Health Needs Assessment for Long Term Neurological Conditions

A report for Oxfordshire PCT

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1. Executive Summary

1.1 Oxfordshire PCT has established a Long Term Conditions Board to oversee the delivery of the National Service Framework for Long-term (Neurological) Conditions (NSF-LTnC) in Oxfordshire. Together with a multi-agency Local Implementation Group (LIG) it has been tasked with developing and delivering a local implementation strategy informed by the views of all key stakeholders.

Aims and Objectives

1.2 The aim of this report is to contribute to a revised health needs assessment (HNA) that will provide an evidence-based assessment of current and future need upon which the LIG can base their implementation plan.

Methodology

1.3 The 13 long-term neurological conditions included in this report were specified by Oxfordshire PCT with reference to the conditions included in the NSF-LTnC and other recent and ongoing work within the PCT.

1.4 The conditions included are: Multiple sclerosis, Parkinson's disease, motor neurone disease, epilepsy, acquired brain injury[1], spinal cord injury, cerebral palsy, chronic fatigue syndrome / myalgic encephalopathy, Huntington's disease, Charcot-Marie-Tooth-syndrome, muscular dystrophy, myasthenia gravis and dystonia.

1.5 Four questions are addressed encompassing the key clinical features, data relating to the prevalence, incidence and service use in Oxfordshire for each of the neurological conditions and information about nationally recognised forms of treatment.

1.6 The information in this report is drawn from a range of existing data sources including published and unpublished reports and web-based NHS and condition-specific resources.

Conditions

1.7 The table below gives the prevalence and incidence numbers for the 13 specified conditions. The prevalence number is an estimate of the number of people in Oxfordshire who are likely to be living with each neurological condition at any one time. The incidence number is an estimate of the number of newly diagnosed cases in Oxfordshire per annum.

[1] It should be noted that whilst the term 'acquired brain injury' was specified as the remit for this report, the available epidemiological data relates to 'traumatic brain injury'. An acquired brain injury is an injury caused to the brain after birth, for example, through traumatic injury, severe viral or bacterial infection, stroke, disease, tumour or aneurysm, or an event that causes a lack of oxygen to the brain. A traumatic brain injury relates to injuries acquired through falls, assaults, road traffic accidents and indstial accidents.

Estimates for the prevalence and incidence numbers of specified long term neurological conditions in Oxfordshire

	Prevalence number	Incidence number	Source for UK incidence and prevalence numbers
Multiple sclerosis	887[2]	25	Neuro Numbers (2003); NEPHO (2009)
Parkinson's disease	1,231	105	Neuro Numbers (2003); NEPHO (2009)
Motor neurone disease	43	12	Neuro Numbers (2003); NEPHO (2009)
Epilepsy	3,078	493	Neuro Numbers (2003); NEPHO (2009)
Traumatic brain injury	7,387[b]	1,077[a]	National Workforce Projects (2008); NEPHO (2009)
Spinal cord injury	308	12	Neuro Numbers (2003); National Workforce Projects (2008)
Cerebral palsy	1,145	Unknown	Neuro Numbers (2003); National Workforce Projects (2008)
Chronic fatigue syndrome / myalgic encephalopathy	1,847-2,462	Unknown[3]	Neuro Numbers (2003); NSF (2005)
Huntington's disease	83[4]	Unknown	Neuro Numbers (2003); NEPHO (2009)
Charcot-Marie-Tooth syndrome	246	Unknown	Neuro Numbers (2003); NEPHO (2009)
Muscular dystrophy	308	Unknown	Neuro Numbers (2003); NEPHO (2009)
Myasthenia gravis	62	Unknown	Myasthenia Gravis Association (2004)
Dystonia	400	Unknown	Neuro Numbers (2003); NEPHO (2009)

[a] leading to hospital admissions
[b] with long term problems (based on hospital admissions 2002-2003)

1.8 This would suggest that the most prevalent of these 13 conditions in Oxfordshire are traumatic brain injury, epilepsy and chronic fatigue syndrome/ myalgic encephalopathy.

1.9 However, in many of these conditions there will be a people who require extensive support from health services and others whose symptoms are mild to moderate and who may be able to manage their condition with medication and/or minimal support. For example:

- A recent local review of people with multiple sclerosis (Wade, 2009) estimated that each year 200 people will have a relapse that requires rehabilitation, 12-15 people will need their first specialist wheelchair assessment and 200 people will be using specialist equipment needing ongoing support
- In epilepsy, 70% of people become symptom free with treatment, suggesting that 923 (30%) of the 3,078 estimated to have epilepsy in Oxfordshire experience ongoing symptoms

[2] The Multiple Sclerosis Society has recently advised that the UK prevalence of multiple sclerosis (MS) may be higher, suggesting a figure of 163 / 100,000 which would equate to 1004 people with MS in Oxfordshire.

[3] An NHS audit is currently taking place which will provide an estimate of incidence for CFS/ME

[4] Figures supplied by the local regional care advisor for the Huntington's Disease Association suggest that this figure is too low as there are currently 122 adults with confirmed symptomatic Huntington's Disease receiving support in Oxfordshire.

- A register of the number of people between the ages of 16 and 65 who suffered head injuries between 1992 and 1995 estimated that 74 per 100,000 people would require services in Oxfordshire, most of whom would be outpatients (Wenden et al, 1998). This would equate to 456 people in Oxfordshire according to 2008 mid-year population rates
- There are several common types of cerebral palsy which are associated with different symptoms. The most severe type, spastic quadriplegia, represents about 6% of cases of cerebral palsy (Westbom et al, 2007), which would equate to about 69 cases in Oxfordshire
- An NHS website suggests that approximately one in four people with chronic fatigue syndrome / myalgic encephalopathy have severe or very severe needs in which they may require support with everyday activities or extended bed rest. This would equate to 462-616 people in Oxfordshire
- In myasthenia gravis, 90% of people become symptom free with treatment (the muscular dystrophy campaign). This would equate to 56 of the 62 people estimated to have myasthenia gravis in Oxfordshire being symptom free with treatment.

1.10 New data continues to be collected and analysed which can be used to inform the estimates for the prevalence and incidence of the different conditions.

1.11 Hospital inpatient admissions data were examined to provide some insight into the use of hospital services by people with these conditions.

Total number of hospital inpatient admissions and aggregated associated costs for specified long term neurological conditions from 2005 to August 2009

	Total number of hospital inpatient admissions*	Total aggregated associated costs (£)
Multiple sclerosis	1,943	4,653,459
Parkinson's disease	2,208	7,250,184
Motor neurone disease	277	981,059
Epilepsy	4,670	10,483,514
Acquired brain injury	685	3,046,478
Spinal cord injury	163	767,753
Cerebral palsy	672	1,726,831
Chronic fatigue syndrome / myalgic encephalopathy	65	149,958
Huntington's disease	27	78,317
Charcot-Marie-Tooth syndrome	44	128,519
Muscular dystrophy	37	63,146
Myasthenia gravis	154	413,069
Dystonia	101	217,411

*This includes all instances where the code for one of the conditions of interest is included in the diagnosis field, whether this is the primary, secondary or tertiary diagnosis

1.12 This data suggests that:

- The conditions with the highest total number of hospital inpatient admissions from 2005 to August 2009 were epilepsy (4,670), Parkinson's disease (2,208) and multiple sclerosis (1,943) (Appendix 2)
- The conditions with the highest total aggregated associated cost from 2005 to August 2009 were epilepsy (£10,483,514), Parkinson's disease (£7,250,184) and multiple sclerosis (£4,653,459) (Appendix 2).

1.13 It is however worth noting that the admissions data will include cases where a single patient has had multiple admissions.

1.14 For most conditions the total number of hospital admissions fluctuated between 2005/ 2006 and 2008/ 2009. However there has been a year on year increase in the number of hospital admissions between 2005/2006 and 2008/2009 for multiple sclerosis, Parkinson's disease and cerebral palsy (Appendix 2).

1.15 Overall, general medicine, trauma and orthopaedics and neurology are the services that are recur most often in the list of specialities used by people across these 13 specified long term neurological conditions (Appendix 3).

1.16 The specialities with the highest total number of admissions between 2005 and August 2009 for all 13 conditions are general medicine (2,344), trauma and orthopaedics (1,228), accident and emergency (966) and neurology (912).

1.17 The specialities with the highest aggregated associated cost between 2005 and August 2009 for all 13 conditions are general medicine (£6,409,952), trauma and orthopaedics (£5,094,927), rehabilitation (£3,084,219) and geriatric medicine (£2,750,473).

Discussion

1.18 The pattern of patients' needs varies considerably.

1.19 In certain conditions, such as myasthenia gravis, the primary use of resources occurs during the diagnosis and the initial treatment stages.

1.20 For others, such as Huntington's disease, the input required in the early stages will be limited but increases as the condition progresses, sometimes to the point of needing domiciliary or hospice care.

1.21 In a few cases the people affected may need a high level of care from birth.

Conclusions and recommendations

1.22 It was concluded that the availability of the high quality data that would be needed to provide a detailed and accurate estimate of peoples' service needs is limited at present.

1.23 There are a number of ways in which this work could be taken forward to better support the implementation of the NSF-LTnC, to inform the prioritisation of areas of work and to inform the rationale for concentrating on specific services or conditions. These include:

- The compilation of data relating to the use of local primary and secondary health care services that do not result in a hospital admission
- Local healthcare needs assessment of people with long term neurological conditions and their pathways of service use
- Longitudinal studies that assess the development of symptoms and health care needs over time.

2 Background

2.1 The National Service Framework for Long-term (Neurological) Conditions (NSF-LTnC) launched in 2005, to be implemented by 2015 focuses on services for people with a long-term neurological condition of working age. It aims 'to promote quality of life and independence' by ensuring that people with a long-term neurological condition 'receive co-ordinated care and support that is planned around their needs and choices'.

2.2 The NSF-LTnC seeks to transform health and social care provision across the care pathway, from symptom onset and diagnosis through acute care and rehabilitation to long-term community support and, when required, end-of-life care. The NSF-LTnC sets out 11 Quality Requirements (QRs), each supported by an aim, rationale and 'evidence-based markers of good practice', drawing upon relevant NICE and other nationally agreed guidelines.

2.3 Oxfordshire PCT has established a Long Term Conditions Board to oversee the delivery of the NSF-LTnC in Oxfordshire, together with a multi-agency Local Implementation Group (LIG) that has been tasked with developing and delivering a local implementation strategy informed by the views of all key stakeholders.

2.4 Earlier in 2009, the LIG, via Oxfordshire PCT, arranged for a health needs assessment (HNA) to be carried out to determine current and future need for services for the population of Oxfordshire with long term neurological conditions. Feedback on the draft report for this work has suggested that further work needs to be completed in order to provide a useful basis for the LIG to develop a detailed implementation plan.

2.5 Therefore, Oxfordshire PCT has approached Solutions for Public Health (SPH) to build upon the existing HNA and provide a revised report for consideration by the LIG.

3 Aims and Objectives

3.1 The aim of this report is to contribute to a revised HNA that provides an evidence-based assessment of current and future need upon which the LIG can base their implementation plan.

3.2 This report will address four questions:

- What are the key clinical features e.g. age of onset, symptoms, range of patients needs (from symptom onset and diagnosis through acute care and rehabilitation to long-term community support and, when needed, end of life care) etc.?
- How many people in Oxfordshire are likely to be living with each neurological condition (the prevalence number)? How many newly diagnosed cases will there be per annum (the incidence number)? How quickly if at all is the prevalent number of Oxfordshire cases likely to increase over the next 5-10 years?
- How many patients with each neurological condition are currently known to NHS services (based on already collected / available data)?
- What are the nationally recognised forms of treatment for patients e.g. which treatments have been endorsed by NICE, professional bodies etc.?

4 Methodology

4.1 The remit of this report was to conduct desktop- based work to address the four questions set out in the introduction section using existing data.

4.2 The information included has been drawn from a number of data sources. These include the original draft HNA report, work done by the South Central Priorities Support Unit, epidemiological data published in a similar needs assessment carried out by the North East Public Health Observatory (NEPHO) and a recent review by the Oxford Centre for Enablement, in addition to published evidence or clinical guidance.

4.3 Data on inpatient hospital admissions in Oxfordshire between the years 2005 and 2009 was also provided by Decision Support at Oxfordshire PCT.

4.4 The following long term neurological conditions are included:

- Multiple sclerosis
- Parkinson's disease
- Motor neurone disease
- Epilepsy
- Acquired brain injury[5]
- Spinal cord injury
- Cerebral palsy
- Chronic fatigue syndrome / myalgic encephalopathy
- Huntington's disease
- Charcot-Marie-Tooth-syndrome
- Muscular dystrophy
- Myasthenia gravis
- Dystonia

4.5 These 13 long-term neurological conditions included were specified by Oxfordshire PCT with reference to the conditions included in the NSF and other recent and ongoing work within the PCT.

[5] It should be noted that whilst the term 'acquired brain injury' was specified as the remit for this report, the available epidemiological data relates to 'traumatic brain injury'. An acquired brain injury is an injury caused to the brain since birth, for example, through traumatic injury, severe viral or bacterial infection, stroke, disease, tumour or aneurysm, or an event that causes a lack of oxygen to the brain. A traumatic brain injury relates to injuries acquired through falls, assaults, road traffic accidents and indstial accidents.

5 Multiple sclerosis

5.1 Unless otherwise stated this information is drawn from NHS clinical knowledge summaries, the Multiple Sclerosis Society and NICE guidance.

5.2 Multiple sclerosis (MS) is an autoimmune condition resulting from damage to the protective sheath (myelin) surrounding the nerve fibres of the central nervous system.

Age of onset

5.3 MS typically starts in early adult life and is usually diagnosed between the ages of 20 and 40. It is almost twice as common in females as in males.

Epidemiology

5.4 The prevalence and incidence of MS in the UK has been estimated at 144 per 100,000 and 4 per 100,000 respectively (Neuro Numbers, 2003; NEPHO, 2009).

5.5 This equates to an estimated prevalence number of 887 and incidence number of 25 for Oxfordshire based on 2008 mid-year population rates.

5.6 A recent study led by researchers from the London School of Hygiene and Tropical Medicine and funded by the Multiple Sclerosis Society used data from the General Practice Research Database to calculate estimates for the number of people in the UK with MS (Thomas et al, 2009). The researchers used two methods to estimate the number of individuals living with a diagnosis of MS in the UK. These resulted in a lower estimate of 88,760 and a higher estimate of 98,110 (using 2007 mid-year population rates). The Multiple Sclerosis Society has recommended that a prevalence of 163 per100, 000 should be used, which would equate to 1004 people with MS for Oxfordshire. This would be a 13% increase on the estimate of 887 people given above.

5.7 A local review by Wade & Green (2001) found that there were about 800 people with MS in Oxfordshire in 1997.

5.8 Table 2 in appendix 1 gives estimates of the prevalence and incidence numbers for MS for all nine PCTs in the South Central region.

Inpatient hospital admissions

5.9 Data supplied by Oxfordshire PCT cites the number of hospital admissions for people with MS between April 2005 and August 2009 to be 1,943.

5.10 Table 4 in appendix 2 gives the number of hospital admissions and the aggregated associated cost for each year in this period. This indicates that both have increased in the last few years with a low of 427 at £1,039,220 in 2006/2007 and a high of 470 at £1,136,995 in 2008/2009.

5.11 Table 6 in appendix 3 gives the total number of admissions by speciality and the aggregated associated costs between the years 2005 and 2009. This suggests that the specialities used most by people with MS are rehabilitation (608), neurology (353), general medicine (293) and urology (142).

Symptoms

5.12 There are a range of symptoms associated with MS although the specific difficulties experienced by different people will vary.

5.13 Fatigue is the most common symptom of MS, experienced by an estimated 75% to 95% of people (MS Matters, The MS Society, 2010). Other common issues include problems with mobility and balance, pain, muscle spasms and tightness and visual problems, numbness, bladder problems, cognitive problems, emotional and mood changes, tremor, bowel problems, sexual problems, speech difficulties and swallowing difficulties.

Diagnosis

5.14 The first symptom that 25% of people with MS experience is optic neurosis affecting their vision, usually just in one eye, and causing pain.

5.15 It can be difficult to diagnose MS due to its complexity and variety of symptoms and it is often mis-diagnosed or takes months to diagnose. In the early stages people with possible MS will be referred by their GP to a neurologist.

5.16 Over 90% of MS cases are diagnosed by an MRI scan. Other tests that the neurologist may consider include an evoked potentials test and a lumbar puncture.

Treatment

5.17 NICE guidance on the management of MS was published in November 2003 and is due for review in November 2010.

5.18 **Drug treatments** - There are a number of drug treatments which can reduce the number and severity of relapses, however, data about whether these drugs will slow down the progression of the condition is not yet available. Patients receive injections of these drugs on a regular basis (ranging from daily to monthly). Some are administered by a health professional, but others can be self-administered following training. They include:

- Beta interferons
- Glatiramer acetate
- Natalizumab

Steroids may be given following a relapse of MS, administered either orally or intravenously.

5.19 **Other treatments** - A number of physical and alternative treatments are mentioned within the NICE guidance (2003) and NHS clinical knowledge summaries. These include physiotherapy, acupuncture, homeopathy, reflexology, yoga, magnetic field therapy, neural therapy, massage, t'ai chi and multi-modal therapy. Whilst NICE concluded that there is insufficient medical evidence to demonstrate that these effectively control MS symptoms it was acknowledged that many people with MS find them beneficial and that they may promote general health and well-being.

5.20 People with MS may also receive treatments in response to the specific symptoms described above such as mobility problems, muscle spasms and swallowing difficulties which may involve surgery.

5.21 Other services such as physiotherapy and occupational therapy may be required to support rehabilitation following a relapse.

Longer term support

5.22 Life for people with MS can be unpredictable with some experiencing periods of relapse and remission, in some cases separated by long periods of time and with or without significantly worsening disability. With time (median twenty years) the majority (but not all) develop progressive disease when disability steadily and unremittingly increases. Some people experience a pattern of rapidly progressing disability.

5.23 Hirst et al conducted a 20-year study looking at change in disability in people with MS (Hirst et al, 2008). Of the 379 people that met the criteria for definite or probable MS at the 20-year stage, 221 (58%) had died and 9 (2%) were untraceable. The researchers found that of the 149 survivors, those with little disability at the start of the study typically needed some assistance with mobility at 20 years, and one third were chair or bed bound. However, they also found that one in eight people were not significantly more disabled. Using the prevalence number for Oxfordshire of 887 cited earlier, one would expect that after the next 20 years

approximately 532 (60%) would have died and of the surviving 355, 44 would not be significantly more disabled and 118 would be chair or bed bound.

5.24 A recent local review (Wade, 2009) estimated that each year in Oxfordshire approximately 200 people with MS will have a relapse that will require rehabilitation, 12-15 people will need their first specialist wheelchair assessment and 200 people will be using specialist equipment needing ongoing support.

End of life care

5.25 MS is a life-long condition. Whilst it is not terminal it can shorten life expectancy and some people may require full nursing care in the later stages.

5.26 MS was recorded as the cause of death for 59 people in Oxfordshire PCT between 2004 and 2008 (appendix 4).

6 Parkinson's disease

6.1 Unless otherwise stated this information is drawn from NHS clinical knowledge summaries, the Parkinson's disease society and related NICE guidelines.

6.2 Parkinson's disease is a progressive neuro-degenerative condition in which the dopamine producing nerve cells of the substantia nigra area of the brain are lost. Once 60-80% of these cells have been lost the co-ordination of body movements by the brain will be affected causing difficulties with, for example, the person's ability to walk, talk and write.

6.3 Parkinson's disease is the most common form of a group of conditions known as Parkinsonism.

Age of onset

6.4 The symptoms of Parkinson's disease usually appear after the age of 50 although in about 5% of cases the person will be under 40. Males are slightly more likely to be affected than females.

6.5 Juvenile Parkinson's disease, diagnosed before the age of 18, is extremely rare.

Epidemiology

6.6 The prevalence and incidence of Parkinson's disease in the UK has been estimated at 200 per 100,000 and 17 per 100,000 respectively (Neuro Numbers, 2003; NEPHO, 2009).

6.7 This equates to an estimated prevalence number of 1,231 and incidence number of 105 for Oxfordshire based on 2008 mid-year population rates.

6.8 Table 2 in appendix 1 gives estimates of prevalence and incidence numbers for Parkinson's disease for all nine PCTs in the South Central region.

Inpatient hospital admissions

6.9 Data supplied by Oxfordshire PCT cites the total number of hospital admissions for people with Parkinson's disease between April 2005 and August 2009 to be 2,208.

6.10 Table 4 in appendix 2 gives the number of hospital admissions and the aggregated associated cost for each year in this period. This indicates that both have increased year on year from 454 at £1,494,933 in 2005/2006 to 571 at £1,759,505 in 2008/2009.

6.11 Table 7 in appendix 3 gives the total number of admissions by speciality between the years 2005 and 2009. This suggests that the specialities used most by people with Parkinson's disease are general medicine (668), geriatric medicine (279), trauma and orthopaedics (212) and accident and emergency (202).

Symptoms

6.12 There are three main groups of symptoms:

- Tremor, usually beginning in the hand or arm, is the first symptom for 70% of people. The tremor tends to decrease when the part of the body affected is being used
- Bradykinesia, which causes difficulties initiating movement and makes movements slow
- Muscle stiffness which can affect the ability to perform everyday tasks.

6.13 Other non-motor symptoms associated with Parkinson's disease include fatigue, constipation, bladder weakness, depression and problems with handwriting and balance.

6.14 About 50% of people with Parkinson's disease experience speech and swallowing difficulties which would equate to approximately 616 people in Oxfordshire.

Diagnosis

6.15 At present there are no tests that can definitely prove that someone has Parkinson's disease. Instead diagnosis is based on medical history and clinical examination by a specialist.

Treatment

6.16 NICE guidelines relating to the management of Parkinson's disease in primary and secondary care were published in June 2006.

6.17 Whilst the symptoms are mild the emphasis will be on monitoring rather than treating. NICE recommends that people with suspected Parkinson's disease should be referred, untreated, to a specialist and should have regular access to specialist nursing care. NICE guidelines also recommend that the diagnosis should be reviewed every 6-12 months.

6.18 There are a number of treatment options to raise or preserve the dopamine levels in the brain and counter the more severe symptoms.

6.19 **Drug treatments** - There are a number of drug options, most of which are taken orally on a regular basis. Many of these drugs cause side effects that may in themselves require further treatment, for example, movement difficulties, nausea and vomiting and confusion or hallucinations. They include:

- Levodopa, usually taken in combination with other medications such as benserazide or carbidopa
- Dopamine agonists
- Monoamine oxidase-B inhibitors

6.20 **Surgery:**

- NICE guidance supporting the use of chronic deep brain stimulation (DBS), where a permanent electrode and pulse generator is surgically implanted to deliver continuous electrical stimulation, was published in November 2003
- NICE guidance, published in June 2004, recommended that subthalamotomy, where very fine needles are inserted into the brain under local anaesthetic, should not be performed without special arrangements for consent and for audit or research.

6.21 **Therapies**

- Physiotherapy to improvement movement and relieve muscle stiffness
- Speech therapy to address communication and swallowing difficulties
- Occupational therapy to assist with modifications in the home and to daily life.

6.22 **Multidisciplinary care** – NICE guidance (2006) suggests that the care of people at each stage of Parkinson's disease is best undertaken in a multidisciplinary way. There is also some evidence to support the use of multidisciplinary rehabilitation for Parkinson's disease (Gage & Storey, 2004).

Longer term support

6.23 The development and progression of the symptoms of Parkinson's disease are usually slow and it can take years to reach the point where the symptoms cause major problems.

6.24 The nature and severity of the symptoms experienced by different individuals do however vary.

End of life care

6.25 Parkinson's disease is not terminal and most people will have a normal life expectancy.

6.26 Parkinson's disease was recorded as the cause of death for 243 people in Oxfordshire PCT between 2004 and 2008 (appendix 4).

7 Motor neurone disease

7.1 Unless otherwise stated this information is drawn from NHS clinical knowledge summaries, the motor neurone disease society and NICE guidelines.

7.2 Motor neurone disease (MND) is a group of disorders in which progressive degeneration of the motor system causes muscle weakness and wasting.

Age of onset

7.3 MND is more common in males with a ratio of 3:2 males to females. It usually occurs between the age of 50 and 70.

Epidemiology

7.4 The prevalence and incidence of MND in the UK has been estimated at 7 per 100,000 and 2 per 100,000 respectively (Neuro Numbers, 2003; NEPHO, 2009).

7.5 This equates to an estimated prevalence number of 43 and incidence number of 12 for Oxfordshire based on 2008 mid-year population rates.

7.6 Table 2 in appendix 1 gives estimates of prevalence and incidence numbers for MND for all nine PCTs in the South Central region.

Inpatient hospital admissions

7.7 Data supplied by Oxfordshire PCT cites the total number of hospital admissions for people with MND between April 2005 and August 2009 to be 277.

7.8 Table 4 in appendix 2 gives the number of hospital admissions and the aggregated associated cost for each year in this period. This indicates that both have fluctuated slightly year on year with a high of 70 at £325,553 in 2005/2006 and a low of 61at £179,329 in 2006/2007.

7.9 Table 8 in appendix 3 gives the total number of admissions by speciality between the years 2005 and 2009. This suggests that the specialities used most by people with MND are neurology (74), general medicine (48) and palliative medicine (40).

Symptoms

7.10 Symptoms usually begin in the arms and legs and tend to be mild at first. Difficulties experienced can include muscle twitching, fatigue, muscle jerking when resting and problems with waking and holding objects.

7.11 Some people experience problems with the muscles of the face and throat leading to difficulties with speech, swallowing and breathing.

7.12 There are four main types of MND:

- Amyotrophic lateral sclerosis (ALS) is characterised by weakness and wasting of the limbs. ALS accounts for about 70% of cases of MND which equates to an estimate of 30 people with ALS in Oxfordshire
- Progressive bulbar palsy (PBP) accounts for approximately 25% of cases of MND which equates to an estimated 11 people with PBP in Oxfordshire. Symptoms may include difficulties with speech and swallowing
- Progressive muscular atrophy (PMA) accounts for about 5% of cases of MND which equates to an estimated 2 people with PMA in Oxfordshire. PMA sometimes progresses more slowly and symptoms usually start in the hands.
- Primary lateral sclerosis (PLS) accounts for about 0. 5% of cases of MND which would suggest that there may be one or less people with PLS in Oxfordshire. Some people may experience difficulties with their hands or speech problems.

Diagnosis

7.13 A person with suspected MND will be referred to a neurologist who may perform an MRI scan, blood tests and an eletromyogram (EMG).

7.14 Other possible tests include a nerve conduction test and transcranial magnetic stimulation (TMS). As yet there is not test that can definitely confirm MND.

Treatment

7.15 **Drug treatments**

- Rilutek has been recommended by NICE (2001) for people with ALS
- Vitamin E is sometimes taken to slow the progression of the condition

7.16 **Surgery** - Surgery may be required for severe symptoms including percutaneous gastrostomy to enable feeding and tracheostomy, with or without ventilator support to aid breathing.

7.17 **Other services** - As MND progresses people will need support from a wide range of services:

- Physiotherapy to improvement movement and relieve muscle stiffness
- Speech therapy to address communication and swallowing difficulties
- Occupational therapy to assist with modifications to the home and solutions to difficulties with everyday tasks
- District nurse support
- Assessment by a dietician
- Mobility and respiratory aids
- Palliative care services.

Longer term support

7.18 MND usually progresses steadily but the rate of progression varies considerably between individuals.

7.19 The level of services required will increase with time.[6]

End of life care

7.20 The survival time with MND varies from two to ten years, depending on the part of the body first affected.

7.21 For ALS life expectancy is between two and five years and for PBP life expectancy is between six months and three years. Most people with PMA live for more than five years and people with PLS may have a normal life span if their symptoms do not progress. Some people with MND have survived for more than 20 years.

7.22 In the latter stages of the condition someone with MND may be completely immobile and the breathing muscles will eventually be affected. Domiciliary or hospice care will be required.

7.23 MND was recorded as the cause of death for 110 people in Oxfordshire PCT between 2004 and 2008 (appendix 4).

[6] The Motor Neurone Disease Association has produced a 'year of care' document outlining the needs and costs of people with MND during the course of the disease. This is available from http://www.mndassociation.org/for_professionals/sharing_good_practice/mnd_year_of_care.html

8 Epilepsy

8.1 Unless otherwise stated this information is drawn from NHS clinical knowledge summaries, epilepsy action, the national society for epilepsy and NICE guidelines.

8.2 Epilepsy is a symptom connected to a range of other conditions in which a sudden burst of excess electricity in the brain causes a fit or seizure. Idiopathic (primary) epilepsy is likely to have a genetic cause and symptomatic epilepsy is related to a known cause, such as some long term neurological conditions, head injuries, infectious conditions, problems during birth and drug and alcohol abuse.

Age of onset

8.3 Epilepsy can begin at any age and affects both males and females. It is most often diagnosed before the age of 18 or after the age of 65.

8.4 Many people who develop epilepsy before the age of 20 are not affected as an adult.

Epidemiology

8.5 The prevalence and incidence of epilepsy in the UK has been estimated at 500 per 100,000 and 80 per 100,000 respectively (Neuro Numbers, 2003; NEPHO, 2009).

8.6 This equates to an estimated prevalence number of 3,078 and incidence number of 493 for Oxfordshire based on 2008 mid-year population rates.

8.7 Table 2 in appendix 1 gives estimates of prevalence and incidence numbers for epilepsy for all nine PCTs in the South Central region.

Inpatient hospital admissions

8.8 Data supplied by Oxfordshire PCT cites the number of hospital admissions for people with epilepsy between April 2005 and August 2009 to be 4,670.

8.9 Table 4 in appendix 2 gives the number of hospital admissions and the aggregated associated cost for each year in this period. This indicates that both fluctuated year on year with a high of 1117at £2,597,379 in 2008/2009 and a low of 965 at 2,189,323 in 2007/2008.

8.10 Table 9 in appendix 3 gives the total number of admissions by speciality between the years 2005 and 2009. This suggests that the specialities used most by people with epilepsy are general medicine (1102), accident and emergency (586), paediatrics (524), trauma and orthopaedics (395) and geriatric medicine (345).

Symptoms

8.11 The severity of seizures varies between individuals from a trance-like state lasting a few seconds or minutes to loss of consciousness and convulsions.

8.12 About 20% of seizures are partial seizures in which only a small part of the brain is affected. The symptoms can include sensory changes, emotional changes, muscle stiffness, twitching and small random body movements.

8.13 About 60% of seizures are convulsive with symptoms including loss of consciousness and twitching arms and legs lasting between one and three minutes.

Diagnosis

8.14 Epilepsy is not the only cause of seizures so diagnosis can be difficult.

8.15 A person who has experienced a seizure will see a specialist, usually a neurologist, who will take a detailed history and may conduct an EEG or MRI scan.

8.16 NICE guidelines (2007) recommend that children and adults with epilepsy should be reviewed at least once a year by their GP or specialist.

Treatment

8.17 Full NICE guidance on the management of epilepsy in adults and children was published in October 2007 with an update due in November 2010.

8.18 **Drug treatments** - There are a range of anti-epileptic drugs (AED) that are taken orally on a daily basis. These can be prescribed individually or, in cases where this has been unsuccessful, in combination. Additional NICE guidance for the use of newer AEDs for adults and children was published in 2004.

8.19 **Surgical interventions**:

- Vagus nerve stimulation, in which a small electrical device is surgically implanted, can reduce the frequency and severity of seizures. NICE guidance published in 2004 also supported its use in children.
- In cases where epilepsy remains poorly controlled surgery to remove an affected area of the brain may be performed. About 1% of people experience a stroke following this type of surgery and 5% experience memory deterioration.

Longer term support

8.20 With treatment about 70% of people with epilepsy become symptom free. This would suggest that 923 (30%) of the 3,078 people estimated to have epilepsy in Oxfordshire experience ongoing symptoms.

8.21 Epilepsy is one of the conditions listed for which there may be an increased risk of complications in pregnancy (NICE, 2007).

End of life care

8.22 Epilepsy is not however normally fatal although physical injury can occur during a seizure.

8.23 There are rare cases of sudden unexpected death in people with epilepsy (SUDEP) and the NICE guidelines (2004) concluded that 39% of adult deaths and 59% of children's deaths could have been avoidable with better access to care or better drug management.

8.24 Epilepsy was recorded as the cause of death for 59 people in Oxfordshire PCT between 2004 and 2008 (appendix 4).

9 Acquired brain injury

Age of onset

9.1 Unless otherwise stated this information is drawn from NHS clinical knowledge summaries, about brain injury, Headway and NICE guidelines.

9.2 An acquired brain injury (ABI) is an injury caused to the brain after birth. There are a number of means by which someone can acquire a long term brain injury including traumatic injury, severe viral or bacterial infection, stroke, disease, tumour or aneurysm or an event that causes a lack of oxygen to the brain.

9.3 Traumatic brain injury relates to injuries acquired through falls, assaults, road traffic accidents and industrial accidents. The prevalence data cited in this report relates to traumatic brain injury and therefore does not include injuries caused by illness or disease.

9.4 Both acquired and traumatic brain injury can affect anyone at any age.

Epidemiology

9.5 The prevalence and incidence of traumatic brain injury in the UK has been estimated at 1,200 per 100,000 and 175 per 100,000 respectively (NWP, 2008; NEPHO, 2009).

9.6 This equates to an estimated prevalence number of 7,387 and incidence number of 1,077 for Oxfordshire based on 2008 mid-year population rates.

9.7 Table 2 in appendix 1 gives estimated prevalence and incidence numbers for traumatic brain injury for all nine PCTs in the South Central region.

9.8 A register of people between the ages of 16 and 65 who suffered head injuries kept between 1992 and 1995 gave a figure of 74 per100, 000 for those who would need services in Oxfordshire, most of whom would be out-patients (Wenden et al, 1998). This would equate to 456 people in the age range 16-65 according to 2008 mid-year population rates, although this does not include children under 16 with head injury.

Inpatient hospital admissions

9.9 Data supplied by Oxfordshire PCT cites the number of hospital admissions for people with ABI between April 2005 and August 2009 to be 685.[7]

9.10 Table 4 in appendix 2 gives the number of hospital admissions and the aggregated associated cost for each year in this period. This indicates that the number of admissions fluctuated slightly year on year with a high of 171 in 2007/2008 and a low of 146 in 2005/2006. The aggregated associated costs also fluctuated with a high of £819,121 in 2007/2008 and a low of £575,383 in 2008/2009.

9.11 Table 10 in appendix 3 gives the total number of admissions by speciality between the years 2005 and 2009. This suggests that the specialities used most by people with ABI are, trauma and orthopaedics (214), accident and emergency (109), neurology (106) and general medicine (90).

Symptoms

9.12 The symptoms experienced will depend on the region of the brain affected and the severity of the injury and can be mild, moderate or severe.

9.13 The effects can be cognitive, emotional, behavioural and physical and might include: sensory loss or alteration; problems with movement or balance; problems with speech or communication; seizures; prolonged or severe headache; nausea; changes in mood, personality or behaviour; problems with memory and/ or concentration; problems with planning or initiating actions and fatigue or drowsiness.

[7] It should be noted that the definition of acquired brain injury includes conditions such as stroke and subarachnoid haemorrhage which may account for a high proportion of the cases recorded.

9.14 In the most severe cases the individual may enter a coma or a vegetative state where they will require assistance with key bodily functions.

Diagnosis

9.15 Tests to confirm and explore the extent of a brain injury include a CT scan and an EEG. The circumstances and timeframes within which a CT scan should be conducted are set out in the relevant NICE guidelines. At present an MRI is not recommended by NICE as a primary investigation tool.

9.16 Observation and a range of medical, cognitive and behavioural tests, such as the Glasgow Coma Scale, will also play a key part in the diagnosis.

Treatment

9.17 An update of the 2003 NICE guidance relating to the triage, assessment, investigation and early management of head injury in infants, children and adults was published in November 2007. Separate guidance on the diagnosis and management of stroke were published in July 2008 and of brain tumours in June 2006.

9.18 The initial injury, infection or event leading to the acquisition of a long term brain injury may require a hospital admission with the most severe cases requiring intensive care. The level of care and range of drugs and therapies required will vary according to the cause and severity.

9.19 **Drug treatments** – These could include:

- Anti-convulsants
- Corticosteroids
- Antiviral or antibiotic drugs

9.20 **Surgical treatments** - Surgery may be appropriate in some cases, for example for the removal of brain tumour or the treatment of an aneurysm or an intracerebral haemorrhage.

9.21 **Rehabilitation** - A wide range of specialties may be involved in rehabilitating an individual with long term problems following a brain injury. These might include:

- Neurology
- Rehabilitation specialists
- Physiotherapy to assist with movement difficulties
- Speech therapy to assist with communication problems
- Occupational therapy to advise on any necessary adjustments to daily living
- Psychology to assess and advise on behavioural and cognitive issues.

Longer term support

9.22 The longer term support required will vary according to the location of the injury and the severity of an individual's need. At one end of the spectrum will be people who require very little ongoing support once the initial cause has been treated and any adjustments required to their daily life have been made. At the other end there may be people who require full time residential or hospital care.

9.23 The prognosis will also vary between individual cases with some people's condition remaining stable, some degenerating, for example if ongoing seizures cause further damage, and some potentially improving.

End of life care

9.24 A severe brain injury can be fatal.

9.25 Figures on the number of recorded instances of ABI as the cause of death were not supplied.

10 Spinal cord injury

10.1 Unless otherwise stated this information is drawn from spinal-injury.net, spinal cord injury.co.uk and NICE guidance.

10.2 Spinal cord injury is related to damage to the spinal cord which results in loss of function or feeling. There are a number of potential causes, the most common being trauma or disease

Age of onset

10.3 A spinal cord injury could occur at any age and affects both males and females. It is however more prevalent in younger males aged 15-35 who have been involved in sporting or vehicle accidents.

Epidemiology

10.4 The prevalence and incidence of spinal cord injury in the UK has been estimated at 50 per 100,000 and 2 per 100,000 respectively (Neuro Numbers, 2003; NWP, 2008).

10.5 This equates to an estimated prevalence number of 308 and incidence number of 12 for Oxfordshire based on 2008 mid-year population rates.

10.6 Table 2 in appendix 1 gives estimates of prevalence and incidence numbers for spinal cord injury for all nine PCTs in the South Central region.

Inpatient hospital admissions

10.7 Data supplied by Oxfordshire PCT cites the number of hospital admissions for people with spinal cord injury between April 2005 and August 2009 to be 163.

10.8 Table 4 in appendix 2 gives the number of hospital admissions and the aggregated associated cost for each year in this period. This indicates that the number of admissions fluctuates slightly year on year with a high of 41 in 2006/2007 and a low of 33 in 2008/2009. The aggregated associated cost also fluctuated with a high of £243,310 in 2007/2008 and a low of £77,348 in 2008/2009.

10.9 Table 11 in appendix 3 gives the total number of admissions by speciality between the years 2005 and 2009. This suggests that the specialities used most by people with spinal cord injury are neurology (71), trauma and orthopaedics (29) and urology (27).

Symptoms

10.10 Spinal cord injuries can be complete, where there is no function below the level of the injury, or incomplete, where there is partial function or feeling below the level of the injury.

10.11 The areas of the body affected are typically divided into two categories:

- In paraplegia there is complete or partial paralysis to the legs and possibly the trunk of the body
- In tetraplegia there is complete or partial paralysis to both the arms and legs.

10.12 The loss of function and sensation following spinal cord injury can have several affects: mobility problems, sometimes requiring the long-term use of mobility aids; impaired breathing; bladder and bowel dysfunction; sexual dysfunction; fertility problems, especially in males; reduced control over blood pressure and body temperature; chronic pain; problems with skin management and pressure sores.

Treatment

10.13 NICE has not produced full guidance relating to spinal cord injury. Spinal cord injury is however encompassed within some wider guidance, for example relating to chronic respiratory failure (2009), cervical spine stabilisation (2005) and faecal incontinence (2004 & 2008).

10.14 People with a spinal cord injury may need extensive specialist hospital care, potentially lasting months after the initial injury. Individual needs will vary during the different phases of their treatment from diagnosis and assessment through to rehabilitation.

10.15 **Diagnosis and assessment:**

- Specialist medical and nursing care
- A range of x-rays and scans
- Steroids to reduce inflammation.

10.16 **Stabilization** - Some people with a spinal cord injury may have to remain immobile for a period of time, potentially months. They may require:

- Specialist medical and nursing care
- Surgical internal or external fixation of the affected bones. NICE (2005) recommends the use of a direct C1 lateral mass screw for cervical spine stabilisation
- Traction to maintain immobilisation
- Physiotherapy to reduce muscle wasting and stiffness.

10.17 **Rehabilitation**- NICE guidance on critical illness rehabilitation was published in March 2009.

- Physiotherapy, including a range of mobility aids
- Respiratory problems - Nice (2009) recommends the use of intramuscular diaphragm stimulation for ventilator-dependent chronic respiratory failure due to neurological disease, including spinal cord injury.
- Specialist equipment for ongoing problems with bladder and bowel dysfunction. NICE recommends sacral nerve stimulation (2004) and transabdominal artificial bowel sphincter implantation (2008) for faecal incontinence in appropriate cases
- Occupational therapy to advise on adjustments to the home and to daily life
- Speech and language therapy if there are difficulties with oral or written communication

10.18 Most people will continue their rehabilitation once they have been discharged from hospital and people with spinal cord injuries do sometimes continue to improve for years after the initial injury.

Longer term support

10.19 Damage to the spinal cord and the effects are usually permanent. The level of disability experienced by individuals will vary according to the location and severity of the damage.

10.20 Individuals with both paraplegia and tetraplegia will require long-term assistance with mobility, in some cases involving the use of either a manual or an electric wheelchair. There may also be a need for ongoing physiotherapy or ongoing assistance with breathing.

End of life care

10.21 Spinal cord injuries can be fatal and can also adversely affect someone's life expectancy.

10.22 Figures on the number of recorded instances of spinal cord injury as the cause of death were not supplied.

11 Cerebral palsy

11.1 Unless otherwise stated this information is drawn from NHS clinical knowledge summaries, SCOPE, and NICE guidance.

11.2 Cerebral palsy describes a set of neurological conditions that affect the brain and nervous system, causing difficulties with movement, posture and co-ordination.

Age of onset

11.3 Cerebral palsy is caused by damage to the brain which normally occurs before, during or soon after birth.

11.4 The symptoms usually become apparent by the age of three.

Epidemiology

11.5 The prevalence of cerebral palsy in the UK has been estimated at 186 per 100,000 (Neuro Numbers, 2003; NWP, 2008).

11.6 This equates to an estimated prevalence number of 1,145 for Oxfordshire based on 2008 mid-year population rates. The UK incidence is unknown.

11.7 Table 3 in appendix 1 gives prevalence number estimates for cerebral palsy for all nine PCTs in the South Central region.

Inpatient hospital admissions

11.8 Data supplied by Oxfordshire PCT cites the number of hospital admissions for people with cerebral palsy between April 2005 and August 2009 to be 672.

11.9 Table 4 in appendix 2 gives the number of hospital admissions and the aggregated associated cost for each year in this period. This indicates that the number of admissions has risen year on year from 135 in 2005/2006 to 183 in 2008/2009. The aggregated associated cost has fluctuated with a high of £490,481 in 2008/2009 and a low of £336,816 in 2006/2007.

11.10 Table 12 in appendix 3 gives the total number of admissions by speciality between the years 2005 and 2009. This suggests that the specialities used most by people with cerebral palsy are trauma and orthopaedics (248), paediatrics (143) and general medicine (48).

Symptoms

11.11 People with cerebral palsy may have problems with muscle tone, causing either hypertonia, where increased muscle tone causes stiffness or rigidness, or hypotonia, where decreased muscle tone causes floppiness. People with cerebral palsy may also experience mild to severe learning difficulties.

11.12 There are several common types of cerebral palsy which are associated with different symptoms. Information on the percentages of the different types of cerebral palsy was taken from a Swedish population study (Westbom et al, 2007).

11.13 Spastic cerebral palsy is associated with muscle stiffness and a decreased range of joint motion.

- In spastic hemiplegeia one side of the body is affected with associated problems including scoliosis, speech difficulties and epileptic seizures. This form represents approximately 30% of cases of cerebral palsy, equating to about 344 cases in Oxfordshire
- In spastic diplegia the legs are affected which may necessitate the use of walking aids such as leg braces or a walking frame. This form represents approximately 38% of cases of cerebral palsy, equating to about 435 cases in Oxfordshire

- Spastic quadriplegia is the most severe type of cerebral palsy. Problems include stiffness in both the arms and legs, potentially affecting the ability to walk, weak neck muscles, speech difficulties, moderate to severe learning difficulties and frequent epileptic seizures. This form represents approximately 6% of cases of cerebral palsy, equating to about 69 cases in Oxfordshire.

11.14 Athetoid or dyskinetic cerebral palsy is associated with both hypertonia and hypotonia leading to frequent, uncontrolled body movements and difficulties maintaining body posture. There can also be problems controlling the tongue and vocal cords causing eating difficulties and drooling. Hearing problems are also common. This form represents approximately 17% of cases of cerebral palsy, equating to about 195 cases in Oxfordshire.

11.15 Ataxic cerebral palsy is associated with problems with balance, spatial awareness and depth perception, causing problems in precise motor movements, unsteadiness when walking and potentially irregular speech. This form represents approximately 11% of cases of cerebral palsy, equating to about 126 cases in Oxfordshire.

Diagnosis

11.16 Children with suspected cerebral palsy will be assessed by a paediatrician. The tests that may be done include blood tests, cranial ultrasound, MRI and CT scan.

Treatment

11.17 **Physical therapy** - This usually starts soon after diagnosis and can help prevent the weakening of muscles that are not normally being used and to prevent contracture where the muscles become fixed in a rigid position.

11.18 **Speech therapy** - Some communication difficulties can be helped by exercises whilst other people with cerebral palsy may need to learn an alternative means of communication, such as sign language. In some cases specialist equipment such as a voice synthesizer may be needed.

11.19 Some people with cerebral palsy may also need assistance with swallowing difficulties.

11.20 **Drug treatments** - A range of drugs may be used to relieve muscular symptoms:

- Muscle relaxants, usually taken in tablet form
- Botulinum toxin injections, which last for up to three months
- Intrathecal baclofen therapy in which a surgically implanted pump delivers regular doses directly into the nervous system
- Anticholinergic drugs can reduce the production of saliva in people with athetoid or dyskinetic cerebral palsy.

11.21 **Surgical treatments**- Surgery may be considered to address specific severe symptoms, for example:

- Orthapaedic surgery to lengthen problematic muscles and tendons
- Selective dorsal rhizotomy (SDR) is considered when other treatments for muscle stiffness have failed and involves the removal of selected nerves in the spinal column. NICE guidance published in November 2006 supported the use of this procedure but noted its limited efficacy.
- Surgery to redirect the saliva gland.

11.22 **Other services** - Someone with cerebral palsy may also require support from a range of services:

- An occupational therapist to advise on modifications to their home and day-to-day activities
- Specialist mobility equipment such as orthotic devices or wheelchairs

- Specialist advisors to assist with problems such as incontinence and drooling
- An educational psychologist to assess intellectual development.

Longer term support

11.23 It is possible for someone with cerebral palsy to have very mild symptoms, however others may require assistance in many, or all, areas of their life. In Westbom et al's study (2007), 66% of four to eleven year olds with cerebral palsy were able to walk independently.

11.24 Cerebral palsy is a persistent but not a progressive condition however it can put considerable strain on the body that can lead to later problems, such as fatigue, muscle weakness, pain, arthritis and repetitive strain injury once the person reaches adulthood.

End of life care

11.25 Cerebral palsy was recorded as the cause of death for 7 people in Oxfordshire PCT between 2004 and 2008 (appendix 4).

12 Chronic fatigue syndrome / myalgic encephalopathy

12.1 Unless otherwise stated this information is drawn from NHS clinical knowledge summaries, www.investinme.org, www.hfme.org, www.chronicfatiguesyndrome.me.uk, Support ME and NICE guidance.

12.2 Chronic fatigue syndrome (CFS) and Myalgic encephalomyelitis (ME) are both terms used to describe a condition which includes long-term fatigue impacting on a person's everyday life. The formation CFS/ ME was used in the full guidance issued by NICE in August 2007 and will also be used in this report.

12.3 Whilst no underlying neurological disease has been identified for CFS/ ME, neurological rehabilitation services can inform the management of severe CFS/ ME.

Age of onset

12.4 CFS/ ME affects both males and females of all ages although it is more common in females. In adults it usually develops between the early 20s and mid 40s. In children it usually occurs between the ages of 13 and 15.

Epidemiology

12.5 The prevalence of CFS/ ME in the UK has been estimated at 300-400 per 100,000 (Neuro Numbers, 2003; NSF, 2005). The prevalence of CFS/ME in children and young people has been estimated at 50-100 / 100,000 (Royal College of Paediatrics and Child Health, 2004).

12.6 This equates to an estimated prevalence number of 1,847 – 2,462 for Oxfordshire based on 2008 mid-year population rates. The prevalence for children and young people cited above would suggest that 308-616 of these will be under the age of 18. The UK incidence is unknown[8]. Table 3 in appendix 1 gives prevalence number estimates for CFS/ ME for all nine PCTs in the South Central region.

Inpatient hospital admissions

12.7 Data supplied by Oxfordshire PCT cites the number of hospital admissions for people with CFS between April 2005 and August 2009 to be 65.

12.8 Table 4 in appendix 2 gives the number of hospital admissions and the aggregated associated cost for each year in this period. This indicates that the number of admissions has fluctuated year on year with a high of 20 in 2007/2008 and a low of 12 in 2006/2007. The aggregated associated cost has also fluctuated with a high of £42,827 in 2005/2006 and a low of £16,927 in 2006/2007.

12.9 Table 13 in appendix 3 gives the total number of admissions by speciality between the years 2005 and 2009. This suggests that the specialities used most by people with CFS are general medicine (12) and trauma and orthopaedics (9).

Symptoms

12.10 The most common, and main symptom for people with CFS/ ME is persistent or recurring fatigue and exhaustion which is not relieved by rest and affects a person's everyday life. Increased activity usually results in loss of physical and mental stamina with a slow recovery period, usually of 24 hours or longer.

[8] An NHS audit is currently taking place which will provide an estimate of incidence for CFS/ME

12.11 Other symptoms include: pain, affecting the muscles, joints, stomach, head, lymph nodes and throat; cognitive difficulties affecting short-term memory, concentration and the ability to organise and express thoughts; sleeping difficulties; sensitivity to light, sound and heat/ cold, intolerance of alcohol and certain foods; difficulties with balance and controlling body temperature and psychological difficulties, such as depression, irritability and panic attacks.

12.12 CFS /ME can affect people to varying degrees and symptoms may vary from day to day. People with CFS/ ME are often divided into groups reflecting the severity of their symptoms:

- In mild CFS/ ME they are usually able to manage the condition within their daily life but may need additional time to rest
- In moderate CFS/ ME they will have reduced mobility and variable symptoms
- In severe CFS/ ME they will be able to manage simple daily tasks but they may require a wheelchair and experience difficulties with concentration
- In very severe CFS/ ME they are unable to carry out daily tasks and may require bed rest for the majority of the day.

12.13 It has been estimated that up to one in four people have severe or very severe needs (NHS clinical knowledge summaries), which would equate to 462 -616 people in Oxfordshire.

Diagnosis

12.14 NICE published full guidance on the diagnosis and management in adults and children with CFS /ME in August 2007. These are due for revision in 2010. The Canadian Consensus Criteria (Carruthers, 2003) for the diagnosis of CFS/ME are increasingly being used in the UK.

12.15 There is no diagnostic test for CFS/ ME however people may have blood tests or scans to rule out other causes for the symptoms. CFS/ME will usually be diagnosed by a GP on the basis of medical history and symptoms that persist, without another cause, for six months or more.

12.16 There are several biochemical and biological tests developed in recent years, for example mitochondrial function (Myhill, 2009), which can select people with CFS/ME once other conditions have been ruled out.

12.17 NICE (2007) recommended that children and young people should be referred to a paediatrician for confirmation of the diagnosis. An international group has adapted the Canadian Consensus diagnostic criteria to children and young people (Jason, 2008).

Treatment

12.18 At present there is limited evidence about which treatments are the most beneficial for CFS/ME. Treatments for more severe cases of CFS/ ME mainly focus on minimising the symptoms.

12.19 **Advice** - Some people will be able to manage the symptoms themselves with appropriate adjustments to their lifestyle, for example, pacing the distribution of periods of activity and rest and adopting a regular sleep pattern. Dietary supplements are also sometimes recommended.

12.20 **Therapies:**

- Cognitive behavioural therapy (CBT) to address the causes of different behaviours
- Graded exercise therapy (GET) to gradually increase levels of aerobic activity.

NICE (2007) recommend that CBT and GET should only be used as an option for people with mild to moderate symptoms. However a recent study has concluded that neither should be used to treat patients with CFS/ME (Twisk & Maes, 2009).

Some people with CFS/ ME also find complementary therapies such as acupuncture, reflexology, homeopathy and massage can promote general health and wellbeing but their benefit has not yet been evidenced by research.

12.21 **Drug treatments:**

- Antidepressants
- Over-the-counter painkillers, possibly with short-term use of prescribed painkillers.

12.22 It has been estimated that approximately half of all people with CFS/ ME will require specialist care consisting of confirmation of the diagnosis and the development of a person-centred treatment plan with the option of CBT or GET (NICE, 2007). For Oxfordshire this would equate to an estimated 924 -1231 people requiring some form of specialist care.

Longer term support

12.23 The prognosis for functional recovery is good, but decreases the longer the condition progresses, stressing the need for prompt and accurate diagnosis.

12.24 For many people the symptoms of CFS/ ME improve over time and others are often able to make the adjustments needed to successfully manage their condition.

12.25 People with severe or very severe CFS/ ME may require ongoing support with their mobility and with many aspects of their daily life.

End of life care

12.26 CFS/ ME is not a life-threatening condition but can be a more serious illness than is generally recognised.

12.27 Figures on the number of recorded instances of CFS/ ME as the cause of death were not supplied.

13 Huntington's disease

13.1 Unless otherwise stated this information is drawn from NHS clinical knowledge summaries, the Huntington's disease association and 'a physician's guide to the management of Huntington's disease (Rosenblatt et al, 2009).

13.2 Huntington's disease (HD) is a hereditary neurological disease in which damage to the nerve cells in the brain causes the deterioration and gradual loss of brain function affecting movement, cognition and behaviour.

Epidemiology

13.3 The prevalence of HD in the UK has been estimated at 13.5 per 100,000 (Neuro Numbers, 2003; NEPHO, 2009).

13.4 This equates to an estimated prevalence number of 83 for Oxfordshire based on 2008 mid-year population rates. The UK incidence is unknown.

13.5 Figures on the numbers of adults and children with symptomatic HD, or at risk of developing HD were supplied by the local regional care advisor from the Huntington's Disease Association. These indicate that in December 2009 there were 122 adults with symptomatic (confirmed) HD, 138 adults at risk of HD, 146 children at risk of HD and 146 carers of people with HD in Oxfordshire. These figures only include the individuals and families who have been referred to and reviewed by the regional care advisor so probably underestimate the number of people with or at risk from HD.

13.6 The local figure of 122 known adults with HD is a 47% increase on the estimated figure of 83 people with HD in Oxfordshire cited above.

13.7 Table 3 in appendix 1 gives prevalence number estimates for HD for all nine PCTs in the South Central region.

Inpatient hospital admissions

13.8 Data supplied by Oxfordshire PCT cites the number of hospital admissions for people with HD between April 2005 and August 2009 to be 27.

13.9 Table 4 in appendix 2 gives the number of hospital admissions and the aggregated associated cost for each year in this period. This indicates that the number of admissions has fluctuated slightly year on year with a high of 8 in 2008/2009 and a low of <5 in 2007/2008. The aggregated associated cost has also fluctuated with a high of £36,270 in 2006/2007 and a low of £7,075 in 2007/2008.

13.10 Table 14 in appendix 3 gives the total number of admissions by speciality between the years 2005 and 2009. This suggests that the speciality used most by people with HD is rehabilitation (12).

Age of onset

13.11 HD affects men and women and the symptoms usually start to appear between the ages of 30 and 50 but can show earlier. The symptoms of HD steadily worsen and the average survival time from diagnosis is 15-20 years, although some have lived for 30-40 years.

13.12 Juvenile HD is more severe and represents about 10% of HD cases, which would equate to eight cases in Oxfordshire. It usually develops before the age of 20 and progresses more rapidly with average survival less than 15 years.

Symptoms

13.13 Behavioural changes are often the first symptoms to emerge and can include mood swings, bizarre behaviour, short-term memory lapses and problems with orientation, concentration

and planning and organisation. People with HD may suffer from mental health problems such as depression, obsessive compulsive disorder, mania and schizophrenia.

13.14 Early symptoms affecting movement include uncontrollable movements of the face and eyes or jerky movements of the body and limbs. The frequency and severity of these movements increase as the condition progresses.

13.15 Impaired breathing can cause problems with speech and associated problems with cognition can make it difficult for people with HD to make themselves understood.

13.16 People with HD can experience difficulties with eating and swallowing which can result in them being underweight and therefore vulnerable to associated difficulties such as increased infections, illness, muscle wasting and slower wound healing.

13.17 About 30% of those with juvenile-onset HD experience epileptic seizures. This would suggest that two of the eight estimated cases for Oxfordshire might experience seizures.

Diagnosis

13.18 Genetic testing can confirm the diagnosis of HD if it is known to be within an individual's family.

13.19 In the latter stages of HD, MRI or CT scans can identify which areas of the brain are affected.

Treatment

13.20 There is no current NICE guidance on HD.

13.21 **Drug treatments** - There are some drugs that can help with the mood and movement symptoms experienced by people with HD.

- Antidepressants
- Tetrabenzine

13.22 **Therapies:**

- Speech therapy can help with communication skills, memory and breathing and swallowing difficulties
- An occupational therapist may be needed to advise on adaptations to the home
- A physiotherapist may be able to help with mobility, balance, musculoskeletal or cardiopulmonary problems.
- Mobility aids such as a wheelchair may be needed as the condition progresses
- Psychiatry, psychology and counselling services may be required to help with mental health issues.

13.23 **Other services**:

- People with HD may see a dietician to help to maintain their weight
- As HD is an inherited condition, genetic counselling will be required

Longer term support

13.24 People in the early stages of HD are usually able to continue with their lives with minor symptoms. In the middle stage they will need some assistance with almost all areas of their life from eating to managing their finances. In the advanced stages they may be bedridden and unable to communicate.

End of life care

13.25 In the latter stages a person with HD will need full nursing care.

13.26 Death usually results from a secondary cause, for example, heart failure or infections such as pneumonia.

13.27 HD was recorded as the cause of death for less than five people in Oxfordshire PCT between 2004 and 2008 (appendix 4).

14 Charcot-Marie-Tooth syndrome

14.1 Unless otherwise stated this information is drawn from NHS clinical knowledge summaries, the muscular dystrophy campaign and CMT UK.

14.2 Charcot-Marie-Tooth syndrome (CMT) is sometimes referred to as hereditary motor and sensory neuropathy or peroneal muscular atrophy. It relates to a set of inherited conditions that cause damage to the periphery nerves which control the muscles and relay sensory information between limbs and the brain. The most commonly affected muscles are those below the knees and in the hands.

Age of onset

14.3 People with CMT can start experiencing symptoms at any time although they usually begin during adolescence or in early adulthood. It affects both males and females.

Epidemiology

14.4 The prevalence of CMT in the UK has been estimated at 40 per 100,000 (Neuro Numbers, 2003; NEPHO, 2009).

14.5 This equates to an estimated prevalence number of 246 for Oxfordshire based on 2008 mid-year population rates. The UK incidence is unknown.

14.6 Table 3 in appendix 1 gives prevalence number estimates for CMT for all nine PCTs in the South Central region.

Inpatient hospital admissions

14.7 Data supplied by Oxfordshire PCT cites the number of hospital admissions for people with CMT between April 2005 and August 2009 to be 44.

14.8 Table 4 in appendix 2 gives the number of hospital admissions and the aggregated associated cost for each year in this period. This indicates that both the number of admissions and associated aggregated costs has fluctuated year on year with a high of 20 at £63,418 in 2008/2009 and a low of <5 at £8,907 in 2007/2008.

14.9 Table 15 in appendix 3 gives the total number of admissions by speciality between the years 2005 and 2009. This suggests that the specialities used most by people with CMT are trauma and orthopaedics (19) and neurology (11).

Symptoms

14.10 People with CMT experience motor symptoms, such as muscle weakness, an awkward gait and curled toes, and sensory symptoms such as numbness or pain.

14.11 Nerve damage can lead to deformities of the limbs, such as flat feet, high arches or less usually a twisted spine (scoliosis).

14.12 CMT is a progressive condition and the hands and forearms typically become more affected as the condition progresses.

14.13 There are rare complex cases where CMT is combined with other issues such as deafness, visual problems, problems with speech and swallowing and breathing difficulties.

Diagnosis

14.14 People with suspected CMT will be referred to a neurologist. The tests typically used to diagnose CMT include a nerve conduction test, an electromyography, a nerve biopsy and the genetic testing of a blood sample.

14.15 Children and teenagers with CMT may see a neurologist annually to monitor the progression of the condition.

Treatment

14.16 There is no current NICE guidance on CMT.

14.17 **Physical therapies** - People with CMT may see a physiotherapist to address muscle weaknesses and slow the progression of the condition.

14.18 **Support** - People with CMT may require mobility aids such as corrective shoes or leg splints. They may also see an occupational therapist for advice on the use of adaptive tools to compensate for muscle weakness in the arms or hands. As CMT is an inherited condition, genetic counselling will be required.

14.19 **Drug treatments:**

- Non-steroidal anti-inflammatory drugs for joint and muscle pain
- Tricyclic antidepressents for neuropathic pain
- Bronchodilator drugs for breathing difficulties. In very severe cases a ventilator may be required.

14.20 **Surgery** - Some people with CMT may have surgery for very highly arched feet or curled toes. Surgery may also be considered in the rare cases where scoliosis is very severe.

Longer term support

14.21 The severity of the symptoms experienced can vary considerably between individuals.

14.22 In some cases gait-correcting shoes will be sufficient whilst others will need leg braces or in the most severe, but rare, cases a wheelchair.

14.23 The severity of the symptoms often does not change after the person has stopped growing although mobility problems for people with CMT can be more of an issue for older people.

End of life care

14.24 CMT is a life-long condition but is not terminal. It is not thought to affect life expectancy.

14.25 CMT was recorded as the cause of death for less than five people in Oxfordshire PCT between 2004 and 2008 (appendix 4).

15 Muscular dystrophy

15.1 Unless otherwise stated this information is drawn from NHS clinical knowledge summaries, www.patient.co.uk and the muscular dystrophy campaign.

15.2 Muscular dystrophy includes over 20 types of genetic disorder caused by mutations in the genes responsible for the structure and functioning of the muscles. The muscular dystrophy campaign highlights eight of the more common types of muscular dystrophy and these same eight will be covered in more detail in this report.

15.3 People with muscular dystrophy experience progressive muscle wasting results in increasing weakness and disability.

Epidemiology

15.4 The prevalence of muscular dystrophy in the UK has been estimated at 50 per 100,000 (Neuro Numbers, 2003; NEPHO, 2009).

15.5 This equates to an estimated prevalence number of 308 for Oxfordshire based on 2008 mid-year population rates. The UK incidence is unknown.

15.6 Table 3 in appendix 1 gives prevalence number estimates for muscular dystrophy for all nine PCTs in the South Central region.

Inpatient hospital admissions

15.7 Data supplied by Oxfordshire PCT cites the number of hospital admissions for people with muscular dystrophy between April 2005 and August 2009 to be 37.

15.8 Table 4 in appendix 2 gives the number of hospital admissions and the aggregated associated cost for each year in this period. This indicates that the number of admissions has remained fairly stable during this period at 9 or 10 per year. The aggregated associated cost has fluctuated with a high of £18,232 in 2006/2007 and a low of £11,818 in 2005/2006.

15.9 Table 16 in appendix 3 gives the total number of admissions by speciality between the years 2005 and 2009. This suggests that the specialities used most by people with muscular dystrophy are trauma and orthopaedics (8), paediatrics (7) and general medicine (6).

Age of onset and symptoms

15.10 Duchenne muscular dystrophy (DMD) affects males with extremely rare exceptions. The symptoms usually emerge between the ages of 1 and 3 and the child will usually require a wheelchair by the time they are 11. Other symptoms associated with DMD include joint contractures, skeletal deformities such as lordosis or scoliosis, osteoporosis, obesity, respiratory problems, cardiomyopathy and heart failure or arrhythmias. Learning disabilities have been observed in one third of cases.

15.11 Becker muscular dystrophy (BMD) affects males with extremely rare exceptions. BMD is a milder form of DMD and the symptoms are not usually apparent until after the age of 10. People with BMD generally have difficulties with walking after the age of 16 and lose the ability to walk between the ages of 40 and 60, although this occasionally occurs much earlier between the ages of 20 and 30. Muscles in the shoulders, upper arms and heart may also be affected.

15.12 Limb-girdle muscular dystrophy (LGMD) affects both males and females. The symptoms of LGMD usually start in late childhood or early adulthood and initially affect the muscles around the hip and shoulder girdle, progressing to a fairly severe level of disability within 20-30 years. People with LGMD may also experience low back pain, health palpitations or cardiac arrhythmias.

15.13 Facioscapulphumeral muscular dystrophy (FSH) affects both males and females, although the symptoms tend to be more severe and progress more rapidly in males. FSH usually develops

between the ages of 10 and 40 and affects the muscles of the face, shoulder and upper arms. The muscles of the legs and lower trunk are sometimes affected and the condition usually progresses slowly. Epilepsy and learning difficulties have also been observed in some cases of early-childhood onset FSH.

15.14 Myotonic dystrophy (MyD) affects both males and females. MyD is the most common form of muscular dystrophy in adults although it can appear at any age from birth to old age. In MyD the smaller muscles such as the face, jaw, neck, hands and feet are affected rather than the larger muscle groups in the legs. Other symptoms that people with MyD can experience include cataracts, irregular heart rhythms, hormonal problems, swallowing difficulties, bowel problems and excessive daytime sleepiness. Behavioural problems and learning disabilities have also been observed in some children. The progression of MyD is usually very slow.

15.15 Oculopharyngeal muscular dystrophy (OPMD) affects both males and females. OPMD usually occurs between the ages of 50 and 60 and affects the muscles of the eyes and throat leading to droopy eyelids and difficulties swallowing. The progression of these symptoms is usually very slow.

15.16 Emery-Dreifuss muscular dystrophy (EDMD) affects both males and females and starts in childhood or adolescence. The muscles of the shoulders, arms and lower leg are affected. Some people with EDMD also experience a slow heart rate which can cause tiredness, giddiness or fainting which may require a heart pacemaker. There may also be a risk of sudden death due to cardiac arrhythmia.

15.17 Congenital muscular dystrophy (CMD) is a rare form of muscular dystrophy which causes muscle weakness and contractures of the joints which become apparent within the first six months of life. Some cases of CMD do not progress any further with the child's muscle strength improving over time and the lifespan being unaffected. In other cases the symptoms are more severe and progressive and the child can also experience seizures, learning difficulties and breathing problems.

15.18 Estimates for the prevalence for DMD, BMD and LGMD were cited in Mazur & Muntoni (2009) as 29, 6 and 7 in 100,000 respectively. For Oxfordshire this would equate to an estimated 179 cases of DMD, 37 cases of BMD and 43 cases of LGMD.

Diagnosis

15.19 Muscular dystrophy can be confirmed by a blood test, usually followed by a muscle biopsy. An electromyography (EMG) test is also sometimes used.

15.20 Evidence of abnormal heart activity may be investigated by an ultrasound and an electrocardiogram.

Treatment

15.21 There is no current NICE guidance on muscular dystrophy.

15.22 **Monitoring** - Children with DMD are monitored by a physiotherapist to assess the development of mobility problems and the functioning of the heart and breathing muscles will be monitored as the condition progresses.

15.23 **Physical therapies** - Exercise and physiotherapy can help maintain muscle strength and flexibility and prevent stiff joints.

15.24 **Surgery** - Surgery is usually reserved for more severe cases or symptoms. This can relate to postural deformities, for example to address scoliosis; the fitting of a pacemaker for people with MyD suffering from an irregular heart rhythm; or the surgical elevation of the eyelids for people with OPMD. People with OPMD who experience swallowing difficulties may have a cricopharyngeal myotomy (cutting of the internal throat muscles) or a gastrostomy to provide an alternative means of feeding.

15.25 **Other support:**

- A speech therapist for advice on mild swallowing difficulties
- Occupational therapy for adaptations to the home and help with daily activities
- Genetic counselling
- Mobility aids such as orthotic devices or wheelchair services.

Longer term support

15.26 Muscular dystrophy is a progressive disease, however the level of disability experienced varies considerably between the different forms of the condition and some people will not need extensive medical help in the early stages.

15.27 For example, the muscular dystrophy campaign suggests that 10-20% of people with FSH will eventually need a wheelchair, whilst 33% may not be aware of any symptoms until they have reached old age.

End of life care

15.28 People with some forms of muscular dystrophy usually live a normal lifespan, for example BMD and FSH.

15.29 For DMD the condition may become severe enough in their late teens or early twenties to affect their life expectancy.

15.30 Muscular dystrophy was recorded as the cause of death for less than five people in Oxfordshire PCT between 2004 and 2008 (appendix 4).

16 Myasthenia gravis

16.1 Unless otherwise stated this information is drawn from NHS clinical knowledge summaries, the muscular dystrophy campaign and the myasthenia gravis association.

16.2 Myasthenia gravis in an autoimmune disease which causes weakness in voluntarily controlled muscles.

Age of onset

16.3 Myasthenia gravis can develop at any age but is most common in females under the age of 40 and males over the age of 60.

Epidemiology

16.4 The prevalence of myasthenia gravis in the UK has been estimated at 10 per 100,000 (Myasthenia Gravis Association, 2004).

16.5 This equates to an estimated prevalence number of 62 for Oxfordshire based on 2008 mid-year population rates. The UK incidence is unknown.

16.6 Table 3 in appendix 1 gives prevalence number estimates for myasthenia gravis for all nine PCTs in the South Central region.

Inpatient hospital admissions

16.7 Data supplied by Oxfordshire PCT cites the number of hospital admissions for people with myasthenia gravis between April 2005 and August 2009 to be 154.

16.8 Table 4 in appendix 2 gives the number of hospital admissions and the aggregated associated cost for each year in this period. This indicates that both the number of admissions and associated cost has fluctuated year on year with a high of 52 at £114,669 in 2008/2009 and a low of 21 at £52,995 in 2007/2008.

16.9 Table 17 in appendix 3 gives the total number of admissions by speciality between the years 2005 and 2009. This suggests that the specialities used most by people with myasthenia gravis are neurology (41), general medicine (30) and cardiology (15).

Symptoms

16.10 In about 10% of cases (an estimated 6 people in Oxfordshire) the only muscles affected are those that control eye and eyelid movement.

16.11 In the other 90% of cases (an estimated 56 people in Oxfordshire) the symptoms are more generalised affecting both the eyes and the muscles involved with facial expression, chewing, swallowing and speech and in the arms and legs. Occasionally muscles involved in breathing may be affected which may necessitate urgent medical attention

Diagnosis

16.12 Myasthenia gravis is usually diagnosed from its symptoms by a neurologist, but tests which can confirm the diagnosis include a blood test, an electromyogram (EMG) or injection of the drug edrophonium.

16.13 10% of cases of myasthenia gravis are associated with a tumour of the thymus so a chest CT scan may also be done.

Treatment

16.14 There is no current NICE guidance on myasthenia gravis. Rest may be sufficient to relieve the symptoms of people with mild myasthenia gravis, however a range of drug and surgical options are available.

16.15 **Drug treatments** - There are a number of drugs, which if taken orally on a regular ongoing basis, can reduce or relieve the symptoms of myasthenia gravis. These include:

- Cholinesterase inhibitors
- Steroids
- Immunosuppressants

16.16 **Surgical treatments:**

- Removal of the thymus gland (thymectomy) in people with early-onset myasthenia gravis who do not have a thymoma has been found to improve the symptoms for more than 70% of people. For about 30% of people the symptoms disappear altogether
- People with a thymoma will also need a thymectomy, however in these cases an improvement in the symptoms of the myasthenia gravis is rare.

16.17 **Other treatments** - Two treatments are available for people who experience severe, life-threatening breathing or swallowing problems:

- Plasmaphoresis
- Intravenous immunoglobulin therapy

Both of these treatments can produce a rapid improvement in the symptoms however the benefits only last for a few weeks.

Longer term support

16.18 The symptoms of myasthenia gravis are usually mild at first but may get progressively worse, reaching their most severe level within a year. In some cases the progression may be more rapid.

16.19 The level of symptoms experienced can vary considerably and may increase with activity, stress or infection. However, with treatment most people with myasthenia gravis are able to live a normal or fairly normal life with few symptoms.

16.20 The muscular dystrophy campaign states that 90% of people with myasthenia gravis become symptom free with treatment. This would equate to 56 of the 62 people estimated to have myasthenia gravis in Oxfordshire being symptom free with treatment.

16.21 Myasthenia gravis is one of the conditions listed for which there may be an increased risk of complications in pregnancy (NICE, 2007) or associated with some drugs, e.g. yellow fever vaccinations (NaTHNaC, 2004).

End of life care

16.22 Myasthenia gravis is a life-long condition but is not terminal.

16.23 Myasthenia gravis was recorded as the cause of death for less than five people in Oxfordshire PCT between 2004 and 2008 (appendix 4).

17 Dystonia

17.1 Unless otherwise stated this information is drawn from NHS clinical knowledge summaries, the dystonia society, NHS choices and NICE guidance.

17.2 Dystonia is a common neurological movement disorder characterised by sustained involuntary and uncontrollable muscle spasms in which affected parts of the body can be forced into abnormal and sometimes painful movements or postures.

Age of onset

17.3 The symptoms of adult onset dystonia most commonly appear in adults between 40-60 years of age and tend to be located in a specific part of the body.

17.4 Early-onset dystonia in children most commonly emerges between the ages of 5 and 16 and is often more generalised.

Epidemiology

17.5 The prevalence of Dystonia in the UK has been estimated at 65 per 100,000 (Neuro Numbers, 2003; NEPHO, 2009).

17.6 This equates to an estimated prevalence number of 400 for Oxfordshire. The UK incidence for dystonia is unknown.

17.7 Table 3 in appendix 1 gives estimates of prevalence numbers for dystonia for all nine PCTs in the South Central region.

Inpatient hospital admissions

17.8 Data supplied by Oxfordshire PCT cites the number of hospital admissions for people with Dystonia between April 2005 and August 2009 to be 101.

17.9 Table 4 in appendix 2 gives the number of hospital admissions and the aggregated associated cost for each year in this period. This indicates that both the number of admissions and aggregated associated cost fluctuated year on year with a high of 29 at £74,776 in 2007/2008 and a low of 12 at £26,724 in 2005/2006.

17.10 Table 18 in appendix 3 gives the total number of admissions by speciality between the years 2005 and 2009. This suggests that the specialities used most by people with dystonia are neurology (26), general medicine (17) and trauma and orthopaedics (12).

Symptoms

17.11 The types of dystonia which usually affect adults include cervical dystonia (neck muscles), blepharospasm (eye muscles), oromandibular (muscles in the face, jaw or tongue) and laryngeal dystonia (vocal cord muscles).

17.12 In early-onset dystonia the leg muscles are usually affected but it can spread to other areas of the body.

Diagnosis

17.13 Dystonia is usually diagnosed according to the symptoms and medical history firstly with a GP and then with a neurologist.

Treatment

17.14 NICE guidance relating to cervical dystonia was published in August 2004 and on the use of deep brain stimulation in August 2006.

17.15 **Drug Treatments** - Adult focal dystonias are most commonly treated with injections of botulinum toxin, usually repeated every three months. This treatment is of limited value in the generalised dystonia in young people. Oral drug treatments include:

- Dopaminergic Drugs - typically prescribed to children or young adults.
- Anticholinergic drugs - for early-onset and more severe cases
- Benzodiazepines, GABA Agonists
- Baclofen, Tizanidine, GABA Agonist – for some patients with focal dystonias
- Antidopaminergic drugs - for more severe cases.
- Anti-convulsant drugs - for the treatment of the rare condition paroxysmal dystonia

17.16 **Surgical treatments** - Surgical interventions are generally reserved to people that fail to respond to drug treatments. Options include:

- Deep Brain Stimulation (DBS) where a permanent electrode and pulse generator is surgically implanted to deliver continuous electrical stimulation. NICE guidance recommends the use of DBS for dystonia however it was also noted that further information on the long-term effects on people undergoing surgery at a young age would be useful
- Selective peripheral denervation, where selective peripheral nerves leading to problematic muscles are cut. NICE guidance on cervical dystonia noted that there was good long term follow up, but that almost all patients suffered some sensory loss.

17.17 **Physical therapies**- There is some evidence that physical and relaxation therapies can benefit some people with dystonia. Many existing studies however relate specifically to people with cervical dystonia and one recent review concluded that further investigation is required (Zetterberg et al., 2008).

17.18 People with dystonia may also need to see a specialist associated with the affected muscle. For example, someone with a blepharospasm may need to see an ophthalmologist.

17.19 Treatments for secondary dystonias associated with brain injuries are similar to those for early-onset dystonia.

Longer term support

17.20 Many people with dystonia are able to control or at least reduce the severity of their symptoms with treatment and many continue with their employment and daily responsibilities. It can however restrict everyday activities such as driving. Dystonia is considered a difficult condition to treat.

End of life care

17.21 Dystonia is a life-long condition but it is not terminal.

17.22 Dystonia was recorded as the cause of death for less than five people in Oxfordshire between the years 2004 and 2008 (appendix 4).

18 Discussion

18.1 This report addresses four questions in relation to 13 specified long-term neurological conditions using existing sources of data.

18.2 There were a number of complicating factors that affected the quantity and quality of the information available and these should be taken into consideration when drawing any conclusions.

18.3 Many of the 13 specified conditions are complex with different sub-types associated with different conditions and also wide variations in the needs of different people, and in the needs of individuals over time. In some conditions the main use of resources is likely to be in the early stages of diagnosis and establishing a treatment regime after which the condition may remain stable or in remission for some time. The typical pattern of other conditions involves the development of new and/or worsening symptoms over periods of time that may encompass a few years or a lifetime.

18.4 The complexity of the conditions will often necessitate a multidisciplinary co-ordinated approach to treatment and care.

18.5 Another complication relates to variations in the definitions of what is encompassed within certain conditions. For example, information concerning head injuries can specifically relate to traumatic injury, for example arising from an accident, or can more broadly relate to any acquired brain injury including those arising through illness or disease.

18.6 The examination of hospital inpatient admissions data provides some insight into the use of hospital services by people with these conditions. This data suggests that:

- The conditions with the highest total number of hospital inpatient admissions from 2005 to August 2009 were epilepsy (4,670), Parkinson's disease (2,208) and multiple sclerosis (1,943) (Appendix 2)
- The conditions with the highest total aggregated associated cost from 2005 to August 2009 were epilepsy (£10,483,514), Parkinson's disease (£7,250,184) and multiple sclerosis (£4,653,459) (Appendix 2)
- For most conditions the total number of hospital admissions fluctuated between 2005/ 2006 and 2008/ 2009. However there has been a year on year increase in the number of hospital admissions between 2005/2006 and 2008/2009 for multiple sclerosis, Parkinson's disease and cerebral palsy (Appendix 2)
- Overall, general medicine, trauma and orthopaedics and neurology are the services that are recur most often in the list of specialities used by people across these 13 specified long term neurological conditions (Appendix 3)
- The specialities with the highest total number of admissions between 2005 and August 2009 for all 13 conditions are general medicine (2,344), trauma and orthopaedics (1,228), accident and emergency (966) and neurology (912) (Appendix 3)
- The specialities with the highest aggregated associated cost between 2005 and August 2009 for all 13 conditions are general medicine (£6,409,952), trauma and orthopaedics (£5,094,927), rehabilitation (£3,084,219) and geriatric medicine (£2,750,473) (Appendix 3)

18.7 It should be noted that the insight into the use of services provided by the hospital admissions service is dependent on providers accurately coding their activity. The data provided also includes all instances where the code for one of the conditions of interest is included in the diagnosis field, whether this is the primary, secondary or tertiary diagnosis. The hospital admissions data will also include cases where a single patient has had multiple admissions.

18.8 Additionally, many of the admissions to trauma and orthopaedics for each of the conditions may relate to falls. Likewise admissions to accident and emergency may relate to falls or to a breakdown in the situation at home.

18.9 Information on the use of services outside of hospital admissions was not readily available.

18.10 An additional consideration in cases of long term illness is the strain that living with such a condition and its symptoms can put an individual and their family. This may result in an additional need for support with depression and anxiety for both the individual with the condition and / or their carers and family.

18.11 Where estimates of the number of people that may be diagnosed with a particular condition or experience a particular symptom have been made these are themselves based on estimates within the published literature or from societies that advocate for each of the conditions. In some cases the estimates from different sources vary widely, for example 1 in 20,000 to 1 in 50,000, and the basis for these estimates was not always provided or clear.

18.12 We were able to find a limited amount of data that focused on the progression of a condition over time and gave some indications about what the needs of different people with the condition might be. However in some cases this information was taken from the websites of charities relating to each of the conditions and the source and evidence base for the information was not always clear. When published studies were found that presented this kind of longitudinal data the sample sizes were usually quite small and related to the patients from a small number of hospitals. There is a need for more of these longitudinal studies in order to provide a basis for calculating what the needs of people might be in the different stages of their condition.

18.13 Population projection forecasts for Oxfordshire (Oxfordshire County Council, 2009) suggest a population rise of 8.3% between 2006 and 2016. Estimates of what such an increase would mean for each of the 13 conditions are provided in the table below.

	Prevalence number	
	2008	**2016**
Oxfordshire Population (thousands)	**616**	**668**
Multiple sclerosis	887	962[9]
Parkinson's disease	1,231	1,336
Motor neurone disease	43	47
Epilepsy	3,078	3,340
Traumatic brain injury	7,387	8,016
Spinal cord injury	308	334
Cerebral palsy	1,145	1,242
Chronic fatigue syndrome / myalgic encephalopathy	1,847-2,462	2,004 – 2,672
Huntington's disease	83	90
Charcot-Marie-Tooth syndrome	246	267
Muscular dystrophy	308	334
Myasthenia gravis	62	67
Dystonia	400	434

[9] At the higher rate of 163 per100,000 the figure would be 1089

19 Conclusions and recommendations

19.1 At present the data that would be required to produce evidence-based conclusions about the service needs of different individuals with these conditions is limited. This therefore impacts on the number and accuracy of the estimates that can be made about people's service needs.

19.2 There are a number of ways in which this work could be taken forward to better support the implementation of the NSF-LTnC, to inform the prioritisation of areas of work and to inform the rationale for concentrating on specific services or conditions. These include:

- The compilation of data relating to the use of local primary and secondary health care services that do not result in a hospital admission. For example, a recent study on multiple sclerosis in the UK found that inpatient costs only accounted for about one third of the costs in the category 'inpatient use and contacts with professionals' (McCrone et al, 2008)
- Local healthcare needs assessment of people with long term neurological conditions and their pathways of service use
- Longitudinal studies that assess the development of symptoms and health care needs of individuals with these conditions over time.

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- Deep brain stimulation for tremor and dystonia. (excluding Parkinson's disease. (Guidance IPG188, August 2006)
- Direct C1 lateral mass screw for cervical spine stabilisation. (Guidance IPG146, December 2005)
- Epilepsy (adults) – newer drugs. (Guidance TA76, March 2004)
- Epilepsy (children) – newer drugs. (Guidance TA79, April 2004
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- Head injury: triage, assessment, investigation and early management of head injury in infants, children and adults. (Full guideline CG56, November 2007)
- Improving outcomes for people with brain and other CNS tumours – the manual. (N1047, June 2006)
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21 Appendix 1:

Table 1: UK incidence and prevalence rates for specified long-term neurological conditions

	UK incidence (per 100,000)	UK prevalence (per 100,000)	Source
Multiple sclerosis	4	144[10]	Neuro Numbers (2003); NEPHO (2009)
Parkinson's disease	17	200	Neuro Numbers (2003); NEPHO (2009)
Motor neurone disease	2	7	Neuro Numbers (2003); NEPHO (2009)
Epilepsy	80	500	Neuro Numbers (2003); NEPHO (2009)
Traumatic brain injury	175[a]	1,200[b]	National Workforce Projects (2008); NEPHO (2009)
Spinal cord injury	2	50	Neuro Numbers (2003); National Workforce Projects (2008)
Cerebral palsy	Unknown	186	Neuro Numbers (2003); National Workforce Projects (2008)
Chronic fatigue syndrome / myalgic encephalopathy	Unknown[11]	300-400	Neuro Numbers (2003); NSF (2005)
Huntington's disease	Unknown	13.5	Neuro Numbers (2003); NEPHO (2009)
Charcot-Marie-Tooth syndrome	Unknown	40	Neuro Numbers (2003); NEPHO (2009)
Muscular dystrophy	Unknown	50	Neuro Numbers (2003); NEPHO (2009)
Myasthenia gravis	Unknown	10	Myasthenia Gravis Association (2004)
Dystonia	Unknown	65	Neuro Numbers (2003); NEPHO (2009)

[a] leading to hospital admissions
[b] with long term problems (based on hospital admissions 2002-2003)

[10] A study funded by the The Multiple Sclerosis Society has recently advised that the UK prevalence of multiple sclerosis (MS) may be higher, suggesting a figure of 163 / 100,000.

[11] An NHS audit is currently taking place which will provide an estimate of incidence for CFS/ME

Table 2: Estimates of incidence and prevalence numbers for specified long-term neurological conditions for South Central

	Population (all ages)[bc]	Multiple sclerosis		Parkinson's disease		Motor neurone disease		Epilepsy		Traumatic brain injury		Spinal cord injury	
		Incidence Number	Prevalence Number	Incidence Number	Prevalence Number	Incidence Number	Prevalence Number	Incidence Number	Prevalence Number	Incidence Number	Prevalence Number	Incidence Number	Prevalence Number
England	51,446	2,058	74,083	87,46	102,892	1,029	3,601	41,157	257,231	90,031	617,354	1,029	25,723
South Central	4,062	163	5,850	691	8,125	81	284	3,250	20,312	7,109	48,748	81	2,031
Berkshire East	391	16	563	66	781	8	27	313	1,954	684	4,688	8	195
Berkshire West	458	18	659[12]	78	915	9	36	366	2,289	801	5,492	9	229
Buckinghamshire	507	20	730	86	1,014	10	36	406	2,535	887	6,083	10	254
Hampshire	1,286	51	1,852	219	2,572	26	90	1,029	6,430	2,250	15,431	26	643
Isle of Wight NHS	142	6	204	24	283	3	10	113	708	248	1,698	3	71
Milton Keynes	238	10	342	40	475	5	17	190	1,189	416	2,852	5	119
Oxfordshire	**616**	**25**	**887[13]**	**105**	**1,231**	**12**	**43**	**493**	**3,078**	**1,077**	**7,387**	**12**	**308**
Portsmouth City Teaching	200	8	288	34	400	4	14	160	1,000	350	2,400	4	100
Southampton City	235	9	338	40	469	5	16	188	1,173	411	2,815	5	117

[b]2008 mid year population estimates (thousands)
[c]Rounded numbers (figures may not add due to rounding)

[12] Feedback from the MS society states that Berkshire West local data gives aprevalence number of 900

[13] A prevalence rate of 163 / 100,000 would equate to 1004 people with MS in Oxfordshire.

Table 3: Estimates of prevalence numbers for specified long-term neurological conditions for South Central

	Population (all ages)[bc]	Cerebral palsy	Chronic fatigue syndrome/myalgic encephalopathy	Huntington's disease	Charcot-Marie-Tooth syndrome	Muscular dystrophy	Myasthenia gravis	Dystonia
England	51,446	95,6890	154,339 – 205,785	6,945	20,579	25,723	5,145	33,440
South Central	4,062	7,556	12,187 – 16,249	548	1,625	2,031	406	2,641
Berkshire East	391	727	1,172 – 1,563	53	156	195	39	254
Berkshire West	458	851	1,373 – 1,831	62	183	229	46	298
Buckinghamshire	507	943	1,521 – 2,2028	68	203	254	51	330
Hampshire	1,286	2,392	3,858 – 5,144	174	514	643	129	836
Isle of Wight NHS	142	263	425 – 566	19	57	71	14	92
Milton Keynes	238	442	713 – 951	32	95	119	24	155
Oxfordshire	**616**	**1,145**	**1,847 – 2,462**	**83**[14]	**246**	**308**	**62**	**400**
Portsmouth City Teaching	200	372	600 – 800	27	80	100	20	130
Southampton City	235	436	704 – 938	32	94	117	24	153

[b]2008 mid year population estimates (thousands)

[c]Rounded numbers (figures may not add due to rounding)

[14] Figures supplied by the local regional care advisor for the Huntington's Disease Association suggest that this figure is too low as there are currently 122 adults with confirmed symptomatic Huntington's Disease receiving support in Oxfordshire.

22 Appendix 2:

Table 4: Hospital inpatient admissions of people diagnosed with specified long term neurological conditions in Oxfordshire PCT 2005 – 2009

Condition	Number of admissions						Aggregated associated cost (£)					
	2005/2006	2006/2007	2007/2008	2008/2009	2009/2010[a]	Grand Total	2005/2006	2006/2007	2007/2008	2008/2009	2009/2010[a]	Grand Total
Multiple Sclerosis	432	427	443	470	171	**1,943**	941,882	1,039,220	1,122,507	1,136,995	412,856	**4,653,459**
Parkinson's Disease	454	470	489	571	224	**2,208**	1,494,933	1,615,219	1,682,883	1,759,505	697,644	**7,250,184**
Motor Neurone Disease	70	61	68	65	13	**277**	325,553	179,329	230,360	209,825	35,991	**981,059**
Epilepsy	1,083	970	965	1,117	535	**4,670**	2,297,024	2,235,454	2,189,323	2,597,379	1,164,334	**10,483,514**
Acquired Brain Injury	146	147	171	155	66	**685**	608,586	800,140	819,121	575,383	243,249	**3,046,478**
Spinal Cord Injury	38	41	37	33	14	**163**	193,700	230,632	243,310	77,348	22,762	**767,753**
Cerebral Palsy	135	140	156	183	58	**672**	364,786	336,816	382,608	490,481	152,140	**1,726,831**
Chronic Fatigue Syndrome	13	12	20	14	6	**65**	42,827	16,927	39,117	39,285	11,801	**149,958**
Huntington's Disease	7	7	<5	8	5	**27**	14,174	36,270	7,075	11,309	9,489	**78,317**
Charcot Marie Tooth Syndrome	13	11	<5	20	<5	**44**	22,461	27,550	8,907	63,418	6,183	**128,519**
Muscular Dystrophy	10	9	9	9	<5	**37**	11,818	18,232	16,118	15,994	985	**63,146**
Myasthenia Gravis	39	25	21	52	17	**154**	108,116	72,516	52,995	114,669	64,773	**413,069**
Dystonia	12	27	29	19	14	**101**	26,724	53,196	74,776	38,981	23,734	**217,411**
Grand Total	**2,452**	**2,347**	**2,408**	**2,716**	**1,123**	**11,046**	**6,452,584**	**6,661,501**	**6,869,099**	**7,130,572**	**2,845,941**	**29,959,697**

[a]The data under this column is for only the first 5 months of the financial year (i.e. from April to August 2009). Source: SUS - U_Reporting (Extracted on 08/10/2009).

Figure 1: Hospital inpatient admissions of people diagnosed with specified long term neurological conditions in Oxfordshire PCT 2005 – 2009

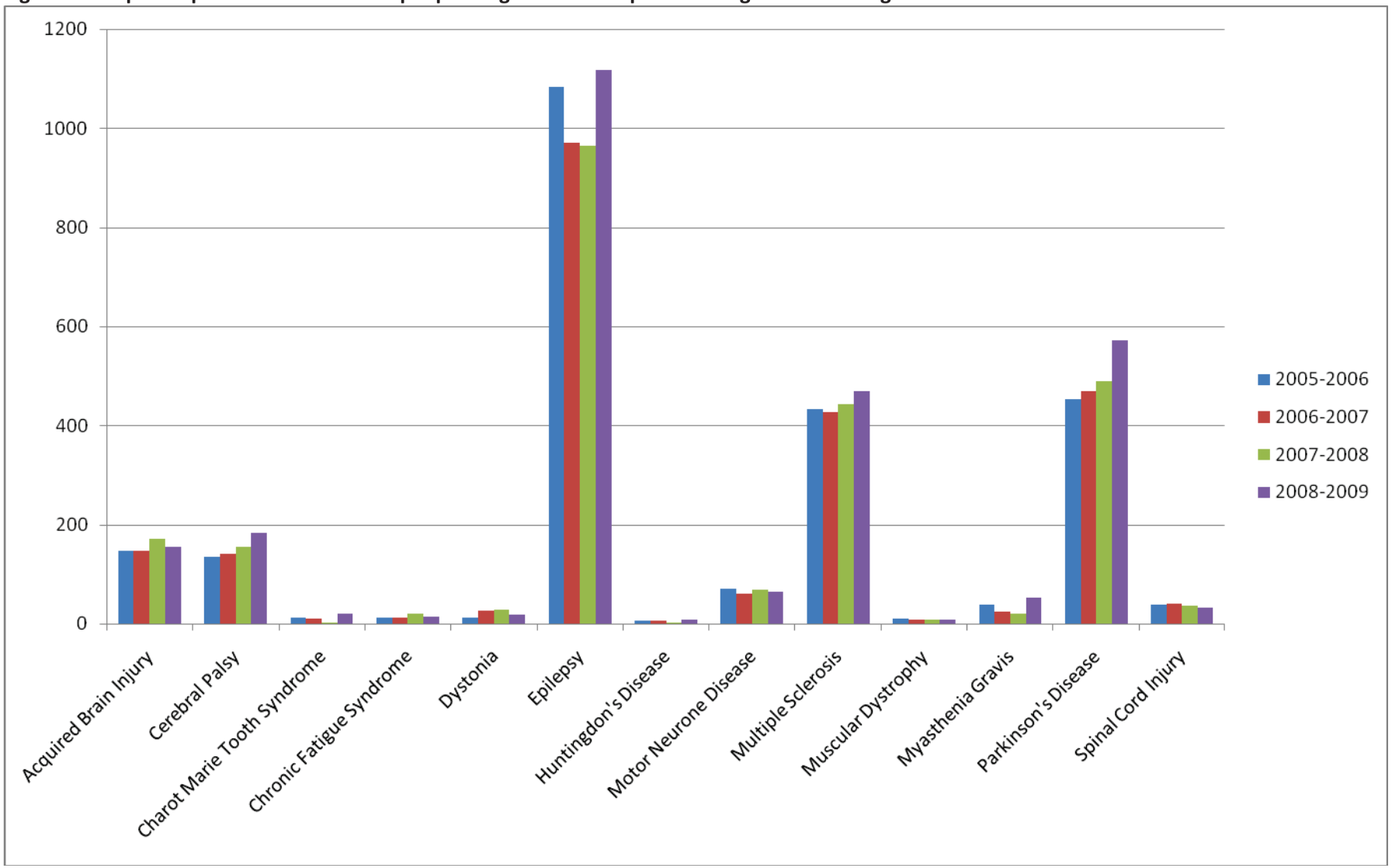

Table 5: Total hospital inpatient admissions and aggregated associated cost by speciality of people diagnosed with specified long term neurological conditions in Oxfordshire PCT 2005 – 2009

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
Accident & Emergency	966[a]	1,397,399
Allied Health Professional Episode	9[b]	29,943
Anaesthetics	37[c]	139,048
Cardiology	163[d]	355,342
Cardiothoracic Surgery	6[e]	67,547
Clinical Haematology	34[f]	55,911
Clinical Oncology (previously Radiotherapy)	15[g]	36,435
Clinical Pharmacology	34[h]	113,487
Clinical Physiology	13[i]	76,674
Community Medicine	<5	5,552
Critical Care Medicine	6	11,759
Dermatology	22[j]	17,369
Endocrinology	74[k]	143,308
ENT	32[l]	90,143
Gastroenterology	140[m]	330,588
General Medical Practice	118[n]	538,766
General Medicine	2,344[o]	6,409,952
General Surgery	473[p]	1,192,412
Geriatric Medicine	794[q]	2,750,473
Gynaecology	55[r]	122,073
Haematology	22[s]	91,553
Infectious Diseases	204[t]	587,919
Medical Microbiology	<5	2,693
Medical Oncology	5[u]	34,522
Midwife Episode	<12	10,994
Nephrology	84[v]	177,970
Neurology	912[w]	1,955,201
Neurosurgery	252[x]	1,288,804
Nursing Episode	<5	1,416
Obstetrics	155[y]	389,849
Obstetrics & Gynaecology	<5	1,348
Ophthalmology	96[z]	89,016
Oral & Maxillo Facial Surgery	6[aa]	16,380
Oral Surgery	34[bb]	70,977
Orthodontics	<5	588
Paediatric Cardiology	<5	1095
Paediatric Neurology	171[cc]	298,632
Paediatric Surgery	83[dd]	271,932
Paediatrics	699[ee]	1,013,534
Palliative Medicine	74[ff]	331,097
Plastic Surgery	79[gg]	129,234
Radiology	11[hh]	42,364
Rehabilitation	744[ii]	3,084,219
Rheumatology	12[jj]	37,827

Thoracic Medicine	127[kk]	367,192
Trauma & Orthopaedics	1,228[ll]	5,094,927
Urology	388[mm]	527,353

[a]This was derived by the summation of data for 2005-06, 2006-07, 2007-08, 2008-09 and the first 5 months (i.e. from April to August) of 2009-10 financial years across all 13 conditions
Source: SUS - U_Reporting (Extracted on 08/10/2009).

[a]plus 6 instances of less than 5 admissions
[b]plus 1 instance of less than 5 admissions
[c]plus 2 instances of less than 5 admissions
[d]plus 6 instances of less than 5 admissions
[e]plus 3 instances of less than 5 admissions
[f]plus 3 instances of less than 5 admissions
[g]plus 3 instances of less than 5 admissions
[h]plus 4 instances of less than 5 admissions
[i]plus 5 instances of less than 5 admissions
[j]plus 1 instance of less than 5 admissions
[k]plus 3 instances of less than 5 admissions
[l]plus 4 instances of less than 5 admissions
[m]plus 6 instances of less than 5 admissions
[n]plus 1 instance of less than 5 admissions
[o]plus 2 instances of less than 5 admissions
[p]plus 6 instances of less than 5 admissions
[q]plus 2 instances of less than 5 admissions
[r]plus 5 instances of less than 5 admissions
[s]plus 4 instances of less than 5 admissions
[t]plus 5 instances of less than 5 admissions
[u]plus 4 instances of less than 5 admissions
[v]plus 5 instances of less than 5 admissions
[w]plus 3 instances of less than 5 admissions
[x]plus 3 instances of less than 5 admissions
[y]plus 7 instances of less than 5 admissions
[z]plus 3 instances of less than 5 admissions
[aa]plus 2 instances of less than 5 admissions
[bb]plus 3 instances of less than 5 admissions
[cc]plus 1 instance of less than 5 admissions
[dd]plus 4 instances of less than 5 admissions
[ee]plus 3 instances of less than 5 admissions
[ff]plus 2 instances of less than 5 admissions
[gg]plus 5 instances of less than 5 admissions
[hh]plus 5 instances of less than 5 admissions
[ii]plus 4 instances of less than 5 admissions
[jj]plus 3 instances of less than 5 admissions
[kk]plus 5 instances of less than 5 admissions
[ll]plus 2 instances of less than 5 admissions
[mm]plus 5 instances of less than 5 admissions

23 Appendix 3:

Table 6: Hospital inpatient admissions by speciality of people diagnosed with multiple sclerosis in Oxfordshire PCT

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
All	**1943**	**4,653,459**
Accident & Emergency	39	72,673
Allied Health Professional Episode	<5	8,731
Anaesthetics	5	6,806
Cardiology	18	56,704
Cardiothoracic Surgery	<5	993
Clinical Haematology	10	4,366
Clinical Oncology (previously Radiotherapy)	<5	1,872
Clinical Pharmacology	<5	7,340
Clinical Physiology	<5	14,338
Dermatology	<5	1,557
Endocrinology	7	11,477
Gastroenterology	34	62,841
General Medical Practice	24	126,456
General Medicine	293	737,432
General Surgery	64	122,007
Geriatric Medicine	88	281,993
Gynaecology	16	30,177
Haematology	<5	3,264
Infectious Diseases	23	72,809
Medical Oncology	<5	6,447
Midwife Episode	<5	2,088
Nephrology	12	23,675
Neurology	353	507,049
Neurosurgery	14	62,531
Nursing Episode	<5	1,416
Obstetrics	37	69,627
Ophthalmology	5	4,749
Oral & Maxillo Facial Surgery	<5	4,196
Oral Surgery	7	14,750
Palliative Medicine	9	19,805
Plastic Surgery	9	14,008
Rehabilitation	608	1,762,301
Rheumatology	<5	4,269
Thoracic Medicine	25	71,858
Trauma & Orthopaedics	71	331,831
Urology	142	129,022

[a]This was derived by the summation of data for 2005-06, 2006-07, 2007-08, 2008-09 and the first 5 months (i.e. from April to August) of 2009-10 financial years
Source: SUS - U_Reporting (Extracted on 08/10/2009).

Table 7: Hospital inpatient admissions by speciality of people diagnosed with Parkinson's disease in Oxfordshire PCT

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
All	**2208**	**7,250,184**
Accident & Emergency	202	389,721
Adult Mental Illness	<5	0
Anaesthetics	5	10,151
Cardiology	56	210,732
Cardiothoracic Surgery	<5	11,201
Clinical Haematology	5	12,094
Clinical Oncology (previously Radiotherapy)	<5	4,380
Clinical Pharmacology	10	41,091
Clinical Physiology	<5	15,809
Dermatology	11	6,858
Endocrinology	16	48,626
ENT	7	20,758
Gastroenterology	29	87,384
General Medical Practice	78	318,059
General Medicine	688	2,333,210
General Surgery	111	262,432
Geriatric Medicine	279	1,225,652
Gynaecology	<5	3,470
Haematology	5	13,169
Infectious diseases	68	221,174
Medical Microbiology	<5	2,693
Medical Oncology	<5	10,148
Nephrology	17	44,537
Neurology	113	186,484
Neurosurgery	37	202,926
Obstetrics	<5	4,054
Old Age Psychiatry	5	0
Ophthalmology	37	30,469
Oral & Maxillo Facial Surgery	<5	1,523
Oral Surgery	<5	7,088
Palliative Medicine	14	49,004
Plastic Surgery	10	8,480
Radiology	<5	2,811
Rehabilitation	27	74,152
Rheumatology	<5	4,496
Thoracic Medicine	32	106,058
Trauma & Orthopaedics	212	1,083,739
Urology	108	195,549

[a]This was derived by the summation of data for 2005-06, 2006-07, 2007-08, 2008-09 and the first 5 months (i.e. from April to August) of 2009-10 financial years
Source: SUS - U_Reporting (Extracted on 08/10/2009).

Table 8: Hospital inpatient admissions by speciality of people diagnosed with motor neurone disease in Oxfordshire PCT

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
All	**277**	**981,059**
Accident & Emergency	10	11,812
Cardiology	<5	849
Clinical Physiology	<5	3,119
Gastroenterology	5	8,446
General Medical Practice	6	38,154
General Medicine	48	207,930
General Surgery	<5	18,107
Geriatric Medicine	12	54,046
Gynaecology	<5	599
Infectious Diseases	<5	7,829
Medical Oncology	<5	1,898
Nephrology	24	37,187
Neurology	74	144,182
Ophthalmology	<5	510
Palliative Medicine	40	216,453
Radiology	<5	1,455
Rehabilitation	33	185,177
Thoracic Medicine	8	29,049
Trauma & Orthopaedics	<5	14,257

[a]This was derived by the summation of data for 2005-06, 2006-07, 2007-08, 2008-09 and the first 5 months (i.e. from April to August) of 2009-10 financial years
Source: SUS - U_Reporting (Extracted on 08/10/2009).

Table 9: Hospital inpatient admissions by speciality of people diagnosed with epilepsy in Oxfordshire PCT

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
All	**4670**	**10,483,514**
	<5	0
Accident & Emergency	586	641,415
Allied Health Professional Episode	9	21,212
Anaesthetics	21	84,495
Cardiology	74	163,171
Cardiothoracic Surgery	6	53,479
Clinical Haematology	19	31,651
Clinical Oncology (previously Radiotherapy)	15	27,064
Clinical Pharmacology	24	51,021
Clinical Physiology	13	35,779
Community Medicine	<5	5,552
Dermatology	11	8,954

Endocrinology	32	64,341
ENT	20	57,691
Gastroenterology	72	146,614
General Medical Practice	10	54,077
General Medicine	1,102	2,478,358
General Surgery	239	614,885
Geriatric Medicine	345	904,660
Gynaecology	39	79,696
Haematology	17	55,702
Infectious Diseases	97	189,710
Learning Disability	<5	0
Medical Oncology	5	14,518
Midwife Episode	<5	6,818
Nephrology	31	52,143
Neurology	209	517,818
Neurosurgery	70	304,536
Obstetrics	118	272,270
Obstetrics and Gynaecology	<5	1,348
Ophthalmology	31	27,179
Oral & Maxillo Facial Surgery	6	10,661
Oral Surgery	22	28,548
Paediatric Neurology	154	232,221
Paediatric Surgery	60	170,663
Paediatrics	524	720,506
Palliative Medicine	11	40,739
Plastic Surgery	52	73,575
Radiology	11	24,059
Rehabilitation	46	317,611
Rheumatology	12	26,102
Thoracic Medicine	62	131,277
Trauma & Orthopaedics	395	1,618,513
Urology	90	122,881

[a]This was derived by the summation of data for 2005-06, 2006-07, 2007-08, 2008-09 and the first 5 months (i.e. from April to August) of 2009-10 financial years
Source: SUS - U_Reporting (Extracted on 08/10/2009).

Table 10: Hospital inpatient admissions by speciality of people diagnosed with acquired brain injury in Oxfordshire PCT

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
All	**685**	**3,046,478**
Accident & Emergency	109	235,468
Anaesthetics	6	28,207
Cardiology	<5	3,780
Clinical Haematology	<5	4,863

Clinical Pharmacology	<5	9,055
Clinical Physiology	<5	5,024
Critical Care Medicine	6	11,759
Endocrinology	9	10,668
ENT	<5	1,164
Gastroenterology	<5	8,419
General Medicine	90	327,953
General Surgery	12	41,429
Geriatric Medicine	31	152,651
Infectious Diseases	5	41,483
Nephrology	<5	3,647
Neurology	8	25,621
Neurosurgery	106	631,862
Oral Surgery	5	17,232
Paediatric Neurology	<5	24,429
Paediatric Surgery	<5	9,493
Paediatrics	25	61,379
Plastic Surgery	<5	8,491
Rehabilitation	30	508,020
Thoracic Medicine	<5	3,780
Trauma & Orthopaedics	214	868,103
Urology	<5	2,500

[a]This was derived by the summation of data for 2005-06, 2006-07, 2007-08, 2008-09 and the first 5 months (i.e. from April to August) of 2009-10 financial years
Source: SUS - U_Reporting (Extracted on 08/10/2009).

Table 11: Hospital inpatient admissions by speciality of people diagnosed with spinal cord injury in Oxfordshire PCT

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
All	**163**	**767,753**
Accident & Emergency	<5	10,902
Anaesthetics	<5	8,633
ENT	<5	2,429
Gastroenterology	<5	3,273
General Medicine	10	29,198
General Surgery	<5	9,606
Geriatric Medicine	<5	9,432
Infectious Diseases	<5	4,484
Neurology	71	415,165
Neurosurgery	<5	15,656
Plastic Surgery	<5	5,153
Radiology	<5	10,836
Rehabilitation	<5	89,303
Thoracic Medicine	<5	562
Trauma & Orthopaedics	29	125,000

Urology	27	28,122

[a]This was derived by the summation of data for 2005-06, 2006-07, 2007-08, 2008-09 and the first 5 months (i.e. from April to August) of 2009-10 financial years
Source: SUS - U_Reporting (Extracted on 08/10/2009).

Table 12: Hospital inpatient admissions by speciality of people diagnosed with cerebral palsy in Oxfordshire PCT

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
All	**672**	**1,726,831**
Accident & Emergency	20	19,400
Cardiology	<5	7,455
Cardiothoracic Surgery	<5	11,954
Clinical Haematology	<5	2,521
Clinical Oncology (previously Radiotherapy)	<5	3,119
Clinical Pharmacology	<5	3,935
Endocrinology	<5	2,374
ENT	<5	1,656
Gastroenterology	<5	3,764
General Medicine	48	114,366
General Surgery	34	83,271
Geriatric Medicine	15	58,058
Gynaecology	<5	6,081
Haematology	<5	5,551
Infectious Diseases	11	42,293
Nephrology	<5	0
Neurology	<5	2,862
Neurosurgery	20	46,411
Obstetrics	<5	7,491
Ophthalmology	10	13,847
Oral Surgery	<5	3,143
Paediatric Neurology	17	31,041
Paediatric Surgery	23	73,239
Paediatrics	143	210,579
Palliative Medicine	<5	599
Plastic Surgery	8	15,972
Radiology	<5	2,520
Rehabilitation	18	58,842
Thoracic Medicine	<5	19,979
Trauma & Orthopaedics	248	831,599
Urology	21	42,907

[a]This was derived by the summation of data for 2005-06, 2006-07, 2007-08, 2008-09 and the first 5 months (i.e. from April to August) of 2009-10 financial years
Source: SUS - U_Reporting (Extracted on 08/10/2009).

Table 13: Hospital inpatient admissions by speciality of people diagnosed with chronic fatigue syndrome/ myalgic encephalopathy in Oxfordshire PCT

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
All	**65**	**149,958**
Accident & Emergency	<5	2,953
Anaesthetics	<5	756
Cardiology	<5	7,204
Endocrinology	<5	3,887
Gastroenterology	<5	514
General Medicine	12	29,437
General Surgery	6	12,433
Geriatric Medicine	6	12,035
Gynaecology	<5	1,163
Haematology	<5	696
Infectious Diseases	<5	2,719
Midwife Episode	<5	2,088
Neurology	6	12,313
Neurosurgery	<5	4,495
Obstetrics	<5	9,127
Paediatrics	<5	2,723
Palliative Medicine	<5	4,497
Plastic Surgery	<5	999
Trauma & Orthopaedics	9	38,933
Urology	<5	986

[a]This was derived by the summation of data for 2005-06, 2006-07, 2007-08, 2008-09 and the first 5 months (i.e. from April to August) of 2009-10 financial years
Source: SUS - U_Reporting (Extracted on 08/10/2009).

Table 14: Hospital inpatient admissions by speciality of people diagnosed with Huntington's disease in Oxfordshire PCT

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
All	**30**	**78,317**
Accident & Emergency	<5	1,554
Adult Mental Illness	<5	0
General Medicine	<5	8,316
General Surgery	<5	5,560
Neurology	<5	450
Ophthalmology	<5	873
Oral Surgery	<5	216
Orthodontics	<5	588
Rehabilitation	12	54,676
Thoracic Medicine	<5	2,784
Trauma & Orthopaedics	<5	2,665

Urology	<5	634

[a]This was derived by the summation of data for 2005-06, 2006-07, 2007-08, 2008-09 and the first 5 months (i.e. from April to August) of 2009-10 financial years
Source: SUS - U_Reporting (Extracted on 08/10/2009).

Table 15: Hospital inpatient admissions by speciality of people diagnosed with Charcot-Marie-Tooth syndrome in Oxfordshire PCT

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
All	**48**	**128,519**
Cardiology	<5	4,464
General Medicine	<5	14,337
General Surgery	<5	830
Gynaecology	<5	887
Infectious Diseases	<5	3,105
Nephrology	<5	10,350
Neurology	11	11,560
Obstetrics	<5	8,653
Rehabilitation	<5	16,938
Trauma & Orthopaedics	19	53,160
Urology	<5	4,235

[a]This was derived by the summation of data for 2005-06, 2006-07, 2007-08, 2008-09 and the first 5 months (i.e. from April to August) of 2009-10 financial years
Source: SUS - U_Reporting (Extracted on 08/10/2009).

Table 16: Hospital inpatient admissions by speciality of people diagnosed with muscular dystrophy in Oxfordshire PCT

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
All	**39**	**63,146**
Accident & Emergency	<5	3,209
General Medicine	6	11,416
General Surgery	<5	4,744
Geriatric Medicine	<5	2,281
Neurology	<5	698
Obstetrics	<5	1,138
Ophthalmology	<5	833
Paediaric Cardiology	<5	1,095
Paediatric Neurology	<5	2,144
Paediatric Surgery	<5	2,676
Paediatrics	7	6,979
Rehabilitation	<5	4,931
Trauma & Orthopaedics	8	21,002

[a]This was derived by the summation of data for 2005-06, 2006-07, 2007-08, 2008-09 and the first 5 months (i.e. from April to August) of 2009-10 financial years
Source: SUS - U_Reporting (Extracted on 08/10/2009).

Table 17: Hospital inpatient admissions by speciality of people diagnosed with myasthenia gravis in Oxfordshire PCT

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
All	**154**	**413,069**
Accident & Emergency	<5	1,671
Cardiology	15	47,050
Clinical Haematology	<5	416
Clinical Pharmacology	<5	1,045
Clinical Physiology	<5	2,605
Endocrinology	<5	1,935
ENT	<5	747
Gastroenterology	<5	7,508
General Medical Practice	<5	2,020
General Medicine	30	81,197
General Surgery	7	16,265
Geriatric Medicine	13	40,944
Haematology	<5	13,171
Infectious Diseases	<5	2,313
Medical Oncology	<5	1,511
Nephrology	<5	2,764
Neurology	41	98,194
Neurosurgery	<5	2,242
Obstetrics	<5	15,581
Ophthalmology	5	4,330
Paediatric Neurology	<5	1,690
Paediatric Surgery	<5	3,233
Paediatrics	<5	3,093
Plastic Surgery	<5	2,035
Rheumatology	<5	2,960
Thoracic Medicine	<5	1,845
Trauma & Orthopaedics	11	54,190
Urology	<5	517

Table 18: Hospital inpatient admissions by speciality of people diagnosed with dystonia in Oxfordshire PCT

Specialty	Number of admissions ([a]Pooled Total)	Aggregated associated cost (£) ([a]Pooled Total)
All	**101**	**217,411**
Accident & Emergency	<5	6,621
Cardiology	<5	733
ENT	5	5,698
Gastroenterology	<5	1,825
General Medicine	17	36,802

General Surgery	<5	843
Geriatric Medicine	5	8,721
Nephrology	<5	3,667
Neurology	26	32,805
Neurosurgery	5	18,145
Obstetrics	<5	1,908
Ophthalmology	8	6,226
Paediatric Neurology	<5	7,107
Paediatric Surgery	<5	12,628
Paediatrics	<5	8,275
Plastic Surgery	<5	521
Radiology	<5	683
Rehabilitation	<5	12,268
Trauma & Orthopaedics	12	51,935

[a]This was derived by the summation of data for 2005-06, 2006-07, 2007-08, 2008-09 and the first 5 months (i.e. from April to August) of 2009-10 financial years
Source: SUS - U_Reporting (Extracted on 08/10/2009).

24 Appendix 4:

Table 19: Deaths of People Diagnosed with Specified Neuromuscular Conditions in Oxfordshire PCT

	Number of Deaths					
***Cause of Death**	**2004**	**2005**	**2006**	**2007**	**2008**	**Total**
Cerebral Palsy	0	<5	<5	<5	<5	7
Charcot-Marie-Tooth Syndrome	0	<5	0	0	<5	<5
Dystonia	0	0	0	0	<5	<5
Epilepsy	14	15	9	9	12	59
Huntington's Disease	<5	0	0	<5	0	<5
Motor Neurone Disease	18	24	23	23	22	110
Multiple Sclerosis	8	13	11	14	13	59
Muscular Dystrophy	0	<5	0	<5	0	<5
Myasthenia Gravis	0	0	0	0	<5	<5
Parkinson's Disease	52	31	44	56	60	243
Other Causes	4,739	4,848	4,856	4,630	4,841	2,3914
Grand Total	4,832	4,935	4,944	4,738	4,952	2,4401

Source: Annual District Deaths Extract (ADDE) for Oxfordshire, 2004-2008

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