Section 4: burden of ill-health: mental health and neurological disorders

Neurological disorders

a single version of the truth

NHS Wiltshire Clinical Commissioning Group

Wiltshire Council Where everybody matters

Wiltshire Assembly Public Services Board

Related briefings in the JSA for Health and Wellbeing

Briefing (and hyperlink)	Section
Physical disability	Burden of ill-health: disability and conditions effecting older people
Visual impairment	Burden of ill-health: disability and conditions effecting older people
Hearing impairment	Burden of ill-health: disability and conditions effecting older people
Dementia	Burden of ill-health: disability and conditions effecting older people
Falls and bone health	Burden of ill-health: disability and conditions effecting older people
Carers	Burden of ill-health: disability and conditions effecting older people
Long term conditions	Burden of ill-health: disability and conditions effecting older people

Outcome Frameworks Summary

The Public Health Outcomes Framework for England, 2013-2016[1] outlines the overarching vision for public health as "to improve and protect the nation's health and wellbeing, and improve the health of the poorest fastest". The NHS Outcomes Framework 2014/15[2] set out how the improvement of healthcare outcomes for all will be the primary purpose of the NHS. The following indicators from these frameworks are relevant to this section.

Framework	Reference	Indicator
Public Health	1.8	Employment for those with a long-term health condition, including those with a learning difficulty/disability or mental illness
Public Health	2.23	Self-reported wellbeing
Public Health	4.13	Health-related quality of life for older people
NHS	2	Health-related quality of life for people with long-term conditions

Edition

Edition	Version no.	Changes/Comments
2012/13	1	N/A
2013/14	1	SWNA report added

Executive Summary

It is estimated that more than one in six people in England have a neurological condition. Some are life-threatening and many can severely affect a person's quality of life and cause lifelong disability.

Neurological conditions account for 20% of acute hospital admissions and are the third most common reason for seeing a GP. An estimated 350,000 people across the UK need help with daily living because of a neurological condition and 850,000 people care for someone with a neurological condition.

The National Service Framework (NSF) for Long-term (Neurological) Conditions (LTnC) was launched in March 2005. The NSF has eleven quality standards and aims to transform the way health and social care services support people to live with long-term neurological conditions.

Also, as part of the remit of the new NHS England commissioning body a Strategic Clinical Network (SCN) for Mental Health, Dementia and Neurological Conditions has been set up for the South West. It will be there to ensure 'a whole system, integrated approach.... to achieve a real change in quality and outcomes of care for patients. Strategic clinical networks will help commissioners reduce unwarranted variation in services and will encourage innovation.'

In Wiltshire the following are estimates for common neurological conditions:

- 71,500 people suffer from migraines,
- 2,400 to 3,800 from epilepsy,
- 550-800 from multiple sclerosis (MS),
- 900 from cerebral palsy (CP).

70% of emergency neurological condition admissions are attributable to epilepsy, migraine and Parkinson's disease. There are more admissions for common neurological conditions amongst the most deprived quintile than in the least deprived quintile.

A survey was carried out by the Swindon and Wiltshire Neurological Alliance revealed low levels of awareness amongst patients about long---term neurological conditions, and the accessibility of services. When patients were asked about information provision in relation to health and social care services, over half of the respondents in each area answered that they did not receive any information at diagnosis regarding services that could help.

An annual Stakeholders event for LTnC has been held in Wiltshire since May 2009. This is an opportunity for service users and carers to come together and consult on needs, services and pathways.

Key considerations

- Community support for client, families and carers.
- Consideration to the need for and capacity of neuro-rehabilitation.
- Improved diagnosis, referral, knowledge and awareness amongst health and social care professionals.
- Increase self-management by increasing knowledge and education.
- Fast response (services / support) when required to reduce crisis / emergency admissions.
- Wider engagement with people with neurological conditions.
- Consider need of those living in more deprived areas, as hospital admissions are higher in these areas.

Why is this area important

"It is estimated that eight million people in England – more than one in six – have a neurological condition and over half a million people are newly diagnosed with a neurological condition each year."[3]

The nervous system consists of the brain, spinal cord and their peripheral nerve connections and the autonomic nervous system. A 'long term neurological condition' results from disease of, injury to, or damage to the body's nervous system. Some are life-threatening and many can severely affect a person's quality of life and cause lifelong disability. Neurological conditions, as a general rule, fall into the 'long-term condition' category and are broadly grouped as follows:

- **Sudden onset conditions** – for example, acquired brain injury or spinal cord injury, followed by a partial recovery.

- **Intermittent and unpredictable conditions** – for example, certain types of headache or early multiple sclerosis, where relapses and remissions lead to marked variation in the care needed at different times.

- **Progressive conditions** – for example, motor neurone disease, Parkinson's disease or later stages of multiple sclerosis, where progressive deterioration in neurological function leads to increasing dependence on help and care from others. For some conditions (e.g. motor neurone disease) deterioration can be rapid.

- **Stable neurological conditions** (but with changing needs due to development or ageing) – for example cerebral palsy in adults.

"The needs of people with neurological conditions are wide-ranging and may cross a number of different sectors, including health, social services, employment, benefits, transport, housing and education. The range of conditions that fall within this category, and their unpredictable nature, complexity and rarity, makes it difficult to reach a consensus on what type of outcomes are achievable for people with neurological conditions and how these outcomes should be measured." [4]

In addition, a number of neurological conditions are inherited or genetic, which needs to be considered when planning services.

Neurological conditions account for 20% of acute hospital admissions and are the third most common reason for seeing a GP. Around 17 people in a population of 100,000 are likely to develop Parkinson's disease, and two people in a population of 100,000 experience a traumatic spinal injury every year. An estimated 350,000 people across the UK need help with daily living because of a neurological condition and 850,000 people care for someone with a neurological condition.[5]

Long term neurological conditions can cause a range of different problems for the individual, including:

- **Physical or motor problems**, such as paralysis, inability to walk, fatigue, incontinence, sexual difficulties and, for some people, impairment of all motor functions

- **Sensory problems**, such as loss of vision or hearing, pain and altered sensation.

- **Cognitive/behavioural problems**, such as: lapses in memory and attention; difficulties in organisation, planning and problem-solving; confusion; apathy; dis-inhibition and lack of insight into difficulties. People with these problems may need additional support to make decisions and take responsibility for their own care.

- **Communication problems**, such as difficulties in speaking or using language to communicate and in fully understanding what is said or written. People with these problems may need additional support to access information or to communicate their needs and wishes.

- **Psychosocial and emotional effects** of the condition for the individual, such as potential personality changes after a brain injury and the emotional and psychological effects of living with a long-term condition generally on the individual, their carer and family. These can include stress, depression, loss of self-image and cognitive/behavioural issues, which may lead to relationship breakdown if not addressed.

Cognitive/behavioural, communication and psychosocial problems cam have wider effects, influencing employment, relationships and concerns around stigma.

Even amongst a single condition within neurological conditions there can be a wide range of severity and need. For example without headache this can range from severe chronic migraines to infrequent tension headaches.

Cost

The most recent estimates show that current spending on neurological health and social care services was £4.26 billion in 2011/12. Expenditure on neurological conditions has grown significantly since the publication of the National Service Framework, increasing from 2.9% to 4.6% of total NHS expenditure between 2004/05 and 2011/12, representing £2.25 billion in extra resources[6].

In 2011/12, NHS Wiltshire PCT spent approximately £71 per weighted head of population on neurological conditions. This was £10 per head lower than the England and South West SHA totals.[7] Future spending comparisons will difficult due to the dissolution of the Primary Care Trusts (PCTs) and the establishment of the new Clinical Commissioning Groups (CCGs).

National policies

The National Service Framework (NSF) for Long-term (Neurological) Conditions (LTnC) was launched in March 2005. The NSF aims to transform the way health

and social care services support people to live with long-term neurological conditions. There are eleven quality standards within the NSFLTnC:

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

A recent report from the Neurological Alliance highlights key recommendations to improve services for people with neurological conditions.
http://www.neural.org.uk/updates/205-New-report-on-improving-outcomes-for-people-with-neurological-conditions

What are the needs of the population?

Data on the incidence and prevalence of long term neurological conditions is difficult to collate due to the complexities of some of the conditions.

There are a large number of neurological conditions and the information in this report only includes detailed data on the more common neurological conditions. In addition neurological conditions can be difficult to diagnose and therefore there may be people living without a diagnosis or with an incorrect diagnosis.

Table 1 provide estimates of the number of people in Wiltshire suffering from some of the more common neurological conditions. Migraine, epilepsy and essential tremor account for a large proportion of the numbers. These are followed by Parkinson's disease (PD), Multiple Sclerosis (MS), Cerebral Palsy (CP) and Myalgic Encephalomyelitis (ME). Dementia estimates are included for reference only, as dementia is covered in detail in the dementia section of the health and wellbeing JSA. Therefore, subsequent data after Table 1 do not include dementia.

Table 1: Incidence, prevalence and estimated numbers in Wiltshire with more common neurological conditions

	Incidence per 100,000	Prevalence per 100,000	Wiltshire estimated numbers
Brain injury with long term problems		228 to 1200	1087 to 5722
Brain tumour	20		95
Cerebral Palsy		186	887
Charcot Marie Tooth		40	191
Dystonia		65	14,304
Epilepsy	50 to 80	500 to 800	310
Essential tremor		850	2,384 to 3,815
Huntington's		13.5	4053
Migraine	400	15,000	64
Migraine, chronic		3,000	71,522
Motor Neurone Disease (MND)	2	7	33
Multiple Sclerosis (MS)	4	120 to 163	572 to 777
Muscular dystrophy		50	238
Myalgic encephalomyelitis		300 to 500	1,430 to 2,384
Myasthenia gravis		30	143
Parkinson's disease	17	200	954
Post-polio syndrome		100 to 300	477 to 1,430
Progressive supra-nuclear palsy		6	29
Spina Bifida and Hydrocephalus		24	114
Traumatic brain injury requiring hospital admission	175		834
Dementia		1,000	6379
Estimated total excluding dementia			**99,721 to 107,599**
Estimated total including dementia			**106,100 to 113,978**

Data sources: Neuro numbers 2003, NSFLTnC 2005, NICE CG137 Epilepsy 2012, MS national audit 2011, Dementia Prevalence calculator (v2), ONS mid-year estimates 2012.

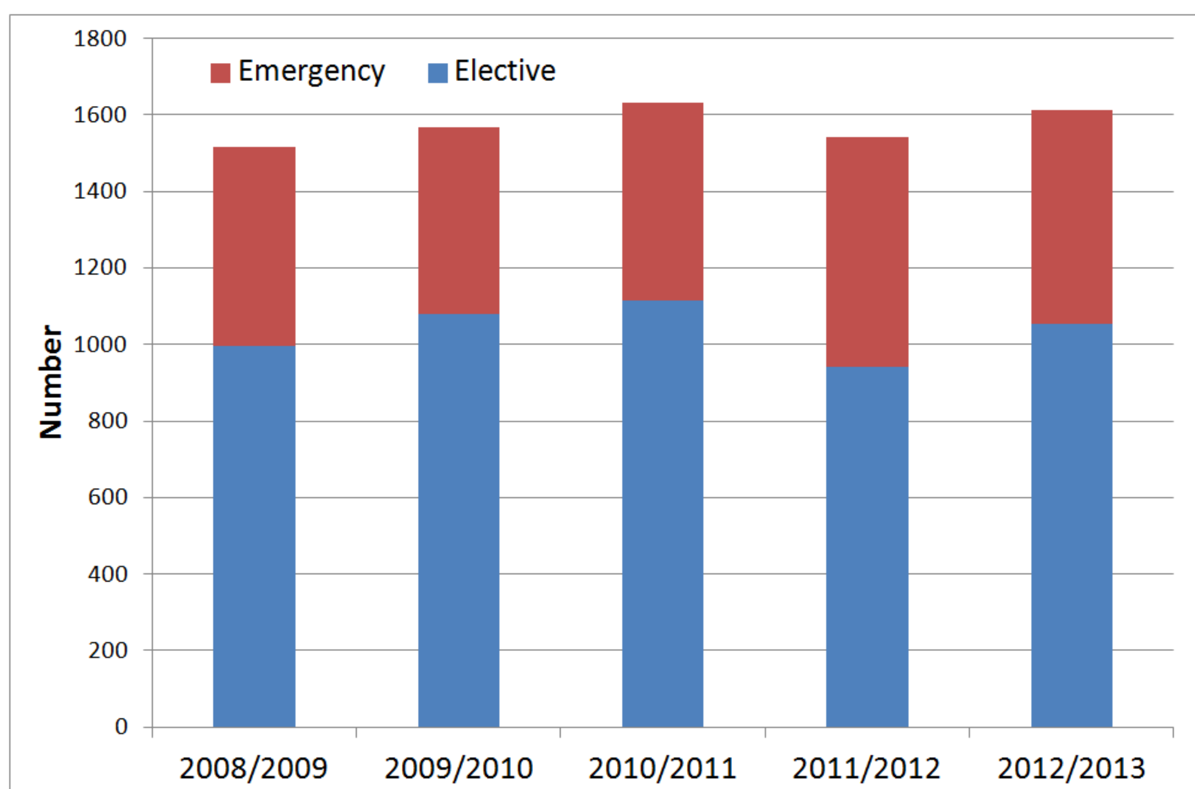
Mortality data for neurological conditions has not been included due to concern that it is unlikely to represent the burden of neurological conditions. This is due to a number of difficulties associated with using death registration data. Death certification may not be fully accurate or complete. Some individuals with long term neurological conditions will die as a result of other causes, and the neurological condition may not be recorded. The numbers are small so year to year variations can be large[8].

It is useful to understand the difference between neurological conditions as the main reason for admission (as derived from the primary diagnosis code) compared to cases where the neurological condition was coded as a secondary diagnosis. An analysis of admissions by primary diagnosis quantifies the direct impact of the neurological conditions on service demand whereas an analysis of secondary diagnoses helps us to understand the wider impact that neurological conditions have on other conditions as well as service configuration[9].

In 2012/13 in Wiltshire there were a total of 1,614 hospital admissions for neurological conditions* as the primary diagnosis. Of these 561 were emergency admissions (Figure 1).

For elective neurological admissions the three main conditions were mono-neuropathy (31.7%), poly-neuropathies (26.7%) and Multiple Sclerosis (22.6%). For emergency neurological conditions the three main conditions were epilepsy (39%), migraine (19.1%) and Parkinson's disease (7.7%). It should be noted that epilepsy is an ambulatory case sensitive condition[10] and so emergency admissions should be more likely to be avoided.

Figure 1: Number of emergency and elective hospital admissions for neurological conditions as primary diagnosis

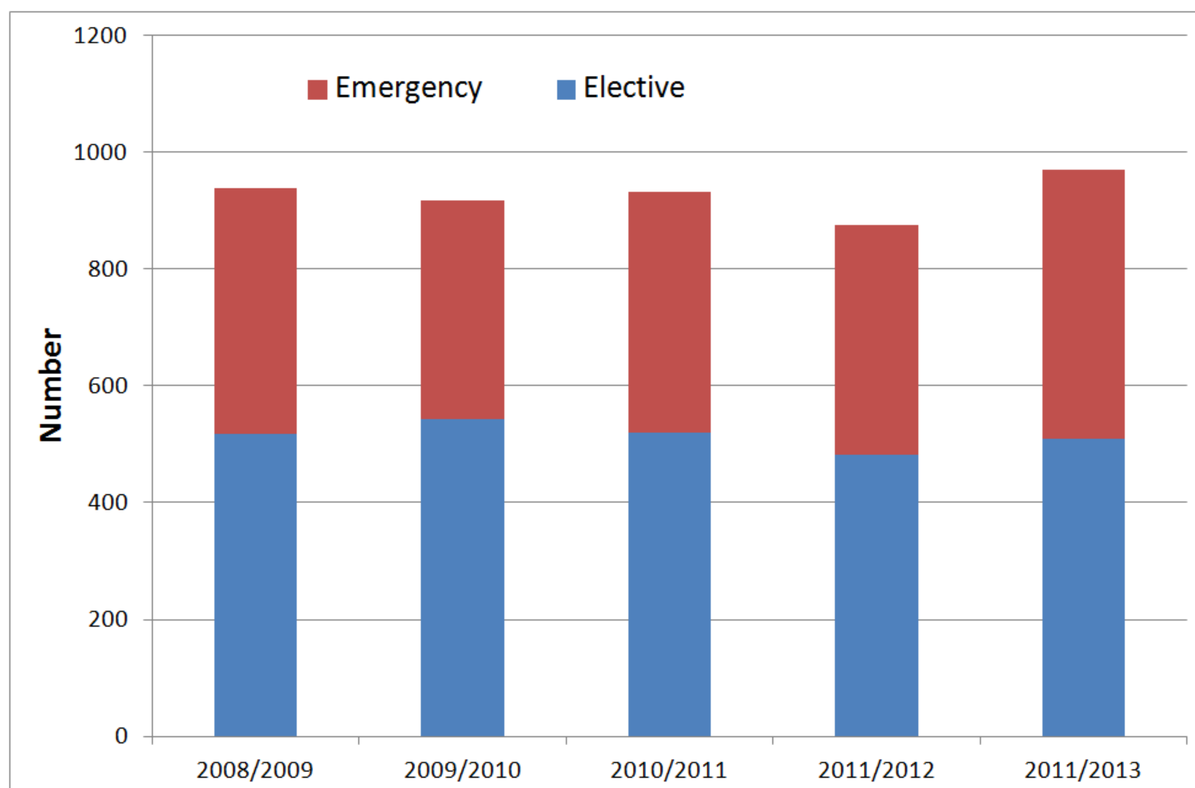


Data source: Central Southern CSU SUS data
* ICD10 Codes: G00-G09, G10-G14, G20-G26, G35-G37, G40-G44, G56-G58, G60, G62, G70-G71, G80-G83, G91.

In addition in 2012/13 there were 1,012 hospital admissions (elective and emergency) where neurological conditions were the (first) secondary diagnosis (Figure 2).

The most common primary diagnoses where a neurological condition was coded as a secondary diagnosis, is found in the ICD10 chapter group of Diseases of the musculoskeletal system and connective tissue (15.1%). The other most common conditions which have neurological conditions coded as a co-morbidity include 'Symptoms, signs and abnormal clinical and laboratory findings' (14.2%) and 'Diseases of the respiratory system' (12.5%).

Figure 2: Number of emergency and elective hospital admissions for neurological conditions as secondary diagnosis.



Data source: Central Southern CSU SUS data
* ICD10 Codes: G00-G09, G10-G14, G20-G26, G35-G37, G40-G44, G56-G58, G60, G62, G70-G71, G80-G83, G91.

In Wiltshire, in 2012/13, there were more admissions for common neurological disorders (epilepsy, MS, headache, PD, paralysis) in people living in the most deprivation quintile compared to those in other groups (427 admissions in most deprived quintile compared to 340 in the least deprived). This difference is actually smaller than in 2011/12 when the gap was 145 compared to 87. In addition, the indirectly standardised admission ratios (SAR) for all deprivation quintiles, apart from the most deprived, are statistically significantly lower than the England value. The SAR for the most deprived quintile is higher than England but not statistically significantly so.

The greater number of admissions and the higher SAR in the most deprived quintile may be due to a higher prevalence or health services issues such as access to care and control of underlying condition. However either way it suggests that the 'need' is greater in areas within Wiltshire with most deprivation but further research would be required to establish the nature of the need, i.e. whether there are more people with neurological conditions in deprived areas or the people with neurological conditions in deprived areas need additional resources manage their conditions better and reduce hospital admissions.

Due to the relatively small numbers of some conditions and variation in prevalence data estimated numbers have not been calculated for Community Area.

Epilepsy

Epilepsy is defined as a tendency to have recurrent seizures caused by a sudden burst of excess electrical activity in the brain. This causes temporary disruption in the normal messages passing between brain cells. Epilepsy is not a single condition; it is currently thought that there are over 30 different epileptic syndromes and 38 different types of seizure[11].

In Wiltshire in 2011/12, 3,018 people are on the GP QOF register as suffering from epilepsy (0.8% of the 18 and over population). Of these[12], 72.0% who were receiving treatment were seizure free in the last 12 months.

Wiltshire has lower (age standardised) mortality rate from epilepsy than England, (1.19 per 100,000 compared to 1.52 per 100,000)[13]. This is not statistically significantly different however.

Multiple Sclerosis (MS)

MS often starts in young adulthood (20-40 years of age) but most patients have a nearly normal lifespan. In an individual patient the course of the condition is unpredictable but can range from a few minor, short-lived problems to a large number of severe and continuing problems. The range of clinical and functional problems it generates is vast and may involve almost any part of any healthcare service.

A national audit in 2011 found none of the six key NICE recommendations made in 2003 had been implemented widely or fully.

Current service provision

Salisbury NHS Foundation Trust has a contract with Southampton for two neurology consultants who run clinics at Salisbury and see inpatients. There is a community neurology therapy team based at SFT which are employed by GWH who cover South Wiltshire for outpatients and the community. Basic neurology therapy input can also be provided by the Neighbourhood teams throughout Wiltshire and some outpatient musculoskeletal services.

Enabling self-management is also a very important aspect of neurological conditions.

The Royal College of Physicians have produced a description of neurology services.
http://www.rcplondon.ac.uk/specialty/neurology

A national report in 2009[14] found:

- Despite NICE guidelines that all people with suspected epilepsy should be seen by an epilepsy specialist, 49% of acute trusts do not employ one.

- Despite NICE guidelines stating that all people with suspected epilepsy should be seen urgently (within two weeks), most trusts (more than 90 per cent) have waiting lists of longer than this.

- Despite NICE guidelines stating epilepsy specialist nurses (ESNs) should be an integral part of the medical team providing care to people with epilepsy; well over half of acute trusts (60 per cent) and PCTs (64 per cent) do not have one.

What works

There are a number of NICE guidance documents available for central nervous system conditions, as well as a number of technology appraisals. NICE guidance is available for:

- Epilepsy; CG 137.
- Multiple Sclerosis (MS); CG8.
- Parkinson's Disease (PD); CG 35.
- Summary of cancer service guidance on brain tumours; CSGBraincns.
- Head Injury; CG56.

http://www.nice.org.uk/

What do the public/service users/people think?

A survey was carried out by the Swindon and Wiltshire Neurological Alliance (SWNA) to identify ways to improve the management of long---term neurological conditions. This survey was completed by patients using the neurological services in Swindon and Wiltshire and the report[15] detailing the findings is a source of intelligence for commissioners regarding the service requirements of neurological service users.

The findings reveal low levels of awareness amongst patients about long---term neurological conditions, and the accessibility of services. When patients were asked about information provision in relation to health and social care services, over half of the respondents in each area answered that they did not receive any information at diagnosis regarding services that could help. This could be improved to provide the same level of access to high---quality neurology services, to all patients across Wiltshire and Swindon.

The key---findings of the survey were:

- A person centred service: Specifies the range and incidence of neurological conditions.

- Care Planning: Awareness and implementation of the written care plan by patients was poor.

- Information Provision: Most patients do not receive any/enough information about their condition and how to access services to manage it. Many patients also did not have a single point of contact for information or advice.

- Early Recognition, prompt diagnosis and treatment: The majority of patients received a definite diagnosis in under 12 months, however many patients waited over year for a confirmed diagnosis.
- Emotional Support: The provision of counselling/emotional support to patients and their families was inadequate.
- Emergency and acute treatment: Patients admitted to hospital as an emergency not concerning their neurological condition reported a low level of neurological support.
- Rehabilitation: Access to community or vocational rehabilitation services was limited.
- Assistive Technology/Equipment Services: Equipment provision was generally positive across both areas.
- Care and Support: Support for carers' of patients with neurological conditions was minimal, with many carers not receiving any education or training to care for their loved ones.
- Patient views: A view of services from the patients' perspective highlights the areas that require improvement, and areas doing well.

A stakeholder group for Wiltshire with Public Health and CCG input meets quarterly to discuss and action current issues. In addition, an annual Stakeholders event for LTnC has been held in Wilshire since May 2009. This is an opportunity for service users and carers to come together and consult on needs, services and pathways. Education events for health professionals have also been conducted to enable a greater understanding of the needs of those with neurological conditions.

The stakeholder group and NHS Wiltshire produced a 'Neurological Condition Information Booklet 2012' which encompasses services available in Wiltshire and how to access different help and support.
http://wiltshireinvolvementnetwork.org.uk/ESW/Files/NeurologyBookletForEmail.pdf

The stakeholder group also supports the Swindon and Wiltshire Neurological Alliance.

Challenges for Consideration

- Community support for client, families and carers including:
  - Expert Patient Programmes.
  - Support groups.
  - Key workers / care co-ordinator.
  - Consider need for specialist nurses (MS, PD, epilepsy)
- Consideration to the need for and capacity of neuro-rehabilitation.

- Improved diagnosis, referral, knowledge and awareness amongst health and social care professionals. This should include understanding on methods of non-verbal communication.
- Increase self-management by increasing knowledge and education.
- Fast response (services / support) when required to reduce crisis / emergency admissions.
- Wider engagement with people with neurological conditions.
- Consider need of those living in more deprived areas, as hospital admissions are higher in these areas.

These challenges were developed from discussions at the 2012 Neurological Event stakeholder day and local data.

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[1] Healthy Lives, Healthy People: Improving outcomes and supporting transparency, Department of Health, January 2012 https://www.gov.uk/government/publications/healthy-lives-healthy-people-improving-outcomes-and-supporting-transparency
2 NHS Outcomes Framework 2014/15, Department of Health, 2013. https://www.gov.uk/government/publications/nhs-outcomes-framework-2014-to-2015
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[4] http://www.neural.org.uk/updates/205-New-report-on-improving-outcomes-for-people-with-neurological-conditions
[5] National Service Framework for Long Term Neurological Conditions, 2005. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4105777.pdf
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[8] North East Public Health Observatory. Health Needs Assessment for Long Term Neurological Conditions in North East England. 2009 http://www.nepho.org.uk/securefiles/120817_1519//Health%20Needs%20Assessment%20for%20Long%20Term%20Neurological%20Conditions%20in%20NE%20England%20Final.pdf
[9] North East Public Health Observatory. Health Needs Assessment for Long Term Neurological Conditions in North East England. 2009 http://www.nepho.org.uk/securefiles/120817_1519//Health%20Needs%20Assessment%20for%20Long%20Term%20Neurological%20Conditions%20in%20NE%20England%20Final.pdf
[10] ACSCs are conditions for which effective management and treatment should prevent admission to hospital. They can be classified as: chronic conditions, where effective care can prevent flare-ups; acute conditions, where early intervention can prevent more serious progression; and preventable conditions, where immunisation and other interventions can prevent illness (Ham et al 2010).
[11] Epilepsy in England: time for change, 2009. http://www.epilepsy.org.uk/sites/epilepsy/files/images/campaigns/Epilepsy_in_England_-_Time_for_change_report.pdf
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