to help them in their role as a carer and to ensure that their own health and social needs are met.

6.6 Involve service users and carers in commissioning and service development processes as they can provide valuable insight into local needs.

7 Data collection

7.1 Consider the use of data systems to more accurately record information about the numbers of people with LTNCs in the local area. These systems could also be used to support the management of care.

Appendix 1: ICD Codes for neurological conditions

Neurological condition group	**Related ICD 10 codes**
Epilepsy	G40, G41
Migraine and headaches	G43, G44
Parkinson's disease and related disorders	G20X, G210, G211, G212, G213, G218, G219, G22XA, G258, G259, G903
Motor neurone disease and spinal muscular atrophy	G12
Multiple sclerosis and inflammatory diseases	G35X, G36, G37
Neuropathies	G519, G540, G541, G56, G57, G58, G59-A, G60, G61, G62, G63, G64, G900, G990A
Other progressive conditions:	G10X, G24, G250, G251, G252, G253, G254, G255, G256, G71, G72, G734A, G735A, G736A, G737A, M60, M62
Cerebral palsy	G80
Central Nervous System Infections	G00-G09, A80-A88
Traumatic Brain Injury	S04, S06

Source: World Health Organisation ICD-10 Version: 2015
http://apps.who.int/classifications/icd10/browse/2015/en

Appendix 2: Summaries of additional LTNCs

Cerebral Palsy

Scope http://www.scope.org.uk/

Classification: Stable with changing needs

Definition

- A group of permanent disorders of the development of movement and posture causing activity limitation, attributable to non-progressive disturbances that occurred in the developing fetal or infant brain.

Symptoms and clinical features

- CP affects muscle control and movement. It is not progressive but the effects may change over time.
- Often accompanied by disturbances of sensation, perception, cognition, communication and behaviour as well as epilepsy and musculoskeletal problems.

Epidemiology

- Cerebral palsy affects approximately one in every 400 children.

Diagnosis

- Children will be assessed by a paediatrician and may have a number of tests performed, including blood tests, cranial ultrasound, MRI and CT.

Treatment and ongoing management

- Effects can be minimal depending on the extent that motor control is compromised.
- Physical therapy and speech therapy can help to prevent muscle weakening and communication difficulties, while drug therapy can relieve muscular symptoms.
- Cerebral palsy can be associated with reduced life expectancy where independent feeding and mental and visual capacities are severely impaired. In such cases cerebral palsy requires ongoing management from a multidisciplinary team of specialists.

Traumatic brain injury

Headway https://www.headway.org.uk/home.aspx

Classification: Sudden onset

Definition

- Injury caused by trauma to the head, eg. road traffic accidents, assaults, falls.

Symptoms and clinical features

- Effects range from mild to severe depending on the type, location and force of injury.
- Ability and timeframe to retain normal functioning varies dramatically depending on the severity of the injury.
- Symptoms such as tiredness, headaches and dizziness often coincide with cognitive difficulties and emotional and behavioural problems following a moderate injury.
- Individuals with a severe injury may have more serious and longer lasting deficits.

Epidemiology

- Prevalence of traumatic brain injury in the UK is estimated to be 1,200 per 100,000.

Diagnosis

- CT scans are the gold standard to determine the extent of injury, with EEGs also performed. MRI is not recommended in the investigation of traumatic brain injury.

Treatment and ongoing management

- A hospital admission is likely for the initial injury, with intensive care for severe cases.
- Drug treatment and surgery may be indicated depending on the nature of the injury.
- Rehabilitation and continuing care look to minimise the long term impact and help the individual and their family and carers to cope with any disabilities.

A brief outline of a number of additional LTNCs are provided below.

Migraine and headaches[47]	These are the most prevalent neurological disorders, causing recurrent pain for individuals and often limiting their ability to conduct normal daily activities. Headaches are diagnosed and classified according to their clinical pattern, including the location and nature of the pain. They can be primary disorders, or secondary to other underlying disorders. Migraines are characterised by episodic severe headaches with associated symptoms such as photophobia, phonophobia and nausea and vomiting. Identification of triggers and lifestyle changes can reduce the frequency of headaches and migraines. There are also a variety of drug therapies available, the choice of which will depend on the specific diagnosis in addition to individual preference, comorbidities and the risk of adverse events. Headache diaries are useful tools to monitor both methods of management and guide follow up and ongoing management.
Neuropathies[48]	Also referred to as peripheral nerve disorders, this group of conditions results from damage to the peripheral nerves. Conditions include Charcot-Marie-Tooth disease, carpal tunnel syndrome and Guillain Barre syndrome and tend to result in motor and sensory symptoms such as muscle weakness, numbness and pain. Treatments involve symptom relief and aiding mobility, with surgical options considered where symptoms cannot be controlled.
CNS Infections[49]	This category of diseases include encephalitis, Meningitis and rabies. The infections affect the brain and spinal cord, usually causing swelling. Medical therapy is usually required to treat the infection and lead to symptom resolution. Complications may occur that require longer term management, particularly in the case of encephalitis.

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[47] NICE (2014) Clinical Knowledge Summaries: Migraine http://cks.nice.org.uk/migraine

[48] PHE (2014) Neurology Intelligence Network http://www.yhpho.org.uk/default.aspx?RID=201343

[49] PHE (2014) Neurology Intelligence Network http://www.yhpho.org.uk/default.aspx?RID=201343

Appendix 3: Drugs included in published prescribing data

CNS Infections	Japanese Encephalitis Vaccine Meningococcal A + C + W135 + Y Vaccine Rabies Vaccine Tick-Borne Encephalitis Vaccine
Epilepsy	Carbamazepine Clobazam Clonazepam Eslicarbazepine Acetate Ethosuximide Felbamate Gabapentin Lacosamide Lamotrigine Levetiracetam Mesuximide Midazolam Hydrochloride Midazolam Maleate Oxcarbazepine Paraldehyde Perampanel Phenobarbital Phenobarbital Sod Phenytoin Phenytoin Sodium Pregabalin Primidone Retigabine Rufinamide Sodium Valproate Stiripentol Sultiame Tiagabine Topiramate Valproic Acid Vigabatrin Zonisamide
Migraine headache	Almotriptan Analgesics with Anti-Emetics Clonidine Hydrochloride Eletriptan Ergotamine Tartrate Frovatriptan Methysergide Naratriptan Hydrochloride Pizotifen Malate Rizatriptan Sumatriptan Succinate Tolfenamic Acid Zolmitriptan
PD and movement disorders/tremor	Amantadine Hydrochloride Apomorphine Hydrochloride Benzatropine Mesilate Botulinum Toxin Type A Botulinum Toxin Type B Cabergoline Carbidopa Co-Beneldopa (Benserazide/Levodopa) Co-Careldopa (Carbidopa/Levodopa) Entacapone Levodopa/Carbidopa/Entacapone Orphenadrine Hydrochloride Pergolide Mesilate Piracetam Pramipexole Procyclidine Hydrochloride Rasagiline Mesilate Riluzole Ropinirole Hydrochloride Rotigotine Selegiline Hydrochloride Tetrabenazine Tolcapone Trihexyphenidyl Hydrochloride
Dystonia	Baclofen Dantrolene Sodium Guaifenesin Methocarbamol Tizanidine Hydrochloride

Source: HSCIS

Appendix 4: Drugs included in local prescribing data

Epilepsy	**BNF: 4.8.1** Carbamazepine Clobazam Clonazepam Eslicarbazepine Acetate Ethosuximide Gabapentin Lamotrigine Levetiracetam Oxcarbazepine	Perampanel Phenobarbital Phenytoin sodium Pregabalin Primidone Retigabine Sodium Valproate Topiramate Vigabatrin Zonisamide
Parkinson's disease	**BNF: 4.9.1** Amantadine Hydrochloride Bromocriptine Cabergoline Co-Beneldopa (Benserazide/Levodopa) Co-Careldopa (Carbidopa/Levodopa) Entacapone Pergolide	Pramipexole Ropinirole Hydrochloride Selegiline **BNF 4.9.2** Orphenadrine Hydrochloride Procyclidine Hydrochloride Trihexyphenidyl