

## **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<sup>1</sup> 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:

---

<sup>1</sup> Merton Joint Strategic Needs Assessment 2013-14

- Merton CCG has a slightly higher spend on neurology for marginally better outcomes.
- 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.