

Long Term Neurological Conditions (LTNC)

Summary

- Little is currently known about the prevalence of Long Term Neurological Conditions (LTNCs) locally in Hampshire or nationally.
- This JSNA section provides a basic overview of LTNCs and presents the data currently relevant to the population of Hampshire.
- The Department of Health has committed to developing a neurology dataset.
- Neurology is one of the four NHS strategic clinical networks.

Recommendations

- There is a need to undertake a LTNC needs assessment to develop a better understanding of LTNCs in Hampshire.

Long Term Neurological Conditions (LTNC)

1. Introduction

Neurological conditions result from damage to the brain, spinal column or peripheral nerves and fit broadly into four groups:

- sudden-onset: for example, acquired brain injury or spinal cord injury, often from an accident;
- intermittent and unpredictable: for example, epilepsy, certain types of headache or early multiple sclerosis;
- progressive: for example, motor neurone disease, Parkinson's disease or later stage multiple sclerosis; and
- stable: for example, post-polio syndrome or cerebral palsy in adults (though cerebral palsy in children is not stable).¹

There is no definitive list of neurological conditions and consequently it is difficult to understand the issue in terms of size, severity and trajectory. Some neurological conditions are life threatening, many severely affect quality of life and cause lifelong disability. They also have a significant impact on the carers and families of those living with the condition. Approximately two million people have a neurological condition in the United Kingdom (excluding migraine).¹

The most recent estimates show that current spending on neurological health and social care services was £5.3 billion in 2009/10. Expenditure on neurological conditions has grown significantly since the publication of the National Service Framework, increasing from 2.6% to 4% of total NHS expenditure between 2005 and 2010, representing £1.7 billion in extra resources¹.

People with neurological conditions may need a wide range of services which are currently provided by a number of organisations including health, social services, employment, benefits, transport, housing and education. The services a person needs can change, particularly where conditions rapidly deteriorate, or fluctuate. Fluctuation can affect access to services, in particular, when people's entitlement is assessed during periods where their condition has temporarily improved¹.

Good outcomes for those with LTNCs depend on:

- Diagnosis: ensuring people that may have symptoms are able to have timely and accurate diagnosis of their condition and receive high quality, treatment, care and support and information as soon as possible.
- Early management: an organised, proactive, multi-disciplinary approach to their management that focuses on prevention and early intervention to help establish good control of the condition, minimise effects of the disease, reduce complications and enable people to remain as well and independent as possible for as long as possible.
- Ongoing care and living with a LTNC: individuals and their carers are supported to develop the knowledge, skills and confidence to care for themselves and their condition effectively.

¹ National Audit Office 2011. Services for people with neurological conditions.
<http://www.nao.org.uk/wp-content/uploads/2011/12/10121586.pdf>

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- Emergency and acute management and management of complications, relapses and crisis: People with LTNCs need to have access to appropriate expertise and services at the right time to support them when circumstances change or there is a deterioration in their condition in order to prevent unnecessary admissions to hospital or reduce any unnecessary length of stay.
- Palliative and End of Life Care: those with LTNCs approaching the end of life and their carers need to have access to a comprehensive range of services and support to manage symptoms, meet their needs for personal, social, psychological and spiritual support and enable them to be able to die in with dignity in the place of their choice and cared for by those with appropriate knowledge and skills.

In 2012 the Department of Health committed to developing a neurology dataset as a result of the National Audit Office review of neurology services. There will also be an increased focus on neurology in 2013 in all areas, as it is included in one of the four NHS strategic clinical networks.

The following conditions may be considered the most common LTNCs but there are many others which are equally important.

1.1 Multiple sclerosis (MS)

Multiple sclerosis (MS) is a condition of the central nervous system. In MS, the coating around nerve fibres (called myelin) is damaged, causing a range of symptoms. Around 100,000 people in the UK have MS. It is normally diagnosed in people between the ages of 20 and 40, and affects almost three times as many women as men. Relapses and remissions can lead to marked variation in the ability of the individual to undertake their normal activities and hence any care needed.²

1.2 Motor neurone disease (MND)

MND is a rare condition of the nervous system when specialist nerve cells in the brain and spinal cord, motor neurones, stop working properly. It leads to a progressive deterioration of muscle function, specifically seen as affecting the ability to walk, grip, speak, swallow and breath. It can affect any adult at any age but most people diagnosed with the disease are over the age of 40, with the highest incidence occurring between the ages of 50 and 70. Men are affected approximately twice as often as women. The incidence or number of people who will develop MND each year is about two people in every 100,000. The prevalence or number of people living with MND at any one time is approximately seven in every 100,000.³

1.3 Epilepsy

This is the most prevalent neurological condition, intermittent and unpredictable which can affect people of all ages; however it is most often diagnosed before the age of 18 or after the age of 65. Repeated seizures affect all ages, with a large cohort being children. It affects 5-10 people per 1,000 UK population. There are over 40 types of epilepsy.⁴

² <http://www.mssociety.org.uk/what-is-ms>

³ <http://www.mndassociation.org/Home>

⁴ <http://www.epilepsysociety.org.uk/>

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1.4 Parkinson's disease (PD)

This is a condition in which a part of the brain becomes increasingly damaged over a number of years. It is characterised by three main symptoms related to movement: characterised by abnormal slow movement, muscle stiffness or rigidity and an involuntary tremor mainly in adults. It affects one person in every 500, or about 127,000 people in the UK. Most people who get Parkinson's are aged 50 or over but younger people can get it too. One in 20 is under the age of 40.⁵

1.5 Acquired brain injury (ABI)

An Acquired Brain Injury (ABI) is an injury caused to the brain since birth. There are many possible causes, including a fall, a road accident, tumour and stroke. It is a sudden onset condition with varying levels of recovery which can affect anyone at any age. In terms of traumatic brain injury (TBI), the two age groups at higher risk are 0-4 year olds and 15 to 19 year olds. The effects of a brain injury can be wide ranging, and depend on a number of factors such as the type, location and severity of injury. Every person's injury is unique, so they will experience any number of the symptoms, which can range from mild to severe.⁶

1.6 Myalgic encephalopathy/Chronic fatigue syndrome (ME/CFS)

This is characterised by excessive exhaustion and intermittently impaired cognitive function. It is thought to affect 4 people in every 1,000 in the UK. The World Health Organization (WHO) has classified CFS as a chronic (long-term) neurological condition and this classification has been accepted by the Department of Health. However, the WHO decision remains controversial and is not accepted by everyone working in the field. The team who drew up the National Institute of Health and Care Excellence (NICE) guidelines for CFS could not agree that this classification is the right decision and 84% of members of the Association of British Neurologists surveyed in 2011 said they did not view CFS as a neurological condition.⁷

2. Level of need in Hampshire

2.1 Epilepsy

Apart from stroke, the only routinely available data on LTNCs are for epilepsy in people age 18+ from general practice registers. Figures 1 and 2 show that the prevalence of epilepsy in people age 18+ in Hampshire is 0.7% (7,958 people), with a national prevalence of 0.8%. Gosport and Havant have the highest prevalence at 0.8% and 0.9% respectively. The trend in epilepsy prevalence during the three year period from 2009/10 to 2011/12 has been stable for Hampshire and England.

⁵ <http://www.parkinsons.org.uk/>

⁶ <https://www.headway.org.uk/home.aspx>

⁷ <http://www.nhs.uk/Conditions/Chronic-fatigue-syndrome/Pages/Causes.aspx>

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Figure 1: Crude prevalence of epilepsy (age 18+) in Hampshire by CCG, 2011/12

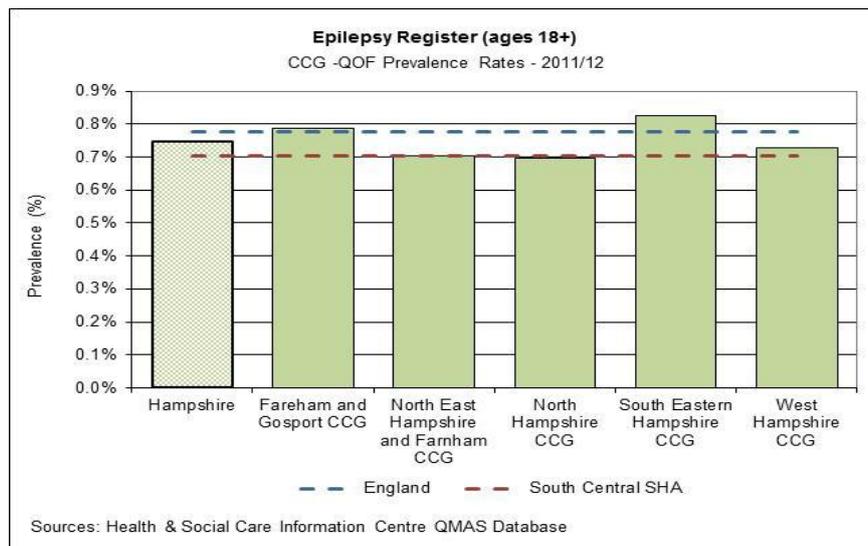
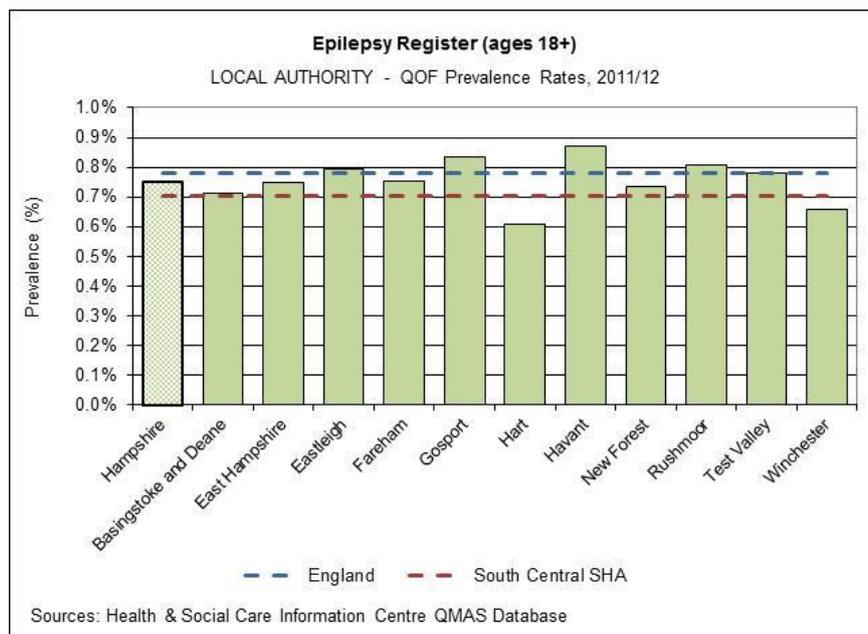


Figure 2: crude prevalence of epilepsy (age 18+) in Hampshire by district, 2011/12



2.2 MND, PD and MS

There are no routinely available data for these conditions. Table 1 contains estimates of the number of people with MND, PD and MS by CCG, which have been calculated by applying national prevalence estimates to the population of Hampshire.⁸

2.3 Stroke

Please see the JSNA chapter on cardiovascular disease for more information.

⁸ <http://www.neuronavigator.org.uk/>

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Table 1: estimates of number of people with MND, Parkinson's and MS in Hampshire, by CCG

	Hampshire	Fareham and Gosport CCG	North Hampshire CCG	North East Hampshire and Farnham CCG	West Hampshire CCG
Total resident population	1,320,000	197,867	214,038	205,729	538,424
Numbers with MND	92	14	15	14	38
Numbers with Parkinson's	2,574	386	417	401	1,050
<i>Diagnosis phase</i>	282	42	46	44	115
<i>Maintenance phase</i>	1,040	156	168	162	424
<i>Complex phase</i>	864	130	140	135	353
<i>Palliative phase</i>	388	58	63	60	158
Numbers with MS	2,125	319	345	331	867
<i>Diagnosis phase</i>	98	15	16	15	40
<i>Minimum-moderate impairment phase</i>	889	134	144	138	363
<i>Complex phase</i>	1,089	163	177	170	444
<i>Palliative phase</i>	49	7	8	8	20

Source: Neuronavigator tool, <http://www.neuronavigator.org.uk/>

3. Current services in relation to need

The numerous and complex effects of neurological conditions means that people with a LTNC may need to access advice and care from a number and variety of health and social care professionals over their lives. Specialist care is provided by consultant neurologists working within a network of specialist nurses, neurophysiotherapists, occupational therapists, speech and language therapists, neuropsychologists, psychotherapists, physicians and surgeons, including GPs with a special interest (GPwSIs) in conditions such as epilepsy, Parkinson's Disease or headache. The Royal College of Physicians recommends that the patient with a neurological illness should easily be able to access a neurology network that includes services at a district general hospital (DGH), neuroscience centre (NC) and regional neurosciences centre (RNC).⁹

The Neuronavigator, a web tool for health and social care commissioners who are planning services for motor neurone disease, MS and Parkinson's, will be helpful in getting some local information. This tool unbundles services and spend, and helps with planning neurology services.¹⁰

⁹ <http://www.rcplondon.ac.uk/projects/clinical-commissioning-hub/commissioning-neurology-services>

¹⁰ <http://www.neuronavigator.org.uk/>

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3.1 University Hospitals Southampton NHS Foundation Trust (UHS)

UHS houses the regional neurosciences centre which provides services for most of central southern England, including Southampton, Winchester, Portsmouth, Basingstoke, Salisbury, Isle of Wight, Chichester, and the Channel Islands. Neurology clinics are held in hospitals around the region as well as in the Wessex Neurological Centre in Southampton. The department's main sub specialty areas are neuromuscular disorders, movement disorders (including Parkinson's disease), neuroinflammatory diseases (including multiple sclerosis), stroke, epilepsy, and cognitive disorders.

UHS also provides a children's neurology service, covering neuromuscular conditions, epilepsy, neuro-oncology, neurorehabilitation, neonatal and developmental neurology, muscular tone management services, including botox clinics and intra-thecal baclofen service, sleep disorders – in conjunction with Solent NHS Trust, and complex headache management.

3.2 Hampshire Hospitals NHS Foundation Trust (HHFT), Portsmouth Hospitals NHS Trust (PHT) and Frimley Park Hospital NHS Foundation Trust (FPH)

These three hospitals provide a district general hospital neurology service. HHFT and PHT have close links with the Wessex Neurological Centre in Southampton; while FPH links with St George's Hospital in London for specialist services. The commonest problems seen are epilepsy, migraine and other headache disorders, multiple sclerosis and Parkinson's disease. The service may include a specialist team being available at the local hospital on a regular basis.

3.3 Solent NHS Trust and Southern Health NHS Foundation Trust

Solent NHS Trust provides a multidisciplinary community neurorehabilitation service which includes community neurologists, specialist nurses, and allied health professionals such as neurophysiotherapists, speech and language therapists and occupational therapists. Southern Health provides MS and Parkinson's Disease nurses.

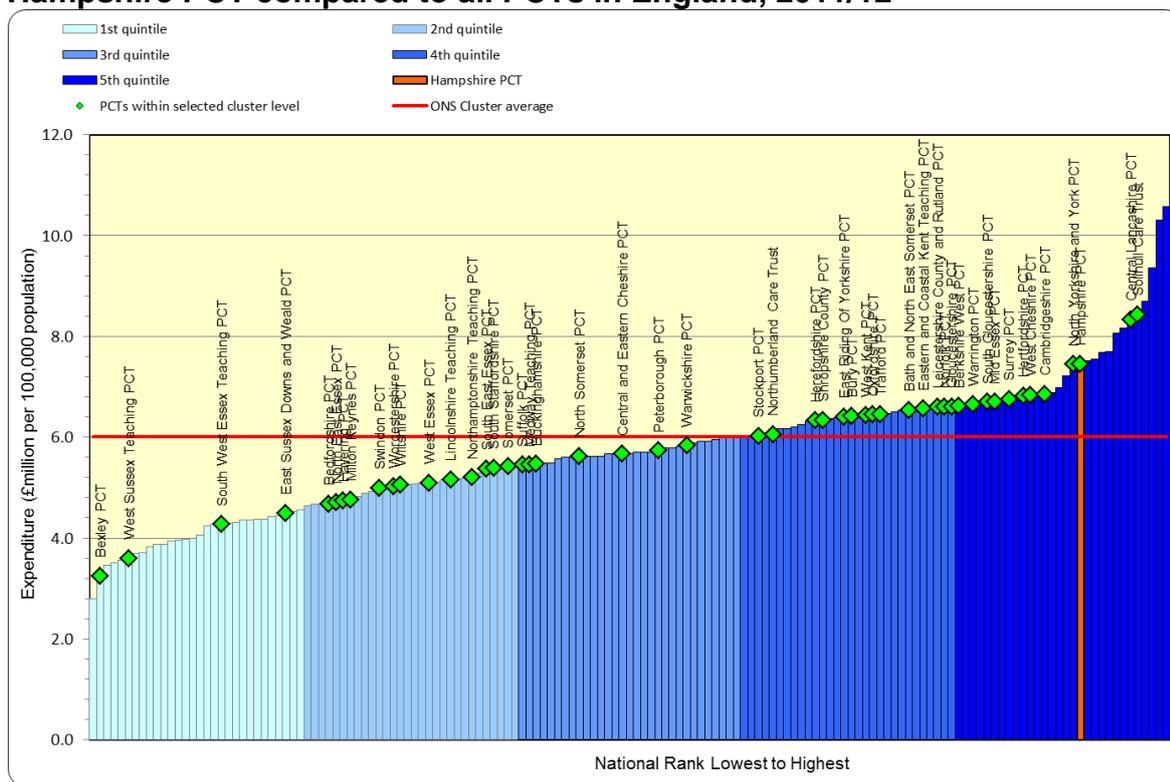
4. Current spend and outcomes

Hampshire PCT spent £85.8 million on neurological disorders (excluding chronic pain) in 2011/12. Figure 3 shows that the PCT was in the highest spending fifth of all PCTs in England. Figure 4 shows that the majority of that spend was on community services.

Figure 5 shows that neurology outcomes for Hampshire are good and the spend is high (the outcome shown in figure 5 is deaths in people under the age of 75 from epilepsy). Hampshire PCT spent far less in 2010/11 but got good outcomes. In contrast, two of Hampshire's statistical comparators (Wiltshire and North East Essex) both spent considerably less in 2011/12 than Hampshire but got just as good outcomes. This suggests there may be scope improve the value for money of Hampshire's neurology services.

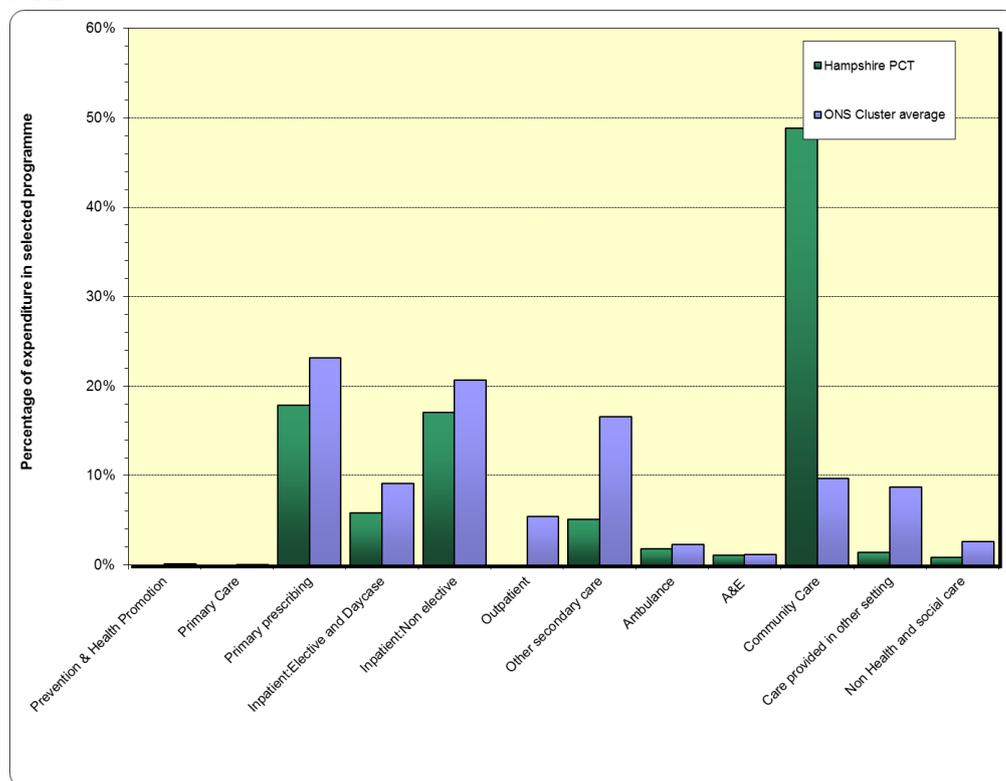
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Figure 3: Spend on neurological disorders (excluding chronic pain) in Hampshire PCT compared to all PCTs in England, 2011/12



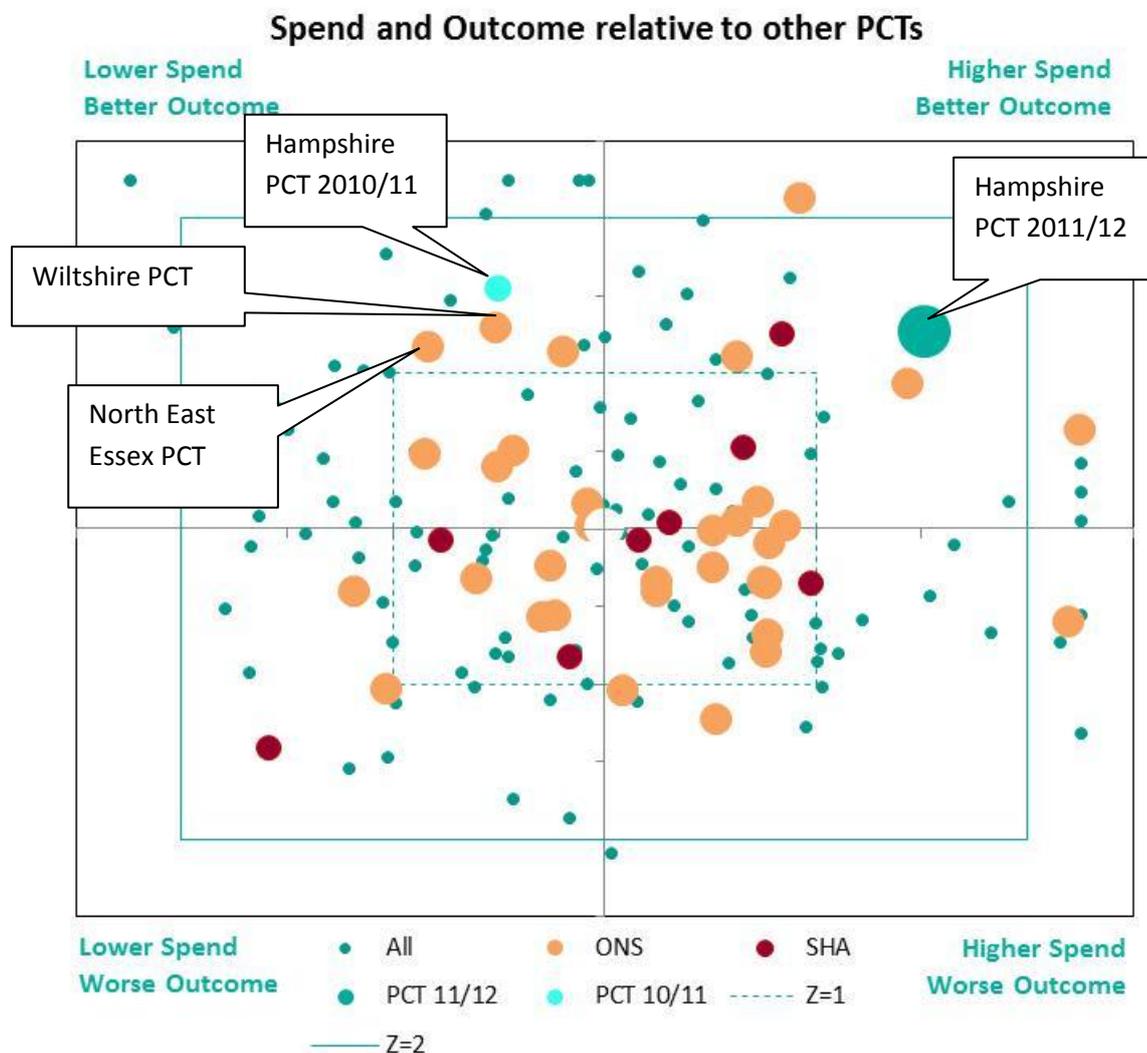
Source: <http://www.networks.nhs.uk/nhs-networks/health-investment-network/news/2011-12-programme-budgeting-data-now-available>

Figure 4: Hampshire PCT spend on neurological disorders by care setting, 2011/12



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Figure 5: Spend on neurological disorders compared to outcome (deaths from epilepsy in people under the age of 75), 2011/12



5. Projected service use and outcome in 3-5 years and 5-10 years

It is likely that need will increase and hence associated service use, as a consequence of an ageing population and an increasing proportion of children surviving into adulthood with long term conditions.

6. User and provider views

Service user issues often mentioned nationally include:

- Difficulties in getting a diagnosis.
- Health professionals knowing very little about specific neurological conditions.
- Physiotherapy was rarely offered or only available short term.
- Difficulty with obtaining appropriate aids and equipment.
- Difficulty with obtaining benefits.

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The Hampshire Neurological Alliance (HNA) covers Hampshire, Portsmouth, Southampton and the Isle of Wight. It is the local voice for people with neurological conditions and their family and carers.¹¹ Hampshire PCT set up a Neurology Programme Board with representatives from the HNA who facilitated a meeting for people with long term neurological conditions to help establish service users' needs and views on what's most valuable for them. These were the personalisation agenda, improved care pathways, and better communication and information sharing.¹²

7. Evidence of what works

This will be established in the needs assessment. The following is a non-exhaustive list of currently published evidence relevant to LTNCs:

- National Institute for Health and Clinical Excellence (NICE): Parkinson's disease: diagnosis and management in primary and secondary care. (2006).
- NICE: Multiple sclerosis: Management of multiple sclerosis in primary and secondary care. (2003).
- NICE: Motor neurone disease. The use of non-invasive ventilation in the management of motor neurone Disease (2010).
- Motor Neurone Disease Association (MNDA): Standards of Care (2010).
- NICE: The epilepsies: The diagnosis and management of the epilepsies in adults and children in primary and secondary care (2004).
- The Royal College of physicians: Medical Rehabilitation in 2011 and beyond (2010).
- British Society of Rehabilitation Medicine: Rehabilitation following acquired brain injury National clinical guidelines (2003).
- Department of Health (DH): National Service Framework for long term conditions (2005).

8. Recommendations

- There is a need to undertake a LTNC needs assessment, to develop a better understanding of LTNCs in Hampshire.

¹¹ <http://www.hampshireneural.org.uk/>

¹² Stronger together. The work of regional neurological alliances. January 2012.
<http://www.neural.org.uk/store/assets/files/259/original/Stronger-Together-The-work-of-Regional-Neurological-Alliances.pdf>