Neurological Commissioning Support (NCS) has produced this report for the Southwest strategic clinical network (SCN). It outlines the current services and support available for people living with 10 neurological conditions.

These conditions have the highest neurology spend in the Southwest according to hospital episodic statistics (HES) for 2011-2012\(^1\). NCS produced a quantitative report from the HES data as part of our work for the Southwest SCN. The two reports can be viewed together. The report also highlights where important needs may not be being met.

\(^1\) Unless stated otherwise, all material contained in Neurowatch reports and therefore the HES data reported on within this report, is covered by a disclaimer and protected by copyright laws. The full disclaimer can be found in the appendices.
Neurology: an overview

In this report we highlight the variation and lack of standardisation across the Southwest. The report emphasises emerging priorities and core neurology indicators that should be considered for neurology service commissioning.

An average clinical commissioning group (CCG) has a population of 225,000, and will have approximately 42,000 people living with a neurological condition such as multiple sclerosis (MS), Parkinson’s, motor neurone disease (MND) or epilepsy. There are many problems with neurology services, including long delays in receiving diagnosis, lack of access to information, and fragmented and poorly co-ordinated care. This is why informed and expert commissioning is essential.

Key guidance

The National Service Framework for long-term conditions (NSF: 2005), published in March 2005 is the single most comprehensive guidance for neurology services. Although no longer recognised as core policy by the government, it provides a framework for the standards that services should seek to meet, supporting development. It is relevant both for people with neurological conditions and those supporting them.

The NSF sets out 11 quality requirements to transform the way health and social care services support people with neurological conditions to live as independently as possible. A midterm review of the NSF for long-term conditions conducted by NCS (NCS: 2010) found that not a single one of the primary care trusts (PCTs) surveyed, was able to meet all 11 of the NSF’s quality requirements.

The NHS Outcomes Framework (DH: 2013) sets out the key outcomes to be achieved by the NHS in five domains. In 2012, the Neurological Alliance produced a document to examine how the health and social care reforms could be used to improve outcomes for the neurology community.
‘Intelligent Outcomes’ (NA: 2012), warns that the government has virtually no accountability measures to address the many serious problems with neurological services. The report also provides a useful interpretation of the NHS Outcomes Framework for neurology, looking at neurology-specific outcomes in each domain.

A recent report for the National Audit Office and the Public Accounts Committee demonstrated that many of the problems faced by patients a decade ago, before the NSF, still persist. Current spending on neurological health and social care services estimated at £5.3 billion in 2009-10, does not provide value for money (NAO: 2012).

Social care spending on services for people with physical disabilities has remained constant at £2.4 billion in 2009-10. While social services are defined by disability rather than clinical condition, estimates are that around 25% of 16–64 year olds with a chronic disability and a third of people in residential care have a neurological condition.
Overview of the data
In addition to the information provided by the National Audit Office (NAO: 2012), analysis of the latest available data (DH: 2012) reveals that on average, a third of PCT expenditure was been spent on non-elective and emergency neurological services.

Across the Southwest, data indicates that there is an increase in admissions (and subsequently costs) year on year from 2009/10–2011/12. Costs rose between 2009/10 and 2011/12, although they dipped slightly between 2010/11 and 2011/12 (see table 1).

There were 174,729 admissions across the region over three years. The overall cost for the three years is particularly significant for the area, reaching over £235 million pounds (£236,458,624).

Table 1: Total admissions and costs across highest 10 conditions 2009/10–2011/12

<table>
<thead>
<tr>
<th>Year</th>
<th>Total admissions</th>
<th>Total costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009/10</td>
<td>53,713</td>
<td>£ 69,610,269</td>
</tr>
<tr>
<td>2010/11</td>
<td>59,110</td>
<td>£ 84,483,519</td>
</tr>
<tr>
<td>2011/12</td>
<td>61,906</td>
<td>£ 82,364,836</td>
</tr>
<tr>
<td>Total</td>
<td>174,729</td>
<td>£ 236,458,624</td>
</tr>
</tbody>
</table>
The most expensive condition is epilepsy at a cost of £74,146,477 over three years for primary and secondary diagnosis.

We examine data briefly by condition in the second half of this report, including a comment on weighted population data. All weighted population data is from 2011–12 and based on primary and secondary diagnosis only.

**National guidance**
A range of national guidance is available about the appropriate support for people living with various specific neurological conditions, and further guidance for some conditions is still in development.

**Table 2: a summary of neurological NICE clinical guidelines for the conditions included in this report**

<table>
<thead>
<tr>
<th>NICE clinical guideline</th>
<th>Publication date</th>
<th>Publication number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head injury</td>
<td>2003</td>
<td>CG 4</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>November 2003</td>
<td>CG 8</td>
</tr>
<tr>
<td>Parkinson’s</td>
<td>June 2006</td>
<td>CG 35</td>
</tr>
<tr>
<td>Epilepsy (adults and children)</td>
<td>January 2012</td>
<td>CG 137</td>
</tr>
<tr>
<td>Headaches</td>
<td>September 2013</td>
<td>CG 150</td>
</tr>
<tr>
<td>Spinal injury assessment</td>
<td>May 2015</td>
<td>Under development</td>
</tr>
<tr>
<td>Motor neurone disease</td>
<td>TBC</td>
<td>Under development</td>
</tr>
</tbody>
</table>

Other guidance for neurology includes:

- The National Service Framework (NSF) for long-term conditions (NSF: 2005)
- Year of care and national care pathways for:
  - Parkinson’s (McMahon and Thomas: 1998)
  - Motor neurone disease (MNDA: 2008)
  - Progressive supranuclear palsy (Peel et al 2012)
Costed care pathways for MS, Parkinson’s and MND (Thomas et al: 2010).

- National end of life care guidance (GSF: 2011) and specifically for neurology (NHS: 2011)
- Parkinson’s UK’s guidance for appropriate medicine access in acute settings (PUK: 2010)
Executive summary

Neurological conditions have been included in the first wave of priority areas for the strategic clinical networks (SCNs). This is an important recognition of both the progress that has been made in prioritising neurological conditions to date, and of the challenge ahead to improve services in the best interests of people with a neurological condition.

This report provides the Southwest SCN with a baseline for the clinical commissioning groups (CCGs) and providers in the network to measure their performance from. It also gives recommendations for a more responsive and cost effective approach to managing neurological conditions in the future. There is no more money in the system and better ways of working that also provide improved outcomes for patients are essential.

This report from Neurological Commissioning Support will help the network to focus on the challenges ahead. It will help the SCN to understand what its immediate priorities should be and what existing work can be draw on.
Key findings and recommendations

Findings

1. The Southwest’s rural nature means that access to services is a challenge across neurology.

2. There are pockets of excellence and positive practice that can be learned from and extended or replicated elsewhere.
   a. There are also examples of positive services for one condition that could be extended to other conditions in the locality.

3. There are challenges in service access and provision for all of the conditions in different ways that need addressing.

4. Where specialist nurses exist, user and carer experience of services is largely better as is access to services. However, most of the nurse posts are covering huge populations (larger than the NICE recommended ratio of nurse to patient is 1:250) and nurses are unable to be as effective as they might otherwise be.

5. GPs are often a person’s point of contact when their condition changes or they need access to extra support, and GPs are therefore the gatekeepers to services. The level of their understanding about the condition will affect the support that people receive which may not be what they need.

6. Some of the most cited positive practice were examples of integrated community-based teams with good secondary care liaison, or spanning both health and social care, demonstrating the value of this service in providing coordinated, holistic care.

7. There are very few care pathways in place, even informally, and those which do exist are not necessarily being implemented.

8. Not all individuals with a neurological condition are under the care of a specialist, including those with Parkinson’s, hydrocephalus and epilepsy. These individuals are managed by their GP who may have little understanding of their condition.
Recommendations

For action:

1. **Identifying best practice**: Ensure examples of current best practice in neurology working are made explicit so that models can be replicated across the network.

2. **Education**: Review education of GPs and clinicians in the community to improve community management of people with neurological conditions.

3. **Leadership**: Identify named GPs or clinicians within each area who will lead on neurology for their health economy.

4. **Planning and monitoring**: Develop a robust plan for how the network will measure and report its achievements; this could include:
   a. Developing key performance indicators for CCGs to work towards and implement a means of gathering the relevant data to monitor these effectively.
   b. Influencing the development of Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies across the network to ensure that the needs of people with neurological conditions are recognised, accurately represented and appropriately prioritised.
   c. Undertaking an annual audit of progress which reflects the priority areas set out in the original strategy and work plan.

5. **Pathway development**: Develop core pathways that are relevant across the Southwest in line with positive practice, and adaptable to local service configurations:
   a. Clear, written or web-based integrated neurological pathways which can be tailored to signpost to local sources of advice and support.
   b. Specific pathways to address some of the more common causes of emergency admission: urinary tract and respiratory infections, falls and senility. These should be developed as a matter of priority.

6. **Data gathering and intelligence**: The SCN should focus on addressing emergency admissions and readmissions for people with neurological conditions across the Southwest, initially addressing common causes of these admissions.
For further investigation:

1. **Involving and empowering patients and carers:** Support for improved information sources and self-care should be established using a range of different models. This should include exploring the use of technology solutions such as apps and telehealth.

2. **Education:** Explore making greater use of professionals not regularly involved in patient management to build capacity in neurology teams.
   
   a. For example, practice in Cornwall shows the value of community pharmacists undertaking medicines management and providing advice and support to patients.

3. **Pathway development:** Explore a common Southwest protocol for referrals, transfers and discharges across the NHS, social care, the voluntary sector and private providers to create ‘maps’ for families to visualise individual condition pathways. These should be co-created by all stakeholders.

4. **Supporting the implementation of national guidance:** Explore an effective means for the SCN to:
   
   a. Support the translation and implementation of national guidance about to neurological conditions at a local level.
   
   b. Lead on measuring progress in achieving the performance indicators outlined in guidance documents (e.g. NICE guidance and quality standards).

5. **Data gathering and intelligence:** The SCN should explore and identify risk stratification tools to be used by CCGs, encouraging them to adopt a more proactive approach to management of unnecessary emergency admissions for neurology. They need to ensure patients are seen by the right professional at the right time.
Condition-specific recommendations
The recommendations given in this executive summary are those relevant to neurology as a whole. Each condition has its own recommendations, some of which are applicable to other conditions, and some which are specific to the condition.

The highest cost: key recommendations for epilepsy
Epilepsy admissions continue to be significant for the network with expenditure of £74,146,477 over the past three years.

Risk of mortality is high. The general population mortality declined by 16% between 1993 and 2005 but has risen for epilepsy to 31% in males and 39% in females.

Full recommendations can be found in the section on epilepsy but overarching recommendations are:

- Request Quality and Outcomes Framework (QOF) payment details from GPs to gather a higher level of information
- Encourage practices to identify and improve their performance
- Identify the practices with the highest admissions and audit those GP practices with the highest admission counts
- Highlight good practice services and encourage transferability to local areas. For example, the first seizure clinic in Cardiff.

Condition-specific recommendations
Each condition has its own specific recommendations. Page numbers for each of these have been noted below for easy navigation.

- Epilepsy (p 36)
- Parkinson's (p 43)
- Multiple sclerosis (p 51)
- Acquired brain injury (p 58)
- Hydrocephalus (p 63)
- Aphasia (p 68)
- Cerebral palsy (p 72)
- Migraine (p 76)
- Spinal cord injury (p 82)
- Myasthenia gravis (p 85)

Please note: The majority of tables containing quantitative data can be found in the accompanying appendices in Excel format for ease of reference and to optimise future use of the data. Qualitative data, text, and social care data which is in grid format, can be also be found in the appendices.
Overview of neurology commissioning, strategy and inclusion in the Southwest

User engagement and involvement
People with neurological conditions are often not well represented as lay members on governance groups. Common symptoms such as fatigue and difficulties with mobility and travel can mean that attending meetings is challenging.

Regional Neurological Alliances (RNAs), affiliated to national membership organisation the Neurological Alliance (www.neural.org.uk), provide one mechanism for feeding in the views of users and carers by representing people living with a neurological condition in their area. (Table 3 in the appendices provides details of the RNAs in the Southwest.)

CQuINs, strategies and incentives

Neurology strategies
There are few neurology strategies in place in the Southwest and sporadic inclusion of neurology within the different areas’ joint strategic needs assessments.

Table 4 (in the appendices) shows which CCGs in the Southwest SCN area have any emphasis on neurology such as through strategies, plans or inclusion of neurology in their joint strategic needs assessment.

Somerset CCG has highlighted their intention to review their neurological service provision between 2013 and 2015 and this is greatly welcomed by the charities operating locally.
Leads for neurology in commissioning

It is rare to have a neurology lead in commissioning. Neurological service commissioning tends to fall under the remit of the ‘long-term conditions’ role.

(Table 5 in the appendices lists the relevant leads for each CCG in the Southwest.)

CQuINS

There are no CQuINS in the Southwest that are specific to people with neurological conditions.
There are CQuINs in some areas that relate to end-of-life care more generally, which will impact on the quality of care provided for people living with a neurological condition. These are in:

- Gloucestershire
- BANES
- Somerset

Other CQuINs, outlined in the various Quality Handover Documents (see appendices) of the different areas, are likely to have an impact on people with a neurological condition even though they are not specific to neurology. These include those relating to:

- general hospital care
- comorbidities such as reduction of urinary tract infections, falls and pressure ulcers
- some associated neurological symptoms such as psychological support.

**Joined up care**
Co-ordinated or integrated care is made challenging across the Southwest as there are no specific structures or plans in place to bring people together who can plan and deliver more joined up services. Charities supporting people living with a neurological condition locally say this is one of the most significant deficits in the region. The current service provision, which should otherwise be largely adequate for the area, is made weaker through poorer planning and coordination.

**Variation in social care**
Adult Social Care Outcomes Framework figures for 2011–12 (HSCIC: 2013) highlight clear variation in provision and waiting times across the Southwest. Looking at the number of council-supported permanent admissions of younger adults to residential and nursing care, for example, the England average is 19.1. However, in the Southwest, that same figure varies from 34.6 in Torbay to 8.6 in Plymouth. For the Southwest as a whole the figure is 22.6, slightly higher than national average.
We have seen data from the National Adult Social Care Intelligence Service (NASCIS: 2013) which gives an indication of performance against the England average. While social care data is not viewed by condition, we have looked at indicators which may have an impact on those living with a neurological condition. (Table 6 in the appendices provides full data given for the county and unitary councils covered by the strategic clinical network area.)

Key findings include:

- Eight out of 12 council areas have a social care related quality of life score the same as or higher than the England average (based on outcome domains of social care).
- The majority of council areas have a proportion of permanent admissions to residential and nursing care homes for older people per 100,000 population the same or higher than the England average.
- Seven out of 12 of the councils were above the England average, when looking at delayed transfers of care from hospital which were attributable to adult social care, expressed as a percentage.
- Nine out of 12 council areas have a proportion of older people offered re-ablement services following discharge from hospital expressed as a percentage 2012/13 which is lower or the same as the England average.
- Overall satisfaction of people who use services with their care support, expressed as a percentage, 2012–13 is equally split between higher and lower than the England average.
Deprivation
The Southwest has relatively low levels of deprivation, although there are pockets of severity, such as in isolated rural areas and urban centres. For example, the health of people in Plymouth is generally worse than the England average. Torbay, Bristol and Plymouth have the greatest proportions of their populations living in deprivation (SWO: 2012).

Overview of neurology service provision for the Southwest

General neurological service provision

Within the condition-specific reporting, any services particular to each condition are noted, as are any challenges with services, or current progress or changes to these.

However, there are a number of services which are largely the same and accessible across all 10 conditions, and these are noted here.

The Southwest Alliance of Neurological Organisations (SWANO) provides an overall directory of neurology services online (SWANO: 2013).

Neurologists and specialist consultants
There are 14 core secondary care acute trust providers across the Southwest providing consultant neurologists and physicians in care of the elderly for those living with a neurological condition.

Some of the neurologists specialise in specific conditions and some condition-specific clinics are run in areas, such as epilepsy or Parkinson’s clinics in Gloucestershire. In most cases, all neurologists see all neurology patients, referring to a colleague with a speciality as and when needed. (Full details of all neurologists and physicians for the elderly leading in movement disorders, as well as their clinics, where known, are available in the appendices.)
In addition to consultants, some neurology or condition-specific specialist nurses are in post across the Southwest. These are noted in each condition-specific section where there is a relevant nurse. (Full details of all specialist nurses and their clinics, where known, are available in the appendices.)

Torbay Hospital neurology department, part of South Devon Healthcare NHS Foundation Trust now has sub-specialties in epilepsy, neuro-inflammatory and neuromuscular diseases. It currently plans to set up local neurophysiology and inflammatory infusion services. Additional long-term plans include the development of inpatient and acute neurology services and of neuro-rehabilitation.

Neuro-rehabilitation and multi-disciplinary care
Mardon Neuro-Rehabilitation Centre, provided by Royal Devon and Exeter NHS Foundation Trust is purpose built and provides a range of inpatient facilities and services for individuals with neurological conditions over the age of 16. It comprises a full multi-disciplinary team including clinical psychology, and provides a range of support from initial assessment and treatment to support and advice for re-integration into the community.

In some areas, specialists in neurology are spearheading new practice or championing changes to service delivery.

Ralph Hammond, clinical specialist physiotherapist (neurological conditions) with Somerset Partnership NHS Foundation Trust, is currently involved in the development of Independent Living Teams (ILTs) throughout Somerset, which will bring together a range of professionals from various disciplines, including physiotherapy, and aim to provide more 'joined up' and seamless services for people affected by neurological conditions.
Benchmarking the Southwest

The main guidance available for neurology service standards, despite being no longer recognised as core policy by the government, is the National Service Framework (NSF) for long-term conditions (NSF: 2005).

A midterm review of the NSF for long-term conditions conducted by NCS (NCS: 2010a) found that not one primary care trust (PCTs) surveyed could meet all of the 11 quality requirements of the NSF.

NCS have an audit and evaluation tool called ‘Quality Neurology’, which measures how well a health and social care economy is meeting the quality standards of the NSF (MS Society et al: 2010). Of the areas in the Southwest, NHS Gloucestershire PCT (now Gloucestershire CCG) and Cornwall and the Isles of Scilly PCT (now Kernow CCG) have been audited. Gloucestershire has had two audits: in 2009 (NCS:2010b) and 2012 (NCS: 2012), while Kernow was audited in 2011 (NCS: 2011).

Table 7 shows the status of Gloucestershire and Kernow CCGs across the 11 quality requirements from their most current audits. The RAG status refers to ‘met’ (green), ‘part met’ (amber) and ‘not met’ (red) for each quality requirement. The rural benchmark gives an average attainment across various rural CCGs that have been audited.
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>QR1 A person-centred service</td>
<td>Not met</td>
<td>Part met</td>
<td>Part met</td>
<td>Part met</td>
</tr>
<tr>
<td>QR2 Early recognition</td>
<td>Part met</td>
<td>Part met</td>
<td>Part met</td>
<td>Part met</td>
</tr>
<tr>
<td>QR3 Emergency &amp; acute management</td>
<td>Not met</td>
<td>Part met</td>
<td>Met</td>
<td>Met</td>
</tr>
<tr>
<td>QR4 Early &amp; specialist rehabilitation</td>
<td>Not met</td>
<td>Part met</td>
<td>Met</td>
<td>Met</td>
</tr>
<tr>
<td>QR5 Community rehabilitation &amp; support</td>
<td>Not met</td>
<td>Met</td>
<td>Part met</td>
<td>Met</td>
</tr>
<tr>
<td>QR6 Vocational rehabilitation</td>
<td>Not met</td>
<td>Part met</td>
<td>Not met</td>
<td>Part met</td>
</tr>
<tr>
<td>QR7 Providing equipment &amp; accommodation</td>
<td>Part met</td>
<td>Part met</td>
<td>Part met</td>
<td>Part met</td>
</tr>
<tr>
<td>QR8 Providing personal care &amp; support</td>
<td>Part met</td>
<td>Part met</td>
<td>Met</td>
<td>Part met</td>
</tr>
<tr>
<td>QR9 Palliative care</td>
<td>Not met</td>
<td>Met</td>
<td>Met</td>
<td>Not met</td>
</tr>
<tr>
<td>QR10 Supporting family &amp; carers</td>
<td>Part met</td>
<td>Part met</td>
<td>Part met</td>
<td>Not met</td>
</tr>
<tr>
<td>QR11 Caring for people in hospital or other health &amp; social care settings</td>
<td>Not met</td>
<td>Part met</td>
<td>Part met</td>
<td>Part met</td>
</tr>
</tbody>
</table>

Thèmes that came through in both Cornwall and Gloucestershire as needing improvement may indicate themes to consider across the Southwest, given the similarities of setting, geography, and demographics. These include:

- Information
- Inequality
- Integrated services
- Maintaining independence
- Transitional services
Some of the specific recommendations for these include:

- Provide appropriate information and advice for services users by an information directory, listing local services and the development of a single point of access such as a neurology care advice line.
- Put equitable access to all treatment, services and methods in place and look at IT solutions which may help with poor transport and rurality issues.
- Develop integrated care pathways and closer partnerships with social care so that care across both areas is more integrated. Consider voluntary sector partnerships to increase service capacity.
- Ensure greater access to rehabilitation, with services and equipment available promptly, and look at providing more targeted exercise facilities.
- Develop clear pathways and guidelines for the transition of patients from paediatric to adult services, and adult to older people services, including support for carers during these times.

Specialist service provision

- **Deep brain stimulation (DBS):** North Bristol NHS Trust hosts the neuro-surgery tertiary care unit for DBS and has a linked team of surgical movement disorder nurses. A national best practice pathway for DBS (NCS: 2013) is included for information in the appendices.
- **Vagal nerve stimulation (VNS):** North Bristol NHS Trust provides VNS at Frenchay Hospital through the neuro-surgery team. VNS is a surgical procedure to reduce seizures in epilepsy patients. Bristol is considered a centre of excellence for epilepsy.
- **Functional electrical stimulation (FES):** The National Clinical functional electrical stimulation (FES) Centre is based in Salisbury District Hospital, Wiltshire. FES is a specialist service which may be required by those with MS experiencing drop-foot.
- **Specialist equipment:** Access to specialist equipment can be challenging because of the cost of more complex, bespoke pieces of equipment needed by those with neurological conditions.
Some charities supply equipment to service users where the NHS does not provide funding. Access to bespoke wheelchairs is particularly problematic, where criteria simply do not meet the needs of some people with neurological conditions.

Anecdotal reports from the voluntary sector in the Southwest report that neurological service users often have to use an exceptional funding route for the services and equipment they require.

**GPs with a special interest**

GPs with a special interest, or GPwSIs, are of huge value to their peers, and, with GPs leading commissioning, could ensure effective service access for people with neurological conditions from planning stages through to delivery.

Across the Southwest, GPs with a special interest in neurology are starting to emerge as leads for their CCGs.

**Table 8: GPwSIs or CCG leads for neurology across the Southwest**

<table>
<thead>
<tr>
<th>Name</th>
<th>Speciality / title</th>
<th>Area based in</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Rob Turner</td>
<td>GP/Clinical Lead Neurology</td>
<td>Taunton and Somerset</td>
</tr>
<tr>
<td>Dr David Kernick</td>
<td>RCGP registered specialist GP lead for migraine</td>
<td>Exeter (Headache Clinic)</td>
</tr>
<tr>
<td>Dr Heinz La Roux</td>
<td>GP/Clinical Lead Neurology</td>
<td>Gloucestershire</td>
</tr>
<tr>
<td>Dr John Garman</td>
<td>GPwSI in Parkinson’s</td>
<td>Cornwall</td>
</tr>
<tr>
<td>Dr Rupert Manley</td>
<td>GPwSI in epilepsy</td>
<td>Cornwall</td>
</tr>
</tbody>
</table>

Contact details, where known, are included in the appendices.

**Challenges for the Southwest**

Given the geography, rurality and level of public transport in of most of the Southwest, there is significant value in community-based and outreach services, particularly as many people with neurological conditions have mobility problems too. Many services in the region are hospital-based and do not offer the range of
outreach services that might be needed. Often the person with the condition will be expected to travel, sometimes significant distances, to receive their care.

Service responsiveness

Little systematic data was explicitly gathered on the responsiveness of services. However, for some conditions, specific services were noted as particularly responsive and cited as positive practice, while others were noted for particularly lengthy waiting times or challenges with access. This is predominantly anecdotal, locally gathered evidence. A few such examples are given here.

Positive responsiveness of services

Positive practice in general has been gathered and is shown throughout the report in yellow boxes marked with a star symbol. Positive practice does not necessarily imply responsiveness of services but it will almost certainly deliver improved overall care. This often results in individuals experiencing the service as being more responsive to their needs.

- Torbay health and social care zone teams, clustered around GP practices and comprising co-located multi-disciplinary teams enable health and social care decisions and arrangements to be made in one place and by one team, improving onward access to services and reducing waiting times and referral challenges (see section on MS).
- North Bristol NHS Trust new Development Worker (carer & support) post visits intensive care, neurology and high dependency units on a weekly basis for acquired brain injury patients. This service has created a smoother inward referral processed for individuals, ensuring access to the services as they are needed.
- The MND clinical specialist post based with Gloucestershire Care Services as part of a community-based team of neurology nurses provides expert advice, co-ordination and education around MND across the county. Data from the first two years of this post showed a marked increase in the number of people with MND who avoided hospital admission at end of life and were able to die at home, in line with their preferences.
Challenges in responsiveness of services

Challenges or potential problems with services, whether owing to levels of responsiveness, local practice, integration or other reasons, are noted throughout the report in red boxes with a red flag symbol.

- Waiting times for psychological services in Cornwall when compared with Devon are very poor (see section on MS).
- The Mardon Neurological Rehabilitation Centre in Exeter has no access to the discharge teams provided by the Royal Devon and Exeter NHS Foundation Trust resulting in minimal access to ongoing community rehabilitation. While they signpost to Headway Devon, the need to seek funding on a case by case basis for the charity often results in delays to ongoing support.
- Access to spare wheelchair parts from the Hayle-based wheelchair service in Cornwall is challenging with over a week’s waiting times for a spare wheel or tyre at times (see section on SCI).
- Social care services across the Southwest are not fully engaged in joining up with health care planning and delivery, leading to delays in care and fragmentation of the care pathway. The exception to this is where integrated care is delivered, such as in Torbay, and through Sirona Health and Care in BANES.
- According to Shine Charity, people with hydrocephalus often experience delays in accessing the care they need because GPs are often reluctant to refer them to neurosurgery services.

Emergency and elective acute care

What the data shows

There is no one pattern across neurology for the data for elective versus non-elective admissions. However, Table 9 shows which conditions have a higher level of elective (planned) admissions, and which have higher non-elective (emergency) admissions. Also noted in the table is the top comorbidity for each condition, to show a likely preventable reason for some of those emergency admissions.
Table 9: Elective vs non-elective admissions across the top 10 neurology spends

<table>
<thead>
<tr>
<th>Condition</th>
<th>Elective admissions</th>
<th>Emergency admissions</th>
<th>Top comorbidity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td>9,525</td>
<td>10,904</td>
<td>Holiday relief care</td>
</tr>
<tr>
<td>Parkinson's</td>
<td>3,285</td>
<td>4,764</td>
<td>Urinary tract infection</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>5,095</td>
<td>1,782</td>
<td>Urinary tract infection</td>
</tr>
<tr>
<td>Acquired brain injury (ABI)</td>
<td>316</td>
<td>1,757</td>
<td>Traumatic subdural haemorrhage</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>953</td>
<td>1,234</td>
<td>Hypertension²</td>
</tr>
<tr>
<td>Aphasia</td>
<td>354</td>
<td>1,247</td>
<td>Urinary tract infection</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>2,318</td>
<td>1,310</td>
<td>Epilepsy (unspecified)</td>
</tr>
<tr>
<td>Migraine</td>
<td>917</td>
<td>1,970</td>
<td>Headache</td>
</tr>
<tr>
<td>Spinal cord injury</td>
<td>484</td>
<td>345</td>
<td>Urinary tract infection³</td>
</tr>
<tr>
<td>Myasthenia gravis</td>
<td>398</td>
<td>267</td>
<td>Other chemotherapy</td>
</tr>
<tr>
<td>Motor neurone disease (MND)</td>
<td>225</td>
<td>275</td>
<td>Respiratory infection</td>
</tr>
</tbody>
</table>

The highest count of non-elective admissions for each condition is shown in table 10, alongside the total cost of those admissions.

² The highest comorbidity for hydrocephalus is ‘presence of cerebrospinal fluid drainage device’ so we have taken the comorbidity which is not the condition itself but a preventable complication associated with the condition.

³ The highest comorbidity for spinal cord injury is ‘other specified diseases of the spinal cord’ so we have taken the comorbidity which is not the condition itself but a preventable complication associated with the condition.
Table 10: The highest spend on non-elective admissions per CCG

<table>
<thead>
<tr>
<th>Condition</th>
<th>Total cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td>£3,086,027</td>
</tr>
<tr>
<td>Parkinson's</td>
<td>£1,720,097</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>£603,054</td>
</tr>
<tr>
<td>Acquired brain injury (ABI)</td>
<td>£925,107</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>£521,108</td>
</tr>
<tr>
<td>Aphasia</td>
<td>£765,669</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>£329,289</td>
</tr>
<tr>
<td>Migraine</td>
<td>£584,396</td>
</tr>
<tr>
<td>Spinal cord injury</td>
<td>£207,785</td>
</tr>
<tr>
<td>Myasthenia gravis</td>
<td>£144,528</td>
</tr>
<tr>
<td>Motor neurone disease (MND)</td>
<td>£93,933</td>
</tr>
</tbody>
</table>

Red flags for emergency admissions

The most common avoidable comorbidities for the top 10 conditions reported on here were:

- Urinary tract infections
- Respiratory infections
- Holiday relief care or respite care

Those individuals most at risk of a urinary tract infection include people with neuropathic bladders such as those with a spinal cord injury, MS and Parkinson’s. Worsening of spasticity can increase the likelihood of developing a UTI, while other

---

4 This considers the top two most common comorbidities for each condition where their neurological condition was either the primary or secondary reason for diagnosis. It notes the most easily preventable comorbidities across all conditions.
individuals considered at risk are those with a catheter in situ, or those who have had recurrent infections (NICE: 2012).

Respiratory infections, including pneumonia and pleurisy, are common in people with neurological conditions who may inhale food particles or saliva, or struggle with swallowing. This affects those with conditions like motor neurone disease, myasthenia gravis, progressive supranuclear palsy, as well as those in advanced stages of Parkinson’s or MS.

Recommendations to further explore the problem or aid reduction of these avoidable admissions are shown in Table 11.
Table 11: Comorbidities and recommendations associated with prevention

<table>
<thead>
<tr>
<th>Comorbidity</th>
<th>Recommendations</th>
</tr>
</thead>
</table>
| Urinary tract infection (UTI)            | • Risk stratify patients likely to experience bladder problems  
                                          • Improve patient education to spot early signs of UTIs and encourage self-management  
                                          • Proactive community management, such as bladder scanning in the home or telehealth solutions for self-testing  
                                          • Utilise continence advisors and establish clear continence pathways across primary and secondary care  
                                          • Red flag conditions with known bladder complications  
                                          • Review services in line with national guidance on bladder management (NICE: 2012; RCN: 2008) |
| Respiratory infections                   | • Risk stratify patients at risk of developing respiratory infection  
                                          • Clear respiratory pathways in place to ensure effective prevention, or, where necessary management of infection  
                                          • Appropriate referral to key professionals such as speech and language therapists  
                                          • Access to appropriate equipment as required |
| Holiday relief or respite care           | • Further exploration is required to understand whether this refers to acute hospital beds, and if so, why  
                                          • Review respite care provision for those with more complex neurological conditions and ensure appropriate facilities are available |
Condition-specific reporting

The top 10 conditions in order of highest spend are:

1. Epilepsy
2. Parkinson’s
3. Multiple sclerosis
4. Acquired brain injury
5. Hydrocephalus
6. Aphasia
7. Cerebral palsy
8. Migraine
9. Spinal cord injury
10. Myasthenia gravis

Peripheral neuropathy and CNS infections were highlighted as a top 10 spend in the actual data report. However these are comorbidities not conditions and while they affect overall neurology spend, they are features of other conditions. We have therefore removed them from the scoping exercise. This has enabled inclusion of two additional conditions.

Motor neurone disease (MND) has been included as an additional ‘11th’ condition. While it did not fall into the top 10, it is a high cost and high impact condition and management of MND has implications which should be considered when reviewing neurology overall.

Neuropathies also link to cardiovascular, renal and diabetes services. We would suggest that the data be followed up by the relevant networks for these conditions to clarify whether the neurology patients with these issues are being appropriately followed up for their comorbid problems.

As much pertinent information has been included for each condition, focussing on both positive practice and challenges with provision across primary, secondary, tertiary and social care. However, this information is reliant on desk research and local information held by charities supporting those with that condition. The extent and depth of data provided, then, does vary from condition to condition, depending on the information available at the time of writing.
Details of each condition’s prevalence are included within their distinct sections with detail per clinical CCG. However, Table 12 demonstrates the approximate prevalence of each of the 10 conditions across the Southwest as a whole.

**Table 12: the prevalence of neurological conditions in the Southwest**

<table>
<thead>
<tr>
<th>Condition</th>
<th>No. of people living with this in the Southwest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td>47,129</td>
</tr>
<tr>
<td>Parkinson’s</td>
<td>9,425</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>7,724</td>
</tr>
<tr>
<td>Acquired brain injury (ABI)</td>
<td>26,298</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>471</td>
</tr>
<tr>
<td>Aphasia</td>
<td>40,136</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>11,782</td>
</tr>
<tr>
<td>Migraine</td>
<td>673,265</td>
</tr>
<tr>
<td>Spinal cord injury</td>
<td>3,299</td>
</tr>
<tr>
<td>Myasthenia gravis</td>
<td>471</td>
</tr>
<tr>
<td>Motor neurone disease (MND)</td>
<td>331</td>
</tr>
<tr>
<td><strong>Total across all conditions</strong></td>
<td><strong>820,331</strong></td>
</tr>
</tbody>
</table>

See *appendices* ‘Prevalence data’ in excel sheet for full details.
Epilepsy

Overview

Prevalence
One person in every 100 has epilepsy. That's more than half a million people in the UK, or 47,089 people in the Southwest (Table 13). Using national prevalence data, approximate numbers of people living with epilepsy are shown in Table 13.

About epilepsy
Epilepsy is the most common serious neurological disorder with an incidence in the UK of 51 per 100,000 per annum and prevalence of 970 per 100,000 per annum (JEC: 2011). The incidence is high in children and rises again in people aged above 65 years.

- Chief economic burdens have been previously identified as inpatient admissions (45%), inappropriate prescribing of antiepileptic drugs (AEDs) (26%), outpatient attendances (16%) and GP care (8%). Accurate diagnosis is therefore key (JEC: 2011; Juarez-Garcia et al: 2006).
- A study of epilepsy mortality and risk factors (Ridsdale et al: 2011) showed that epilepsy is the fifth highest amenable cause of years of life lost before 75 for males and eighth highest for females.
- Between 1993 and 2005 mortality for all causes in the general population of England and Wales declined by 16%. In contrast mortality with epilepsy recorded as an underlying cause increased by 31% in males and 39% in females during this period.
- People at particular risk from death from epilepsy include those:
  - with alcohol problems
  - who do not collect repeat prescriptions for AEDs
  - who have recent injuries
  - receiving treatment for depression
- Patients who are seizure free for more than 12 months have a much lower risk of seizures generally.
- Epilepsy was the seventh most common reason for re-admission in 2006/7 in a Department of Health review (DH: 2008).
General comments on services for epilepsy across the Southwest

Anecdotally, there is a significant variation in the quality and provision of services across the area. There is a centre of excellence in Bristol (Frenchay Hospital, North Bristol NHS Trust) which provides a high quality of care, while some people in the Southwest will travel to the other centre of excellence close by, at University Hospital Southampton NHS Foundation Trust.

In Devon there is a perceived north-south divide between areas supported by a specialist nurse and those which are not. Nurses who are community based are regularly involved in pastoral care, supporting groups, activities, events, or providing education and training to schools and employers. Some provide community clinics for rural areas while others can prescribe, reducing consultant appointments. Individual reports to Epilepsy Action demonstrate the perceived difference in quality of care from areas supported by a nurse, and those which are not.

South Devon and Torbay Clinical Commissioning Group has carried out patient audits to measure satisfaction with the current service and proposes to continue involving patients to measure the impact of a new nurse post.

A brief glance at the data

Headlines from the data include:

- Total admissions (primary and secondary diagnosis) for epilepsy have increased across the Southwest over the last three years from 17,470 in 2009/10 to 20,432 in 2011/12 (see Table 14).
- Costs have also increased from £21,800,882 to £25,969,041.
- The three most common co-morbidities (where epilepsy was the secondary diagnosis) cost over a million pounds (£1,180,296) and were for:
  - Holiday relief care costing £171,127.
  - Hypertensive renal disease with renal failure, costing £54,158
  - Urinary tract infections with a significant cost of £955,011.
Table 14: Total admissions and costs for epilepsy: 2009/10 - 2011/12 at a glance

<table>
<thead>
<tr>
<th>Year</th>
<th>Total admissions</th>
<th>Total costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009/10</td>
<td>17,470</td>
<td>£ 21,800,882</td>
</tr>
<tr>
<td>2010/11</td>
<td>19,255</td>
<td>£ 26,376,554</td>
</tr>
<tr>
<td>2011/12</td>
<td>20,432</td>
<td>£ 25,969,041</td>
</tr>
</tbody>
</table>

Local services

Primary and community services
Individuals with epilepsy are likely to see their GP as a first point of contact if something changes with their condition, particularly if there is no specialist nurse in their area.

GPs specifically need to understand the risks associated with epilepsy. Education for GPs is a paramount requirement. For example, a common group at risk of seizure are young women beginning to take contraceptive medication, as some contraceptives can interfere with anti-epileptic drugs (AEDs) rendering them less effective.

There is a shortage of medical care staff with training and expertise in epilepsy and many people with epilepsy travel long distances to regional neuroscience centres for tests and treatment. As a result, acutely ill neurology patients are often not under the care of an epilepsy specialist. They will either have to wait for a long time for expert diagnosis, treatment and advice or they may not receive this at all.
Secondary and tertiary services
All of the hospital providers support epilepsy patients, although not all have a consultant who specialises in epilepsy, or specialist nurses to provide follow-up care and a point of contact. Nurse specialists bridge the gap between hospital and community care, are patient advocates and provide practical support including medication management and prescribing. The map below highlights the specialist nurse provision for epilepsy across the Southwest (see table 40, appendices).

South Devon Healthcare NHS Foundation Trust is currently appointing a fourth consultant neurologist with understanding of epilepsy in order to provide ‘urgent neurology clinics’. These will allow first seizure patients to be seen by a specialist within two weeks. The specialist nurse supporting the area is also highly proactive, providing clinics, residential care visits, emergency support and training every week both to carers of those supporting someone with complex epilepsy, and to practice nurses.

Those consultant neurologists with a specialist interest in epilepsy are listed in table 39 of the appendices.
North Bristol NHS Trust offers vagal nerve stimulation (VNS) at Frenchay Hospital, a service which will come under specialised commissioning regulations.

Reducing mortality is a key aim for CCGs both around the CCG Outcomes Indicator Set (CCGOIS: 2013) and to achieve their Quality Payments (QP: 2013). Early death from epilepsy is not uncommon and ensuring preventative care and risk stratification of epilepsy populations can make a huge difference in reducing epilepsy mortality.

A recent study in Cornwall into epilepsy mortality in the county (SUDEP: 2013) has found that the deaths are not as ‘sudden’ as is thought, with most patient’s seizures getting worse prior to death. Many of the patient who died were not engaged with their GP or specialist in the months prior to death. Interestingly, very few people who died were in the higher risk learning disability population, suggesting community based learning disability services in Cornwall may be protective (service practices anecdotally have a strong risk management and communication strategy as well as excellent outreach with GPs). Further research findings are expected shortly.

**Psychological services**

Mental health is a key issue in epilepsy but services are largely poor across the Southwest. There is a real need across the area for access to psychosocial support for people with epilepsy and their carers.

There is also a need for liaison with other services including psychology support for patients with epilepsy and those with non-epileptic attack disorder.

More focus also needs to be given to the most vulnerable groups in society with epilepsy such as children and young people, minority ethnic groups, prisoners, the elderly and women, all of which experience very specific problems due the current epilepsy service provision.

**Social care and other local services**

Social care provides a number of services which may be needed by those with epilepsy. Core services, though, are educational and vocational support, to ensure individuals with epilepsy are able to work as fully and independently as possible. This may require some specialist equipment, but more commonly requires education of the employer.
In Cornwall, there is a dedicated learning disabilities and epilepsy service. The service practices strong risk management and communication, as well as having excellent outreach with GPs. In the recent SUDEP (2013) mortality study for epilepsy in Cornwall, very few people who died were in the higher risk learning disability population. This suggests that the community-based learning disability service may be protective.

Given that those with epilepsy who have regular seizures are unable to drive, access to appropriate public transport is important to enable their independence. Transport systems in the Southwest are often challenged by rurality. Cornwall and Gloucestershire particularly struggle with public transport facilities (NCS ‘Quality Neurology’ audits; reports available on request).

Voluntary sector services
Epilepsy Action and Epilepsy Society are the two biggest national charities supporting people with epilepsy:

- Epilepsy Action provides a helpline, information and advice as well as supporting local branches.
- Epilepsy Society also provides advice and support, as well as a centre of excellence for diagnostic testing and assessment, and facilities for respite care for people with highly complex epilepsy.

Recent user and carer opinion and needs mapping
Epilepsy Action recently undertook research into services for epilepsy, reported on in ‘A critical time for epilepsy in England’ (EA: 2013). Seven of the nine core NHS providers in the Southwest chose not to respond to Epilepsy Action’s survey for this research.

Findings across England include:

- 80% of people with suspected epilepsy have to wait more than the recommended 2 weeks to see a specialist consultant for diagnosis.
- 73% of people having seizures have never been referred to a specialist centre.
- Trusts do not provide their populations with specialist epilepsy doctors in 34% of cases, or access to specialist epilepsy nurses in 46% of cases.
Recommendations

- Identify service gaps across the Southwest to ensure prompt diagnosis and establish first seizure clinics where these are not available.
- Benchmark areas using NASH (National Audit of Seizure management in Hospitals)\(^5\).
- Improve professional awareness to identify those with epilepsy who may be at risk of death. This could be aided by:
  - Ensuring education is in place for GPs (training is available through the RCGPs, national lead for which is Dr Greg Rodgers).
  - Developing key performance and quality indicators for practice.
- Ensure regular reviews of people with epilepsy taking medication, ideally including wellbeing and lifestyle checklists.
- Access to epilepsy specialists is essential for correct diagnosis and initial treatment.
- There should be equity of access to epilepsy nurse specialists who can:
  - Prevent admission through more regular monitoring of seizure frequency.
  - Improve seizure freedom rates by monitoring concordance and supervising titration regimens with which a GP may feel unfamiliar or uncomfortable.
  - Prevent admission by ensuring medication errors are minimised.
  - Shorten length of stay by minimising medication errors and facilitating early discharge.
  - Prevent unnecessary admissions by seeing epilepsy patients quickly in the emergency department.
  - Improve pharmacy involvement to ensure medication errors are minimised.
- Greater involvement of General Practice to flag patients for review and those not collecting prescriptions.
- Consider the development of a GPwSI across the Southwest to work alongside the specialist epilepsy teams.

\(^5\) National Audit of Seizure management in Hospitals (NASH) [http://www.nashstudy.org.uk](http://www.nashstudy.org.uk) (email: info@nashstudy.org.uk)
Parkinson's

Overview

Prevalence
One person in every 500 has Parkinson’s. That's about 127,000 people in the UK, or 9,611 people in the Southwest (table 15). Using national prevalence data, approximate numbers of people living with Parkinson’s are shown in table 15.

There is a higher than average elderly population in the Southwest, however, so the numbers of those living with Parkinson’s are expected to be higher than average.

About Parkinson’s
Parkinson’s is a progressive neurological condition caused by a loss of nerve cells in the brain which leads to a deficit of the neurotransmitter dopamine and causes Parkinson’s symptoms to appear.

Without dopamine people can find that their movements become slower so it takes longer to do things. The main symptoms of Parkinson’s are tremor, rigidity and slowness of movement. As well as affecting movement, people with Parkinson’s can find that other issues, such as tiredness, pain, depression and constipation, can have an impact on their day-to-day lives. The symptoms someone has and how quickly the condition develops will differ from one person to the next (PUK: 2013).

General comments on services for Parkinson’s across the Southwest
Although Parkinson’s is a neurological condition, around 75–80% of people living with Parkinson’s are managed by a care of the elderly physician, with only approximately 20–25% regularly seeing a neurologist. This situation represents a challenge to whole-systems working and to the development of joined up care pathways.

The Southwest, as well as having a high elderly population also has a very high number of care homes. Unfortunately, there are is a high volume of anecdotal evidence that people with Parkinson’s have moved into a care home only to cease access to specialist and other important services due to the capacity of individual services to engage with this group – something of great concern.

People with Parkinson’s commonly find it challenging to get their medication on time in inpatient facilities. This is often a particular problem when the individual has been admitted as an emergency not directly related to their condition, such as a urinary
tract infection or a fall. People with Parkinson’s have an individual medicines regimen which must be adhered to. Missed doses can lead to extreme difficulties, causing discomfort and deterioration to the individual and increased length of stay and greater rehabilitation needs creating higher costs per stay. In some cases it can lead to irreversible deterioration in the person’s functional abilities.

A brief glance at the data
Headlines from the data include:

- Total admissions (primary and secondary diagnosis) for Parkinson’s have increased across the Southwest over the last three years from 7,031 in 2009/10 to 8,049 in 2011/12 (see Table 16).
- Costs have also increased from £11,928,363 to £13,781,537.
- The two most common co-morbidities (where Parkinson’s was the secondary diagnosis) had a combined cost of over £2 million (£2,093,862) and were for:
  - Urinary tract infections costing a significant £1,530,601.
  - Senility, costing £563,261.

Table 16: Total admissions and costs for Parkinson’s: 2009/10–2011/12 at a glance

<table>
<thead>
<tr>
<th>Year</th>
<th>Total admissions</th>
<th>Total costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009/10</td>
<td>7,031</td>
<td>£11,928,363</td>
</tr>
<tr>
<td>2010/11</td>
<td>7,335</td>
<td>£12,961,677</td>
</tr>
<tr>
<td>2011/12</td>
<td>8,049</td>
<td>£13,781,537</td>
</tr>
</tbody>
</table>

Weighted data (Parkinson’s): admissions per 1,000 pop

- NHS Gloucestershire CCG: 2.24
- NHS Bristol CCG: 1.03

Weighted data (Parkinson’s): Costs per head of pop

- NHS North Somerset/NHS Bristol CCG: £4.69
- NHS Bristol CCG: £1.50
Local services

Primary and community services
The primary care service most accessed by people with Parkinson’s is the GP service. GPs tend to be the first point of contact for individuals when their condition changes, particularly if they do not have access to a specialist nurse.

GPs are explicitly advised by NICE Guidance (NICE: 2006) to identify symptoms as possible Parkinson’s but not to diagnose or to treat directly, but to refer the individual to secondary care for diagnosis and to follow subsequent medication recommendations. Unfortunately, Parkinson’s UK holds anecdotal incidences of people who have never seen a consultant for formal diagnosis, meaning they are unlikely to be accessing the range of services they need, or to have their condition under control through effective medication management.

Out-of-hours services are often essential for people with Parkinson’s to access as crisis intervention instead of referring to Accident and Emergency. This can only be the case where people know about the out-of-hours service and it is responsive to their needs, which unfortunately is not always the case.

Lyn Gill, Parkinson’s nurse at North Devon District Hospital in Barnstaple operates a rapid response service to GPs to avoid unnecessary hospital admissions.

Important community-based services for people with Parkinson’s include specialist nurses, some of whom are community-based, and the wider multi-disciplinary teams. Multi-disciplinary working is not consistently coordinated and often relies on individual professionals rather than agreed structures.

The Parkinson’s specialist nurses across the Southwest are roughly depicted below, whilst Table 17 in the appendices (excel) contains details of all these nurses.
Secondary and tertiary services
In secondary care, the main provider for Parkinson’s is the consultant neurologist or care of the elderly physician. In some hospitals, a specific neurologist with a specialism in Parkinson’s may see the majority of Parkinson’s patients. However, in most hospitals care is split across between consultants. This can lead to inequity of care or lack of uniformity of referral into specific services, such as the specialist nurse or multi-disciplinary team, particularly where an agreed care pathway does not exist.

(Table 18 in the appendices lists all of the main movement disorder leads in neurology and care of the elderly for each secondary care provider across the Southwest.)
Historically people with Parkinson’s have had challenges accessing medication on time in Gloucestershire Hospitals NHS Foundation Trust. Claire Pollock, specialist nurse, is working hard to progress a Get it on Time campaign (PUK: GIOT) but is currently struggling to instigate system change without senior management support.

There is a Bristol Health Integration (HIT) team being developed which intends to link clinical services, research and education for Parkinson’s across the Bristol, North Somerset and South Gloucestershire area. There will be a ‘hub’ based at Southmead Hospital with an information area where the local Parkinson’s UK Information and Support Worker would base themselves.

Integrated acute and community service providers exist in Great Western Hospital NHS Foundation Trust (Swindon) and Northern Devon Healthcare NHS Trust, which should improve patient flow through the system and aid coordination of care.

Mobility training groups, developed in the Chippenham / Malmesbury area in partnership with the trust (Great Western), local support group and Parkinson’s UK, have been very well received by attendees.

**Psychological services**

A specific form of dementia is associated with Parkinson’s, known as Parkinson’s dementia. There can be challenges in accessing appropriate mental health support for people with Parkinson’s dementia, however, because the individual is already perceived to be receiving specialist care from a consultant, or because facilities for mental health support are not equipped to manage the other physical needs of someone with Parkinson’s.

Other cognitive challenges for someone with Parkinson’s include depression, apathy and other emotional problems. These may be symptomatic of, or secondary to the condition itself, or a side effect of the medication used to manage the Parkinson’s. In either case, often psychological support would be beneficial, but is difficult to access.
Social care and other local services
Social care services likely to be needed by people with Parkinson’s include domiciliary care, vocational support, residential and respite care, benefits, equipment and adaptations. However, social care services are not fully engaged in joining up with health care planning and delivery, leading to delays in care and fragmentation of the care pathway, however informal it is.

Other concerns about social care are common across the country:

- Personal care assessments do not fully acknowledge the fluctuating and individual nature of the condition.
- Access to appropriate services are not always available to those in residential care, who seem to be largely ‘forgotten’ to the system.

Voluntary sector services
Parkinson’s UK is the national charity supporting people with Parkinson’s, and they have a strong local focus.

- Forty-five local groups provide a range of things from peer support and activities to exercise classes and training.
- Local staff provide:
  - Information and support
  - Training and education
  - Promotion of best practice and support to commissioners and providers.

Recent user and carer opinion and needs mapping
The Somerset LINk (as was) supported the Somerset Neurological Alliance in a survey of people with neurological conditions, which had a separate Parkinson’s report due to the high number of people with Parkinson’s who responded (LINK: 2013)\(^6\).

Headline findings of the survey include:

- Most respondents had positive and negative experiences of neurological care and services in Somerset.
- People need more timely diagnosis
- More should be done to ensure rehabilitation services meet the needs of patients with Parkinson’s

\(^6\) A copy of this report is available on request.
• A significant minority of patients with Parkinson’s were not given sufficient information about their condition or where and how they could access support services.
• Communication by health care professionals with patients with Parkinson’s, and their carers, is poor in too many instances.

Other recent surveys include those by Bristol PCT (as was) and Swindon and Wilshire Neurological Alliance. The main finding of both is the value placed on specialist nurses.

Recommendations
• Equity of access to:
  o A Parkinson’s specialist for diagnosis and initial management of the individual, including compliance with the best practice tariff for Parkinson’s
  o A Parkinson’s nurse specialist with models in place that ensure cross-boundary provision is given.
• Access to:
  o community therapists with specialist knowledge of Parkinson’s
  o community pharmacy to support medication reviews
  o psychology support, memory clinics and community mental health teams
  o age appropriate respite or short breaks
  o palliative care, and later, specialist palliative care services.
• Risk stratification of people with Parkinson’s to ensure appropriate follow up with the right professional.
• Access to individual’s medication on time when in an acute setting to ensure length of stay and quality of life is not compromised.
Multiple sclerosis

Overview

Prevalence
164 people in every 100,000 have multiple sclerosis (MS). That's about 100,000 people in the UK, or 7,410 people in the Southwest (Table 19). Using national prevalence data, approximate numbers of people living with MS is shown in Table 19.

The higher than average elderly population in the Southwest may cause the number of people living with MS to be higher than average.

About MS

- MS is a progressive neurological condition affecting almost three times more women than men. Most people are diagnosed between the ages of 20–40, but it can affect younger and older people too.
- Every person’s MS is different, from the symptoms they experience to the way it affects them, their family, and wider community.
- The condition changes over time, gradually or suddenly, and can vary from day to day for some people.
- Individuals may have complex and fluctuating needs requiring a broad range of services, support, equipment and medication.
- Effective management means taking a long-term and proactive approach from diagnosis until the end of life, and ensuring individuals can access the services they need, when they need them.

General comments on services for MS across the Southwest

People with MS often have mobility difficulties, meaning challenges with access to, or availability of local transport can make access to services more difficult, as well as being a primary cause of social exclusion (MS Society: 2013 - in progress).

Disparities and inequalities in service provision across the Southwest mean that people commonly experience a ‘postcode lottery’ in the care and support available to them. For example, the waiting time to see a neuropsychologist in Cornwall is around seven months, yet if the same person lived in Plymouth they would have to
wait just six to eight weeks\textsuperscript{7}. These variations are echoed in social care (ASC OF: 2013).

**A brief glance at the data**

Headlines from the data include:

- Total admissions (primary and secondary diagnosis) for MS have increased across the Southwest over the last three years from 5,921 in 2009/10 to 6,878 in 2011/12 (see Table 20).
- Costs have also increased from £5,342,655 to £6,713,426.
- The two most common co-morbidities (where MS was the secondary diagnosis) were for:
  - Urinary tract infections costing £501,209.
  - Hypertensive renal disease with renal failure (cost uncalculated).

**Table 20: Total admissions and costs for MS: 2009/10-2011/12 at a glance**

<table>
<thead>
<tr>
<th>Year</th>
<th>Total admissions</th>
<th>Total costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009/10</td>
<td>5,921</td>
<td>£5,342,655</td>
</tr>
<tr>
<td>2010/11</td>
<td>6,745</td>
<td>£8,325,000</td>
</tr>
<tr>
<td>2011/12</td>
<td>6,878</td>
<td>£6,713,426</td>
</tr>
</tbody>
</table>

\textsuperscript{7} Correct at time of writing, July 2013. Information obtained from neuropsychologist Dr Sarah Kenyon, based in Plymouth, and the psychology team based at the Royal Cornwall Hospitals Trust.
Local services

Primary and community services
Multi-disciplinary management is key for people with MS, helping to coordinate care, ensure people are regularly reviewed as their condition changes, and that they receive the services and support they need as they need it.

In both Bristol and South Gloucestershire, new community multi-disciplinary teams with their own administration support, are now offering assessment through to treatment across occupational therapy, physiotherapy, psychology, speech and language therapy and rehabilitation support. Appointments can be home-based if necessary. Sirona healthcare offer a similar community neurology service.

Community matrons are also highly supportive, particularly for those with more complex needs, or who have recently relapsed or been discharged from hospital. There are several teams operating across the Southwest who support people with MS.

In Cornwall, two community-based Neurology Care Advisors work in Cornwall’s neuro-rehabilitation service to give support and advice to all those in Cornwall living with a long-term neurological condition.

The majority of specialist nurses available for people with MS are hospital-based, although a number do outreach clinics. The MS or neurology nurses supporting people with MS are roughly depicted in the following map:
Full details of the nurses are given in Table 21 of the appendices (excel).

A recent study into the BRAMs specialist nursing team, provided by North Bristol NHS Trust, found that the team of three nurses, through phone calls alone, potentially divert around 6,864 calls per year from GP or other community service use (BRAMs: 2010). While this equates to around 5.68 hours per week of phone calls for the nurses, the potential cost of 6,864 GP appointments amounts to £295,152 (Kent: 2012) – far more costly than the nurses, and with significantly less specialist knowledge (see appendices).

Secondary and tertiary services
Diagnosis and ongoing treatment should be given by a consultant neurologist, and medicines management maintained via follow up appointments with the neurologist, or through a prescribing specialist nurse. Table 22 provides details of all of the consultant neurologists with an interest in MS across the Southwest.

A service required by many people with MS is intrathecal baclofen, proven to reduce spasticity and spasm-related pain as well as improve overall ease of care (Rizzo et al: 2004; LSHTM: 2009; Sampson et al: 2000). At the moment, people in Devon, including those receiving treatment in Exeter, have to travel to Plymouth for this. This
may require overnight stays if the individual is affected by fatigue or other symptoms making travel a challenge, causing more cost.

**Table 23: Maximum potential travel cost to the Devon-based patient of intrathecal baclofen provided in Plymouth**

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Mileage</th>
<th>Cost (15p per mile)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial assessment and trial</td>
<td>150</td>
<td>£22.50</td>
</tr>
<tr>
<td>Pump implantation</td>
<td>150</td>
<td>£22.50</td>
</tr>
<tr>
<td>Pump refill every 3 months for one year</td>
<td>600</td>
<td>£90.00</td>
</tr>
<tr>
<td>Pump refill every 3 months for 7 year life of pump</td>
<td>4,200</td>
<td>£630.00</td>
</tr>
<tr>
<td>Total cost to patient over 7 years</td>
<td>4,500</td>
<td>£675.00</td>
</tr>
</tbody>
</table>

**Psychological services**

Psychological support is often needed by people with MS who may be affected by emotional lability or behavioural changes as well as potentially experiencing depression, or difficulty coming to terms with the condition. In a number of places around the Southwest LIFT Psychology operates, offering stress and mood management courses, group and individual courses. The service operates a self-referral policy and has around a 6–8 week waiting list.

However, some individuals need more clinical psychological support. This is often far harder to access. In Gloucestershire there is a seven month wait for the neuropsychologist, while in Cornwall there is only one neuropsychologist based in Truro serving the entire population. As of July 2013 the service was still clearing referrals from September 2012 and onwards into 2013 whilst waiting times to be seen are in excess of seven months. Referrals are taken from GPs and consultants only.
Social care and other local services
Cornwall Adult Care, Health & Wellbeing, Devon County Council and Somerset Adult Social Care will each provide and commission services for people assessed in the critical and substantial bands of risk, but not for those in the moderate and low bands.

Assessment criteria and bands can cause a particular problem for people with MS who experience significant fluctuation in their condition. For many living with MS, how easy or difficult it is to carry out tasks can vary hugely, and is often markedly different during bad periods or a relapse.

Devon County Council adult social care service operates a central phone system called Care Direct, which provides information and advice to callers on staying independent, equipment, personal care, support for carers, blue badges, and benefits. The MS Society has worked with Care Direct to help them understand the needs of people with MS, particularly about cognitive and memory-related symptoms.

Somerset County Council is not a housing authority so residents have to approach district councils with housing-related queries. Some individuals use ‘Homefinder Somerset’, a partnership of local authorities and housing associations working together to make the process of finding a suitable home more simple. However, concerns have been raised by the MS Society that this service is not appropriate for people challenged by cognitive, dexterity and general mobility and movement issues.

Torbay health and social care zone teams are clustered around GP practices and comprise co-located multi-disciplinary teams. This means that health and social care decisions and arrangements can be made in one place and by one team. This minimises the risk that people accessing health and social care services have to tell their story several times and to several different people and aids coordination of care.
Independent Living Centres, where they exist offer practical solutions to daily living. For example, the Independent Living Centre in Semington supports the Wiltshire, Bath and Mendip areas and has in-house occupational therapists and a benefits advisor.

The Vassall Centre Trust in Bristol, led by disabled people, promotes and champions the employment of disabled people throughout the UK. Providing advice on disability and employment, it promotes inclusive workplaces for disabled people, offering a template for barrier-free environments.

**Voluntary sector services**
The Merlin Centre in Cornwall, a charity, offers a range of services for people affected by MS and some other neurological conditions, including hyperbaric oxygen and other complementary therapies, as well as the following clinical therapies: neurological physiotherapy, occupational therapy, exercise therapy, Core Renew Programme (exercise programme (Dawes: 2010)), podiatry and Functional Electrical Stimulation (FES) Assessment.

The Bristol, North Somerset and South Glos. Neurological Alliance (BNSSGNA), formed last year, is currently developing a neurological information booklet. Based on NCS’s template created alongside users and carers and developed in Gloucestershire and Cornwall, the booklet format has been very successful elsewhere.

A number of the local MS Society branches offer information, support, education, exercise classes, social activities and, in some cases, benefits or counselling support depending on the volunteers at the branch.

The MS Society itself offers a helpline, a number of informative and supportive publications, social media, and websites tailored to different audiences. Locally, service development officers support the development of services and sharing of best practice, and local support development officers assist branches and individuals in challenging situations.
Recent user and carer opinion and needs mapping
The MS Society recently undertook a UK-wide survey ‘My MS, my needs’ (MS Society: 2013). National findings include:

- 71% of people with MS need support from their family and friends.
- The greater an individual’s financial insecurity, the more likely they are to need social care support, and the less likely to receive it.
- 1 in 5 people find it difficult or impossible to access a professional when they need one.
- 51% of people who need it are able to access support for emotional or mood issues, symptomatic of MS.

**MS Society national survey finding: Wiltshire was deemed one of the worst places in the UK to access physiotherapy.**

Local surveys include:

- Swindon and Wiltshire Neurological Alliance: key findings on improvements to information access, a clear point of contact, and use of care plans were all required.
- Salisbury MS focus group, which deemed that, overall, the MS coordinator makes the biggest difference to people’s lives.
- Working Locally (Bristol): where the importance of places like the therapy centre, where they can access exercise classes and specialist physiotherapy was highlighted.
- Working Locally (Swindon): which noted the importance of a single point of contact.

Recommendations

- Access to:
  - Specialists for diagnosis and initial management
  - MS specialist clinics for access to disease modifying therapy and in situations where management is complex.
- Risk stratification to identify those patients with complex needs or at risk of relapse.
- Increased community therapy provision by therapists with knowledge of MS
- Increased community MS nurse provision for:
- Ongoing monitoring, education and support
- Anticipation of problems that might prompt an admission to hospital
- Case management in liaison with community matrons
- Signposting to other services including rehabilitation and continence services.

- Access to age appropriate respite care, short breaks and day care.
- Improved management towards complex and end-of-life stages of MS including:
  - an integrated approach to palliative care, advanced care planning and end-of-life care in advanced MS resulting in prevention of avoidable hospital admissions at the end of life.
  - inclusion on end-of-life care registers in general practice.
Acquired brain injury (ABI)

Overview

Prevalence
558 in 100,000 people have an acquired brain injury (ABI). Headway estimates that over one million people in the UK are living with the effects of a brain injury. In the Southwest, this equates to around 25,921 people (Table 24). Using national prevalence data, approximate numbers of people living with ABI is shown in Table 24.

About ABI
ABI is defined as non-degenerative injury to the brain occurring since birth. It can be caused by an external physical force or by metabolic derangement. The term ‘acquired brain injury’ includes traumatic brain injuries, such as open or closed head injuries, or non-traumatic brain injuries, such as those caused by strokes and other vascular accidents, tumours, infectious diseases, hypoxia, metabolic disorders (e.g. liver and kidney diseases or diabetic coma), and toxic products taken into the body through inhalation or ingestion. (UKABIF).

The majority of people with an ABI will have at least some cognitive, physical, emotional or behavioural symptoms and difficulties. Some people will recover from their brain injury within a few weeks, while others will have disabilities for the rest of their lives.

General comments on services for ABI across the Southwest
The Southwest is a vast geographical area, with the main neuro and trauma centres based in Plymouth and Bristol. The ABI survivors with the greatest need are those who do not ‘fit’ with the stroke pathway and require a longer specialised approach to rehabilitation. This includes people with mild to severe cognitive disabilities and those with high complex care needs as a result of their disability.

Initial rehabilitation for those with complex care needs generally takes place in the acute trusts. There are insufficient recognised or known services to provide the post-acute rehabilitation needed. The risk is that the ABI survivors will be admitted to a residential home, and miss out on their rehabilitation opportunity. The rurality of the Southwest and scarcity of services causes real challenges to accessing local rehabilitation and support services in the local community.
For people who do receive post-acute rehabilitation, if there is no step-down facility locally, the individual may still be admitted to a residential home, or be transferred somewhere away from family and friends which can be detrimental to mental wellbeing and overall recovery.

Those with mild cognitive disability are often ‘lost’ in the system, appearing to have recovered and to communicate effectively. They may be experiencing hidden difficulties such as memory problems, cognitive understanding, or poor control of emotions. People with these symptoms need community support to help them to live independently in their locality. Without support, these individuals often become known to social services as a ‘problem’.

Community support for people with ABI is predominantly funded by the local authority. However, with the recent reduction in services people with ABI and their families are becoming increasingly isolated. Ongoing community-based rehabilitation is very variable across the region and where community services can offer a service, this is generally only for a limited period. People with an ABI who are assessed with low to moderate need often do not qualify for ongoing support despite evidence indicating that ongoing rehabilitation enables individuals to remain in their own homes and reduces the need for a residential placement.

The lack of coordination across health and social care is recognised as an ongoing issue. Without a clear integrated care pathway, people with ABI may not be referred to social care services after discharge from an acute setting, especially if they do not have obvious care needs. Those discharged from a post-acute rehabilitation provider are more likely to be referred to social services, as they are already in the system but this does not guarantee they will receive the support they need.

A brief glance at the data
Headlines from the data include:

- Total admissions (primary and secondary diagnosis) for ABI have increased across the Southwest over the last three years from 2,058 in 2009/10 to 2,074 in 2011/12 (see Table 25).
- Costs have also increased from £4,517,954 to £5,463,130.
- The two most common co-morbidities (where ABI was the secondary diagnosis) were for:
  - Traumatic subdural haemorrhage costing £472,484.
  - Traumatic subarachnoid haemorrhage costing £153,894.
Table 25: Total admissions and costs for ABI: 2009/10- 2011/12 at a glance

<table>
<thead>
<tr>
<th>Year</th>
<th>Total admissions</th>
<th>Total costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009/10</td>
<td>2,058</td>
<td>£ 4,517,954</td>
</tr>
<tr>
<td>2010/11</td>
<td>2,099</td>
<td>£ 4,794,221</td>
</tr>
<tr>
<td>2011/12</td>
<td>2,074</td>
<td>£ 5,463,130</td>
</tr>
</tbody>
</table>

Local services

Primary and community services
Rehabilitation is essential for people with ABI, and the best outcomes are where rehabilitation is commenced as soon as a person is medically stable. This can lead to ongoing improvements for up to five years or more. The greatest visible progress tends to occur in the first six months post-injury.

Community rehabilitation may be appropriate, provided the service has a good understanding of ABI and the implications for this condition on the individual. Specialist community support is available through privately provided services such as Active Assistance (http://www.activeassistance.com/) and Tracscare (http://www.tracscare.co.uk/).

Core primary care services may also be needed by those with an ABI such as district nursing or podiatry. The GP needs to be involved to ensure that the individual’s needs are met in the community but unless the GP understands the person’s needs, they may not get the support they need.
Secondary and tertiary services
Care pathways are essential for ABI services, particularly with the crossover from acute specialist care to community and social care and support.

The Rehabilitation prescription is being implemented by the Trauma Centre at Plymouth and Bristol NHS Trusts with an aim that the individual will be followed up for two years post injury, although this is not yet evident in practice.

Several years ago Yeovil District Hospital NHS Foundation Trust also developed a pathway, but this was not used in practice.

The Brain Injury Rehabilitation Unit at Frenchay Hospital is an example of an independent provider working in partnership with the North Bristol NHS Trust. They provide post-acute rehabilitation and facilitate discharge. The service works with the Head Injury Therapy Unit (providing psychological support and care) and the Burden Unit (providing psychiatric support) for people with a brain injury. These combined services mean that North Bristol NHS Trust is acknowledged to be the brain injury area of excellence, both for the Southwest and nationally.

The Brain Injury Team at Gloucestershire Royal Hospital, provided by Gloucestershire Hospital NHS Foundation Trust, has an agreed ABI pathway which differs from, but runs alongside, the Stroke pathway there.

An example of where pathways are not integrated is the Mardon Neurological Rehabilitation Centre in Exeter, which has no access to the discharge teams provided by the Royal Devon and Exeter NHS Foundation Trust. Many of the people discharged from Mardon have had very serious brain injury. Mardon do refer to Headway Devon but the time negotiating for funding for individual services can delay the ongoing support that people need.
North Bristol NHS Trust recently introduced a Development Worker (carer & support) who visits ICU, neurology and HDU units on a weekly basis. Since this post came into place, anecdotally there has been noticeably smoother referral processes and improved transition of service users to the services they need.

People with ABI may have their injury as a result of stroke. There are several stroke units in Devon but only those with critical or substantial need receive access to necessary services. Headway Devon report that several care managers have admitted that the RAS system of analysis does not make allowance for the cognitive difficulties associated with ABI. As a result, people with ABI often do not qualify for care that they need.

Psychological services
Emotional and behavioural challenges are common symptoms of ABI, and access to appropriate psychological support to manage these changes is a key part of rehabilitation. However, it is an element which is often under-resourced in the community compared to physical, communication and life skills rehabilitation. Psychologists are usually made available to people referred to specialist services as a result of their cognitive or behavioural disability or deficit.

For family members there may be significant adjustment to the person with ABI, or to the family as a whole. Access to counselling services either individually or as a family can greatly aid rehabilitation, but this tends not to be offered and those who seek it will usually pay privately for the service or use charities like Relate for the support they need. Supporting the families and carers is essential to enable people with ABI to stay at home or in the community.

Social care and other local services
Where someone with ABI needs a residential placement outside a hospital setting, the Southwest has a relatively small number of units or facilities that are able to offer this specialist provision for people with ABI. This may be short or long term, and is irrespective of the person’s stage along the care pathway.

Because of this, people can be placed considerable distances from their homes and families, which is difficult for all involved, and can increase the stress or emotional distress felt by the individual and their families.
A wider number of other facilities across the Southwest will accept people affected by ABI for residential placement. However, there is no expectation of a level of condition-specific knowledge or trained staff, meaning provision may not adequately or appropriately support the individuals.

Voluntary sector services
Local Headway organisations, affiliated to the national charity Headway, provide information, support and advocacy to people who contact them. Headway Bristol also provides visits to hospital wards and liaises with families to give support.

Referral to local Headway is not as prolific as it might be and the support offered could be used far more if professionals signposted to it more systematically.

Recent user and carer opinion and needs mapping
A number of recent user surveys have been carried out locally:

- ‘Shaping our lives’, by Headway Somerset in partnership with Somerset LINk (as was) (March 2013)
- ‘Access to Neurological Services in Devon’ by Devon LINk (January 2013)
- ‘A review of neurological services in Somerset’ by the Somerset Neurological Alliance and Somerset LINk (February 2013)

Key findings included:

- People with a brain injury have had both good and poor experiences of health and social care services.
- From health and social services, communication with, and information provision to, patients and carers are largely poor.
- Insufficient consultation time is allotted to a patient with a brain injury.

Recommendations
- Review care pathway development in Plymouth Hospitals NHS Trust and consider both implementation and sharing of the pathway elsewhere if appropriate.
- Carry out mapping and gap analysis of services for ABI, considering current provision, potential provision, and new ways of providing more equitable and cost effective rehabilitation services.
- Co-develop a Southwest network for referrals, transfers and discharges across the NHS, social care, the voluntary sector and private providers, creating ‘maps’ for families to visualise the pathway.
- Review education of GPs and clinicians within the community to improve self- and community management of people with ABI.
Hydrocephalus

Overview

Prevalence
6.46 in 10,000 births are affected by hydrocephalus, but this does not represent the full proportion of people living with the condition. Shine, the national charity for hydrocephalus, estimate around 5,000 people have hydrocephalus in the Southwest.

According to the prevalence data, however, 38,400 people in the UK, or 2,828 people in the Southwest have hydrocephalus (Table 26). This is significantly lower than Shine’s estimate, demonstrating the challenges in working with conditions where insufficient data is held. Using the national prevalence data, however, approximate numbers of people with hydrocephalus are shown in Table 26.

About hydrocephalus
Hydrocephalus is caused by cerebro-spinal fluid (CSF), around 400-600 millilitres of which is produced naturally in the brain every day, failing to drain into the bloodstream.

Hydrocephalus is incurable, but inserting a shunt system to drain away the excess CSF can help to control it. There are a number of complications which can arise from over-drainage to blockage or infection.

A brief glance at the data
Headlines from the data include:

- Total admissions (primary and secondary diagnosis) for hydrocephalus have decreased marginally across the Southwest over the last three years from 2,200 in 2009/10 to 2,187 in 2011/12 (see table 27).
- However, costs have increased from £4,794,914 to £5,051.044.
- The two most common co-morbidities (where hydrocephalus was the secondary diagnosis) were for:
  - Presence of cerebrospinal fluid drainage device costing £780,717.
  - Essential (primary) hypertension costing £645,294.
Table 27: Total admissions & costs for hydrocephalus: 2009/10–2011/12 at a glance

<table>
<thead>
<tr>
<th>Year</th>
<th>Total admissions</th>
<th>Total costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009/10</td>
<td>2200</td>
<td>£4,794,914</td>
</tr>
<tr>
<td>2010/11</td>
<td>2129</td>
<td>£5,509,976</td>
</tr>
<tr>
<td>2011/12</td>
<td>2187</td>
<td>£5,051,044</td>
</tr>
</tbody>
</table>

For information, weighted population in the data appendices for hydrocephalus have been calculated by 100,000 population rather than 10,000 as with the other conditions. However, this has been taken into account and recalculated for the infographics on weighted population here.

Local services

Primary and community services
People commonly visit their GP if their condition changes, whether new symptoms appear or the condition deteriorates, and rely on timely referrals to ensure they have access to the services they need as they need them.

Secondary and tertiary services
North Bristol NHS Trust provides services for people with hydrocephalus from Frenchay Hospital, the main contact for which is Mr Ian Pople.

Additional services specific to hydrocephalus are provided at Derriford Hospital under Plymouth Hospitals NHS Trust.
Anecdotally, it is understood from Shine that people with hydrocephalus have commonly faced delays in treatment due to:

- Their GP being reluctant to refer to neurosurgery services
- Being admitted to a hospital without a neurosurgery department, with consequent delays in transferring to neurosurgery due to a lack of knowledge by the admitting hospital, and occasionally by lack of beds at the neurosurgery unit.

**Psychological services**
Many of the ‘hidden’ elements of the condition affect the individual’s mental health and wellbeing. However, access to neuropsychology services can be challenging to obtain, and is not offered routinely.

**Social care and other local services**
People with hydrocephalus may have subtle brain damage and learning difficulties which can affect their day-to-day lives. They may struggle with spatial awareness, doing tasks in a logical order making them seem erratic, with their memory, particularly short-term, or with their behaviour. They may not have the insight or ability to cope with these elements of their condition.

For this reason, it is likely that people with hydrocephalus require support from social care services, particularly about education and employment. However, as these are hidden elements of the condition, it is possible that they may be overlooked.

**Voluntary sector services**
The nationally-based charity Shine provides information and support at a national level and has a local Support & Development worker for the Cornwall and Devon areas.

**Recent user and carer opinion and needs mapping**
Shine conducted a national survey in 2012. Their main finding, across the whole of England was that individuals found it difficult that they would be discharged when their condition was stable. This becomes problematic if their condition deteriorates or changed and referral is necessary as many people experience long delays with these referrals. This was no different for the Southwest of England.
Specifically in the Southwest:

- The majority of respondents are happy with their neurosurgery centre.
- Specialist hydrocephalus nurses, where employed, are popular for providing easy access to advice on the condition.
- The distance to travel in an emergency from rural areas causes anxiety.

Recommendations

- Review information available to people with hydrocephalus to enable improved self-management, for example around recognition of potential symptoms indicating a shunt blockage or infection.
- Encourage GPs to signpost patients to the Shunt Alert cards from Shine to improve emergency care (the card notifies that, if the card-holder is showing signs similar to those that occur when there is shunt blockage or infection, urgent assessment of shunt function should be carried out in a specialist neuro-surgical unit to eliminate shunt failure as a cause).
Aphasia

Overview

Prevalence
Exact prevalence data for aphasia is not known. However, about a third of people who have a stroke will have aphasia, and Connect, the communication disability network, estimate there are therefore around 250,000 people with aphasia in the UK. The Stroke Association suggests that there are roughly 120,408 people with stroke in the Southwest, which suggests around 40,136 people with aphasia in the region. (Unfortunately, given the limited data on prevalence, there is no prevalence table by CCG population available.)

About aphasia
Aphasia is a communication disability which occurs when the communication centres of the brain are damaged. It is usually caused by stroke, but can also be caused by brain haemorrhage, head injury or tumours.

Each person with aphasia experiences it differently. Some people cannot speak at all; some people have just a few words. Others can no longer read, write or use numbers.

Everyday activities such as having a conversation, answering the phone, watching television, may suddenly become a source of profound frustration and anxiety both for the person with aphasia and for their families, friends and carers (Connect: 2013).

Because aphasia results from brain injury, services are usually determined in the earlier stages by the dominant medical condition. Aphasia is often one of many symptoms and is a condition rarely even identified by commissioning bodies (CQC: 2011).

General comments on services for aphasia across the Southwest
Aphasia is most typically secondary to stroke and as such people typically follow the Stroke care pathway (National Stroke Strategy 2007). Others may be picked up by primary care and other specialist secondary services.

For those with aphasia resulting from stroke, the recent FAST Campaign identifies a clear emergency response, with rapid admission to the hyper acute, where clinical assessment, CT scan and potential thrombolysis can take place. Most people are then admitted to an acute stoke unit, though some with TIA or very mild stroke may
be discharged home. Aphasia should be identified during assessment for rehabilitation.

**A brief glance at the data**

Headlines from the data include:

- Total admissions (primary and secondary diagnosis) for aphasia have increased across the Southwest over the last three years from 1,396 in 2009/10 to 1,609 in 2011/12 (see Table 28).
- Costs have also increased from £2,619,537 to £3,311,401.
- The two most common co-morbidities (where aphasia was the secondary diagnosis) were for:
  - Urinary tract infections costing £192,926.
  - Cerebral infarct costing £197,149.

**Table 28: Total admissions & costs for aphasia: 2009/10–2011/12 at a glance**

<table>
<thead>
<tr>
<th>Year</th>
<th>Total admissions</th>
<th>Total costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009/10</td>
<td>1,396</td>
<td>£2,619,537</td>
</tr>
<tr>
<td>2010/11</td>
<td>1,609</td>
<td>£3,360,907</td>
</tr>
<tr>
<td>2011/12</td>
<td>1,601</td>
<td>£3,311,401</td>
</tr>
</tbody>
</table>

**Weighted data (aphasia): admissions per 1,000 pop**

- NHS NEW Devon CCG: 0.54
- NHS Swindon CCG: 0.34
- Average: 0.42
- NHS NEW Devon CCG: 0.13

**Weighted data (aphasia): Costs per head of pop**

- NHS NEW Devon CCG: £1.24
- NHS Swindon CCG: £0.23
Local services

Primary and community services
Rehabilitation following stroke is often the time where people with aphasia receive the support they need, although the style of rehabilitation varies from place to place. It can take the form of inpatient rehabilitation on a ward, through early supported discharge, community rehabilitation teams or step teams to name a few.

For aphasia specifically, referral to a speech and language therapist is preferable, although in many cases individuals are referred to one of the charitable bodies supporting people with aphasia.

Royal Cornwall Hospitals Trust invites volunteers from Connect, the communication disability charity, to visit their stroke ward regularly, meeting the individuals affected by communication problems and their families, and offering advice and support.

Secondary and tertiary services
The main acute stroke units in the Southwest, where the majority of people with aphasia resulting from stroke will be identified, are shown on the map below.

![Acute stroke units in the Southwest](image-url)
There is very little information on aphasia apart from stroke, or on services specifically noted to cater for aphasia in its own right. A number of services found for aphasia are either provided by the voluntary sector or are private services established by people who have seen a gap in the system.

Aphasia-now in Gloucestershire, established by people with aphasia, provides communication support, structured conversation exercises, coordination activities and family support for £4 per session. Chaired by a retired doctor who is aphasic through a stroke herself, the group is also supported by qualified therapists and artists as well as volunteers.

Social care and other local services
A report by the Care Quality Commission (CQC: 2011) found that around three-quarters of social services could direct people to community-based services to help them with their physical disabilities, but less than half could signpost similar services for people with aphasia. The report also notes that while two-thirds of local transport plans surveyed addressed physical disabilities, only 43% addressed communication-related disabilities.

Voluntary sector services
The vast majority of services specifically for people with aphasia are provided by the voluntary sector (see appendices for full details). In the Southwest, these include:

- Speak Ability which has 10 groups across the southwest
- The Stroke Association’s ‘communication support service’ which operates in seven locations in the Southwest
- Connect which operates in 12 locations across the Southwest and also offers a befriending scheme which provides visits both in acute settings and at home.

Recent user and carer opinion and needs mapping
Connect ran an online survey in 2011 and found that even people with aphasia are unaware of the condition, with 28% of those questioned unaware they had aphasia until some 6 months after their stroke.
Recommendations

- Speech and language assessment should become a standard part of post-stroke rehabilitation with a follow up appointment three to four months on to ensure people with aphasia are appropriately supported.

- Services for people with aphasia are largely unknown apart from where it is symptomatic of another condition, and yet coding for it seems high; further exploration is needed to look at why this is.
Cerebral palsy

Overview

Prevalence
1 in 400 children is born with cerebral palsy. That’s about 160,000 people in the UK, or 11,782 people in the Southwest (Table 29). Using national prevalence data, approximate numbers of people living with cerebral palsy is shown in Table 29.

About cerebral palsy
Cerebral palsy affects muscle control and movement. It is usually caused by an injury to the brain before, during or after birth.

Affecting one in every 400 children, people with cerebral palsy have difficulties controlling muscles and movements as they develop, continuing into adulthood. Depending on the precise area of the brain that is affected, individuals may have difficulties with their vision, hearing, learning and behaviour.

Cerebral palsy itself is not progressive in that the injury to the brain does not change. However, the effects may change over time for better or worse. No two people will be affected by their cerebral palsy in the same way and it is important to ensure the focus of treatments and therapies are tailored to individual needs (Scope: 2013).

A brief glance at the data
Headlines from the data include:

- Total admissions (primary and secondary diagnosis) for cerebral palsy have increased across the Southwest over the last three years from 2,936 in 2009/10 to 3,629 in 2011/12 (see Table 30).
- Costs have also increased from £3,830,674 to £4,257,963.
- The two most common co-morbidities (where cerebral palsy was the secondary diagnosis) were for:
  - Epilepsy (unspecified) costing £541,139
  - Gastrostomy status costing £342,611.
Table 30: Total admissions & costs for cerebral palsy: 2009/10-2011/12 at a glance

<table>
<thead>
<tr>
<th>Year</th>
<th>Total admissions</th>
<th>Total costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009/10</td>
<td>2,936</td>
<td>£3,830,674</td>
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<tr>
<td>2010/11</td>
<td>2,962</td>
<td>£3,936,655</td>
</tr>
<tr>
<td>2011/12</td>
<td>3,629</td>
<td>£4,257,963</td>
</tr>
</tbody>
</table>

For information, weighted population in the data appendices for cerebral palsy has been calculated by 100,000 population rather than 10,000 as with the other conditions. However, this has been taken into account and recalculated for the infographics on weighted population here.

Local services
Primary and community services
People with cerebral palsy may need a range of services depending on their needs and how they experience their condition. Health services such as speech and language therapy, physiotherapy and occupational therapy will commonly be required too.

The more community-based these services, the easier access is likely to be, especially as people with cerebral palsy may have difficulties travelling or be reliant on public transport.
Secondary and tertiary services
Much of the more specialist secondary services, such as those carrying out selective dorsal rhizotomy (SDR) are more likely to be provided to people with cerebral palsy when they are children. For example, SDR is most effective between four and 11 years.

However, depending on the symptoms of the individual, Botox or intrathecal baclofen may be needed to treat spasticity.

Intrathecal baclofen is only provided by Plymouth Hospitals NHS Trust at Derriford Hospital in the Southwest, causing potential access difficulties and travel challenges for people with cerebral palsy. (See earlier section on MS for more extensive information.)

Social care and other local services
The majority of services likely to be needed by adults with cerebral palsy are provided by adult social care, or through the coordinated working of specific health professionals such as occupational therapists, with social (care) workers.

Vocational and adult education support, respite care or other short breaks, domiciliary care, advice and support about equipment, adaptations and benefits are all potential requirements of those with cerebral palsy. Access to these services is essential to ensure that people with cerebral palsy are able to live as independently and fully as possible.
A number of people, as the cuts and changes to social care continue, are struggling with the changes being made to their care packages which is impacting their levels of independence and potentially increasing their reliance on public services.

Plymouth is one of just two pilot sites where Scope is running a Department for Education-funded pilot. The scheme sees parents of disabled children supported to pool personal budgets from the council to jointly buy short breaks and other leisure and recreational activities such as clubs, sports and visits to the park, horse riding and the cinema.

The hope is that the two-year, £702,000 pilot will see parents work out where the gaps are, and then plug those gaps, and in doing so stimulate the local markets so that provision better meets their needs.

**Voluntary sector services**

Scope, the national charity for cerebral palsy, offers a range of services and support from information and advice through to education and training, mentoring, supported short breaks, and even residential care and supported independent living.

The nearest centres to the Southwest providing domiciliary care, tailored support and short breaks are in Hereford (near Gloucestershire) and Eastleigh, Hampshire.

**Recommendation**

- Vocational and educational support are key areas to ensure independence.
Migraine

Overview

Prevalence
One person in every seven has migraine. That's about 9,142,897 people in the UK, or 673,265 people in the Southwest (Table 31). The Migraine Trust estimates that of these, 74,347 people in the Southwest have chronic migraine (defined as headache on 15 days of the month or more of which at least 8 are migrainous). Using national prevalence data, approximate numbers of people with migraine are shown in Table 31.

About migraine
Migraine is the most common neurological condition with two thirds of those affected being female. All migraineurs are more likely to experience migraine between the ages of 20–50 years. A migraine attack can last from 4 to 72 hours, with most migraineurs keeping well between attacks.

Migraine is more than a headache with symptoms including: visual disturbances, nausea and vomiting, sensitivity to light, noise and/or smells, disorientation and confusion, and tingling/pins and needles/weakness/numbness in the limbs (Migraine Action).

Migraine remains undiagnosed and undertreated in at least 50% of patients, and less than 50% of migraine patients consult a physician (Pavone et al: 2007) (Migraine Trust).

A brief glance at the data
Headlines from the data include:

- Total admissions (primary and secondary diagnosis) for migraine have increased across the Southwest over the last three years from 1,832 in 2009/10 to 2,887 in 2011/12 (see Table 32).
- Costs have also increased from £1,794,381 to £2,991,158.
- The two most common co-morbidities (where migraine was the secondary diagnosis) were for:
  - Headache costing £94,923
  - Hypertensive renal disease with renal failure (cost not calculated).
Table 32: Total admissions & costs for migraine: 2009/10-2011/12 at a glance

<table>
<thead>
<tr>
<th>Year</th>
<th>Total admissions</th>
<th>Total costs</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
<tr>
<td>2010/11</td>
<td>2,450</td>
<td>£2,873,077</td>
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<tr>
<td>2011/12</td>
<td>2,887</td>
<td>£2,991,158</td>
</tr>
</tbody>
</table>

Local services

Primary and community services
Less than 50% of people with migraine consult a physician (Pavone et al: 2007), and many who do raise the issue will go through their GP. The national Royal College of General Practitioners’ lead for migraine is a GP in Exeter who runs a GPwSI migraine clinic based at the Exeter Headache Clinic.

People will not be consistently referred to a specialist and anecdotally, it seems that many individuals access treatment after researching the options for themselves and requesting referrals from their GP.

A number of individuals may need to control their migraine through medication, and for some, will require prescriptions for stronger medication to manage their condition. Those individuals will need to see their GP more regularly to have their needs assessed and to be prescribed the best option for them.
Secondary and tertiary services
There are three headache and migraine centres in the Southwest which are shown in the map below. They are provided by Plymouth Hospital NHS Foundation Trust, Royal United Hospital Bath NHS Trust and the Exeter Headache Centre which is a private practice that holds NHS contracts for Devon.

Some individuals close to the border may travel across to Dorset to the Migraine clinic provided by Poole Hospital NHS Foundation Trust.

Some people with migraine benefit from manipulative therapies such as physiotherapy or chiropractic, although these are not commonly funded through the NHS.

Some people with migraine may benefit from dentistry also, and an integrated approach to the various means of controlling their condition is very important.

Social care and other local services
Individuals with extreme cases of migraine may require vocational support, specifically in ensuring their employer understands the nature of their condition and can accommodate them accordingly.
Voluntary sector services
The Migraine Trust provides advocacy services and an information and enquiry service which operates nationally. National charity Migraine Action also provides advice and support, and particularly supports younger people affected by migraine.

User and carer surveys and needs mapping
The Migraine Centre recently sent out a request for any comments about services for migraine across the Southwest in order to inform this report. Comments include:

- The specialist consultant in headache, Dr Stuart Weatherby, is provided by Plymouth Hospitals NHS Trust, and is valued by those who see him.
- People living in Cornwall have to travel to Plymouth to see a specialist as there is no equivalent in Cornwall – one individual from Cornwall noted waiting four hours in order to see Dr Weatherby, while another paid to do so privately.
- The headache clinic in Exeter is considered a good service once accessed, but people note a need to be re-referred to the service every time they want to make an appointment, including for a follow-up appointment having already seen the headache specialist there.
- A number of respondents from across the Southwest noted requesting referral, or being recommended referral, to London for treatment. All were pleased with the level of care in London, but noted the challenge of consistent travel and their preference for something closer to home where possible.

Recommendations
- Review provision of specialist migraine support across the Southwest to enable equitable access without leaving the region.
- Consider outreach services from existing migraine services to enable better access to relevant support in the community or in areas lacking a specialist of their own, such as Cornwall.
- Look at improving awareness of headache management courses for people with migraine such as those run by the Migraine Trust. These can promote increased awareness of how to prevent and better manage headache.
Spinal cord injury

Overview

Prevalence
Spinal cord injury has a prevalence of 0.0007%. That's about 40,000 people in the UK, or 3,299 people in the Southwest (Table 33). Using national prevalence data, approximate numbers of people living with cerebral palsy are shown in Table 33.

About SCI
SCI can occur at any age. Depending on the level and severity of injury to the spinal cord, it leaves a person with various degrees of paralysis and loss of sensation affecting either the lower limbs (paraplegia) or all four limbs (tetraplegia). The effects of SCI are usually permanent, and affect the ability to walk, use of arms and hands, reduced bowel, bladder and sexual functions and in some cases the ability to breathe. Currently there is no cure.

Learning to live with SCI can require huge personal and psychological adjustment for both the individual with the SCI and their family members. This is in addition to the enormous physical challenges that are faced in order to learn how to optimise day-to-day independence. There is evidence that a period of high-quality specialised inpatient treatment and rehabilitation is necessary to achieve optimum quality of life after SCI (Spinal Injuries Association [SIA] 1997).

General comments on services for SCI across the Southwest
People with SCI commonly face poor understanding of their condition in general health settings such as hospitals and GP surgeries. Spinal cord injured people who are fortunate enough to be rehabilitated in one of the UK’s eleven spinal cord injury centres are likely to be experts in their condition because of the unique way that they are rehabilitated and cared for.

However, despite a lack of understanding of the condition, this patient expertise is often not recognised, and this can lead to inappropriate treatment, if not harmful practice, by general and community health services.

People with SCI in the Southwest will predominantly be treated in the specialist SCI centres: Duke of Cornwall Spinal Treatment Centre in Salisbury, with a smaller proportion likely to be treated in the Wales SCI Centre, Rookwood (Cardiff). Where they are admitted to general hospitals for other reasons, or for comorbidities,
professional liaison with, or patient transfer to, the spinal cord centre is important to make sure the individual is treated appropriately but this is not standard practice.

A brief glance at the data
Headlines from the data include:

- Total admissions (primary and secondary diagnosis) for SCI have increased across the Southwest over the last three years from 818 in 2009/10 to 829 in 2011/12 (see Table 34).
- Costs have also increased from £1,561,795 to £1,637,836.
- The most common co-morbidities (primary diagnosis) were ‘other specified diseases of the spinal cord’ and ‘urinary tract infection’. These amounted to costs of £104,168 in total across the two.

Table 34: Total admissions and costs for SCI: 2009/10- 2011/12 at a glance

<table>
<thead>
<tr>
<th>Year</th>
<th>Total admissions</th>
<th>Total costs</th>
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<td>2009/10</td>
<td>818</td>
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<tr>
<td>2010/11</td>
<td>764</td>
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</tr>
<tr>
<td>2011/12</td>
<td>829</td>
<td>£1,637,836</td>
</tr>
</tbody>
</table>
Local services

Primary and community services
Common community services accessed are district nursing teams for bladder and bowel management, or checks for skin integrity to prevent pressure ulcers, as well as treatment of any ulcers. In rural areas, particularly where an individual is only recently discharged from an acute setting or is without a carer, this service is incredibly important. However, prevention of bladder and bowel problems and pressure ulcers is far preferable and appropriate information and education at the time of rehabilitation for an SCI is essential.

There are concerns about physical access to many community health services in the Southwest including GPs, dentists and mental health services. This may relate not only to premises but also car parks, toilets and equipment such as examination benches at surgeries.

In Cornwall, there is a directory of wheelchair accessible dental practices for those who use a wheelchair, such as people with SCI, to refer to when making bookings.

Secondary and tertiary services
Anecdotal evidence from specialist SCI centres suggests it is becoming increasingly common for patients to be admitted them with pressure ulcers that they have developed in a district general hospital, often while awaiting transfer to a specialist centre. This delays the rehabilitation of an acute SCI patient by several months, as well as causing ongoing health concerns which can dramatically affect a person’s chances of reintegrating back into society.

The cost of healing such pressure ulcers increases significantly when treated in a specialist SCI Centre, with consultants at the SCI Centre in the Royal National Orthopaedic Hospital, Stanmore, estimating the overall cost of pressure ulcers to the NHS for SCI patients alone to be in the region of £1 billion per year.
The management of an SCI person’s bowel in a district or community hospital setting is another key concern. People with SCI frequently complain of a lack of understanding of their needs or an unwillingness to undertake critical management, such as manual bowel evacuation.

Despite guidelines produced by the Royal College of Nursing (RCN: 2005), hospitals will frequently refuse to conduct manual bowel evacuation or fail to have a bowel management policy in place. Anecdotal evidence held by spinal cord injury charities (SIA, Back Up, Aspire) and a recent survey they undertook in Cornwall supports this concern.

It is essential that basic understanding of spinal cord injury is found in general acute settings, but this is often not the case. Anecdotal evidence of a lack of equipment such as a hoist, or a misunderstanding of what it means to be paralysed by staff can cause delays, confusion and mistreatment.

The specialist SCI centres in Salisbury and Cardiff are those likely accessed by people in the Southwest, and provide high quality, specialised, holistic care for those with SCI, supporting them from their initial rehabilitation, throughout the rest of their lives. Recent national guidance (National SCI Strategy Board: 2012) from key leads in SCI recommends that all newly spinal cord injured people should be immediately transferred to a specialist centre for treatment.

The Care Pathways for spinal cord injury were launched in September 2012, and document the optimal processes for managing a spinal cord injured person. These are relevant to general hospitals, neurology centres, GP surgeries and many other services.

A number of spinal cord injured people are eligible for continuing healthcare, although unfortunately many are denied access even though their needs may far exceed what social services are able to cater for.

**Psychological support and services**
People with an SCI often benefit from psychological support given the drastic changes that the condition can cause to both them and their families.
Anecdotally there may be challenges with appropriate referrals from GPs to psychological services in Cornwall. Either mis-referrals or inability for mental health services to provide outreach has meant that some individuals who are bed-bound have not been able to receive the services they urgently require.

Social care and other local services
Newly rehabilitated people with SCI may require vocational rehabilitation, and personal assistants or care workers might also be needed, particularly where the individual does not have a family member who has chosen to care for them – something which is often wrongfully assumed.

People with tetraplegia or older paraplegics are likely to require support from social care services to enable them to live independently in the community. A care plan, discussion of personal budgets, and an understanding of the range of services available to an individual to enable them to live as fully and independently as possible are essential.

Voluntary sector services
The Spinal Injuries Association (SIA), Aspire and Back Up are the three leading charities supporting SCI people in England. They each provide a range of differing services, which across the three include:

- advice
- information and support
- housing
- assistive technology
- grants for support
- mentoring
- vocational support
- wheelchair skills training

Recent user and carer opinion and needs mapping
SIA, Aspire and Back Up have just completed a needs mapping of people with SCI in Cornwall. Key findings include:

- The lack of understanding and knowledge of SCI is a core problem when receiving services outside the specialist SCI centres.
  - This has caused anecdotal challenges with treatment of pressure ulcers and urinary tract infections.
  - This has also caused difficulties in other departments, such as treatment for a gall stone, were noted because staff could not
understand that the individual could not ‘feel’ – caused by their paralysis.

- Delays in, or necessary rescheduling of outpatient appointments at Royal Cornwall Hospitals NHS Trust were noted by a number of people due to a hoist being unavailable or notes not having been pre-read to understand an individual’s needs ahead of their appointment.
- Significant delays in wheelchair parts have occurred since the wheelchair service moved to a single base in Hayle, leaving individuals house-bound awaiting a new tyre or wheel for over a week at a time.

Recommendations

- Explore psychological service provision in rural localities for people unable to travel directly to the service.
- Review / consider SCI care pathways to ensure they are in line with national guidance and that district general hospitals refer to specialist SCI centres for advice for spinal cord injured patients as necessary.
- Consider preventative practice for bladder and bowel management and pressure ulcers, particularly in general acute centres to avoid unnecessary costs and length of stay for the NHS and loss of quality of life for the individual.
Myasthenia gravis

Overview

Prevalence
One person in every 10,000 has myasthenia gravis. That's about 6,400 people in the UK, or 471 people in the Southwest (Table 35). Using national prevalence data, approximate numbers of people living with myasthenia gravis are shown in Table 35.

About myasthenia gravis
Myasthenia gravis is an auto-immune condition which is experienced by people as if their muscles have weakened, and muscles seem to get tired far more quickly than is usual. It is caused by the junction between the nerve cell and the muscle, meaning the nerve cannot easily cause the muscle to contract.

About 15% of individuals with the condition only ever have eye muscle weakness, known as ocular myasthenia. Others will have both this and a more general weakness. This can include facial muscles, swallowing, and chewing muscles, and weakness of the limbs and neck. In severe cases, weakness of the breathing muscles can occur. Difficulties with swallowing or coughing can cause choking.

A brief glance at the data
Headlines from the data include:

- Total admissions (primary and secondary diagnosis) for myasthenia gravis have increased across the Southwest over the last three years from 613 in 2009/10 to 665 in 2011/12 (see Table 36).
- Costs have decreased from £939,180 to £932,031.
- The two most common co-morbidities (where myasthenia gravis was the secondary diagnosis) were for:
  - Other chemotherapy costing £307,908
  - Essential (primary) hypertension costing £258,995.

### Table 36: Total admissions & costs for myasthenia gravis: 2009/10- 2011/12

<table>
<thead>
<tr>
<th>Year</th>
<th>Total admissions</th>
<th>Total costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009/10</td>
<td>613</td>
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</tr>
<tr>
<td>2010/11</td>
<td>709</td>
<td>£ 1,043,604</td>
</tr>
<tr>
<td>2011/12</td>
<td>665</td>
<td>£ 932,031</td>
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</table>
For information, weighted population in the data appendices for myasthenia gravis has been calculated by 100,000 population rather than 10,000 as with the other conditions. However, this has been taken into account and recalculated for the infographics on weighted population here.

Local services

Primary and community services
The most common means of treating myasthenia gravis is through medication, so it is very important that their GP understands the condition and the best way to treat it.

A number of the medications have side effects that also need to be managed, and the GP will also need to monitor this. Regular blood monitoring is also required if the individual is taking immunosuppressants. Without appropriate monitoring of side effects and bloods, complications and comorbidities could arise.

Secondary and tertiary services
Where a person is experiencing swallowing or breathing difficulties as a result of their condition, access to a speech and language therapist, or respiratory team may be needed. This is essential to give effective education and treatment to avoid chocking or asphyxiation, as well as respiratory infections.

In some cases of myasthenia gravis, surgery to remove the thymus gland (a thymectomy) may be recommended, which can lessen the symptoms to varying degrees according to the individual. This is carried out by a cardiothoracic surgeon.
While cardiothoracic teams are located at the Bristol Royal Infirmary, Plymouth Hospitals NHS Trust, and Royal Devon and Exeter, it is not clear from desk research whether thymectomies are available for people with myasthenia gravis in these hospitals. The nearest specialist providing this service specifically for myasthenia gravis patients is at Southampton General Hospital, which is outside the Southwest area.

Social care and other local services
People with myasthenia gravis predominantly rely on healthcare services, and the erratic nature of the condition can mean that it is under control for a while before something happens to cause an emergency admission, such as a throat collapse.

However, individuals may need support managing at home depending on the nature of their condition, particularly if they do not have family there to support them. This might call for domiciliary care or short-term agency carer support.

Vocational support might be needed to help them get back into work again, and advice and information on driving may also be needed.

Voluntary sector services
The Myasthenia Gravis Association offers information and support, and has supported three specialist nurse posts across the UK. The nearest post to the Southwest is Lisa Joyce, based at Southampton General Hospital.

Recommendation
- Clarify support services available for both patients and professionals across the Southwest so that this information is readily available.
Motor neurone disease

Overview

Prevalence
7 in every 100,000 people are estimated to have motor neurone disease (MND), or 4,424 in the UK. A total of 304 people living with MND in the Southwest are known to the MND Association as of 8 July 2013. This is in line with estimates based on a prevalence of 7:100,000 population (see Table 37).

These individuals are spread across the area, consistent with the distribution of the population. Estimates of those with MND in each CCG population are shown in Table 37.

About MND
MND is a progressive neurological condition which leads to muscle weakness and wasting. As it progresses it can affect walking, hand and arm movements, head and trunk control, speech, swallowing and breathing. Common fatal complications as the condition progresses and becomes more complex include respiratory difficulties.

One of the particular challenges with MND is the speed of progression; 50% of people with MND will die within fourteen months of diagnosis. This rapid progression can mean that it is difficult to provide services in a timely manner, and unfortunately some people with MND go into crisis before they can access the services they need.

A few people present with a fronto-temporal dementia before developing other signs of MND, and in these cases mental health services need to be involved. For the remainder, a significant minority (around 40%) may experience cognitive changes which may make management of the condition more challenging.

General comments on services for MND across the Southwest
A wide range of disciplines usually need to be involved to provide effective management of symptoms, and this can cause problems with communication and coordination of care. Regular multi-disciplinary meetings in many areas in the Southwest help to promote co-ordination, but the best services are in areas where there is a named co-ordinator or keyworker for each person with MND.
A brief glance at the data

Headlines from the data include:

- Total admissions (primary and secondary diagnosis) for MND have increased across the Southwest over the last three years from 491 in 2009/10 to 500 in 2011/12 (see Table 38).
- Costs have also increased from £764,341 to £804,236.
- The two most common co-morbidities (where MND was the secondary diagnosis) were for:
  - Pneumonitis due to food and vomit costing £49,263
  - Respiratory infection costing £15,047.

Table 38: Total admissions & costs for MND: 2009/10 - 2011/12 at a glance

<table>
<thead>
<tr>
<th>Year</th>
<th>Total admissions</th>
<th>Total costs</th>
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<tbody>
<tr>
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<td>491</td>
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<tr>
<td>2010/11</td>
<td>498</td>
<td>£ 835,233</td>
</tr>
<tr>
<td>2011/12</td>
<td>500</td>
<td>£ 804,236</td>
</tr>
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</table>

Local services

Primary and community services

Due to the complex nature and rapid progression of MND, it is essential that a keyworker, or other clinician with understanding of MND supports access to services where at all possible. (All specialist nurse or coordinator posts for MND are listed in Table 41 of the appendices.)
The MND Association has found that people with a keyworker access more services than those without one. GPs often do not have the expert understanding to provide this service, although some are proactive in seeking advice from experts to enable them to support their patients.

There is a MND clinical specialist post based within Gloucestershire Care Services as part of a community-based team of neurology nurses. She provides expert advice, co-ordination and education around MND across the county. Data from the first two years of this post showed a marked increase in the number of people with MND who avoided hospital admission at end of life and were able to die at home, in line with their preferences.

It is important for GPs to monitor their patients with MND to ensure that they are referred to the services they need in a timely fashion. This is particularly important when, for example, communication challenges begin so that access to specialist palliative care is made at a time the person can communicate their wishes, and when approaching the end of life, to ensure they are placed on the General Practice end-of-life register.

Respiratory services are essential for people with MND who may develop breathing and swallowing problems at any point during their condition. These difficulties can lead to choking and asphyxiation, and commonly lead to respiratory infections (the top reason for comorbid emergency admission with MND) when not managed and prevented.

Community-based respiratory services in the Swindon and Wiltshire area need improvement. There is a good case for a respiratory physiotherapist or nurse based within the community who would be able to support people with MND who are having non-invasive ventilation.

There are very few MND specialist nurses or community coordinators in the area, although in some patches there are neurology specialist nurses who provide support to conditions including MND.
There are three neurological nurses in the community in Wiltshire based in the west, south and north. All are stretched, the northern post especially as it covers a population of approximately 200,000. The nurse is therefore not able to meet the needs of those people with some of the most complex needs and there is a significant need for additional capacity in this area.

For many people with MND, in lieu of a specialist nurse, they rely on a good multi-disciplinary service for information, access to services and coordinated care. Where community-based integrated multi-disciplinary teams exist, this provides an excellent service to those with MND, allowing an individual’s needs to be understood across a wide range of disciplines and for referral across disciplines to be made swiftly and seamlessly.

There are a number of these teams in the Somerset, Avon, Bristol and Wiltshire area, shown on the map to the right, (and detailed in the appendices).

In South Gloucestershire, community services have now been split into four localities which has diluted the neurological expertise in the area and caused barriers to coordinated care.
In Bath and Northeast Somerset, an integrated community neuro-rehab and stroke service provided by Sirona is highly valued. It includes physiotherapy, occupational, and speech and language therapy, and psychology services. It is unfortunately coming under strain at present due to extra demands being put on the team, causing some concern locally. Ideally, links with or inclusion of the community dietetics team would improve the service further.

**Psychological services**
The provision of neuropsychology services is highly variable across the Southwest. Psychological support is essential for people with MND who may be struggling with the emotional and behavioural changes brought about by their condition, or are finding it difficult to come to terms with the condition itself.

Counselling for family members or for the family as a whole is especially important. MND can affect young people with families who may particularly struggle to come to terms with the condition and what it means for their loved one. However, this is often challenging to access.

**Secondary and tertiary services**
Most individuals are managed locally by a consultant neurologist, with referrals to the MND Specialist Centres reserved for complex cases, and to obtain second opinions, as well as for involvement in research.

All of the MND Specialist Centres in England are noted in the appendices. In the Southwest, the MND Care Centre is run from Frenchay Hospital, provided by North Bristol NHS Trust. The Care Centre Director is Dr Andria Merrison, who provides a co-ordinated tertiary care service in conjunction with Dr Rebecca Tunstall, Consultant in Palliative Medicine and Dr James Catterall, Consultant in Respiratory Medicine.

The service, which has four-year funding from the MND Association for the employment of the MND Care Centre Co-ordinator and a respiratory technician, consists of:

- Two clinics per month at Frenchay Hospital, specifically for people with diagnosed or suspected MND.
- One joint neurology and respiratory clinic per month at Bristol Royal Infirmary.
- An MND Care Centre co-ordinator based at Frenchay and linking with community-based multi-disciplinary teams.
Within Royal United Hospital Bath NHS Trust, there is a good consultant-to-
consultant referral pathway to Dr Malin, the respiratory consultant, so that
baseline respiratory assessments are performed shortly after diagnosis for
all people with MND. For those where respiratory failure is identified and who
would benefit from non-invasive ventilation, a referral is then made to the
Sleep Unit in Bristol.

The Peninsula MND Care Network across Devon and Cornwall has a four-
year grant from the MND Association. The steering group meet every three
months and is attended by co-directors Stuart Wetherby (Plymouth) and
Jonathan Stuart (Cornwall) as well as commissioners. The care network co-
ordinator, Tracy Thomas, is based in Plymouth and liaises closely with the
neurologists, making contact with newly-diagnosed people with MND and
liaising with the relevant community staff to help coordinate care.

Application of continuing health care criteria is anecdotally inconsistent. In
particular, the rapidly progressive nature of MND is often not taken into
account during assessments, resulting in repeated assessments. In addition,
some fast-track arrangements for accessing CHC funding are not sensitive
enough to allow for timely care packages to be implemented, resulting in
avoidable hospital admissions.

People with MND can experience sleep disturbance, or difficulties with breathing or
swallowing during sleep. Sleep clinics can be of great help, although these are not
widely available. The Bristol Sleep Unit is anecdotally known to be highly valued by
those with MND. However, it is often difficult to access for those using wheelchairs in
its current position in the Old Building of Bristol Royal Infirmary.

Social care and other local services
The particularly rural nature of some parts of the Southwest make the provision of
social care support particularly difficult, for example in Wiltshire due to Salisbury
Plain, and across mid and north Devon.
Care agencies frequently struggle to cover rotas, and this causes difficulties with the particular needs of people with MND being met, particularly where they are unable to communicate easily with new staff. This challenge is found across England. Use of appropriate care planning, education of agency staff, and where possible, consistency of care staff per individual can really assist with this difficulty.

The timely provision of appropriate wheelchairs remains a challenge across the whole of the Southwest and the current criteria do not fit the needs of people with MND, whose mobility may deteriorate rapidly.

Electric-powered indoor-outdoor chairs (EPIOCs) can be a lifeline. However, in most wheelchair services an outdoor manual chair cannot be issued unless the person has been using a manual indoor chair for a specified amount of time (difficult when arms are weak or if there is no room indoors for a wheelchair). Once the person is assessed as being suitable for a powered chair, a further period has to elapse until they can be assessed as being safe to use it outside. This whole process can take months.

The Association has been trying to address this by developing specialist hubs, funded jointly by NHS England and the MND Association. However, the nearest hub to the Southwest will be in Oxford.

In Gloucestershire, changes to the wheelchair service have reduced waiting times dramatically from 8 weeks to 2.8 weeks in just under two years following support from NCS to streamline the processes for people with MND. (Find a case study at http://www.ncssupport.org.uk/ncs-showcase/gloucestershire-2/)
**Voluntary sector services**

The MND Association provides services and support nationally and in the Southwest. National support includes information, advice, grants, access to equipment including wheelchairs and a helpline, MND Connect.

Locally, two Regional Care Development Advisors cover the Southwest, while trained volunteers known as Association Visitors, and branch networks provide advocacy, companionship, information and signposting.

In addition to the MND Association, a number of local hospices are run by charities and have good access to specialist palliative care services which is invaluable to those with MND as they progress.

Finally, carer associations are often highly supportive to people caring for someone with MND, or recently bereaved. (Both charity-run hospice and carer associations are detailed in the appendices.)

**Recent user and carer opinion and needs mapping**

In addition to the neurology-wide surveys noted elsewhere in this report, such as by the Somerset LINk, and various Regional Neurological Alliances, an MND national survey on living with MND was recently undertaken.

A preliminary report will be available very soon direct from the MND Association and it is expected to be possible to break down the data to a Southwest regional level.

**Recommendations**

- Review respiratory pathways across the Southwest and ensure they are in place and followed to effectively manage respiratory problems.

- Ensure:
  - timely access to provision of equipment
  - access to communication aids.
References


BRAMs (2010) ‘MS Nurse Service Incoming Phone Log’, Directorate of Neuroscience North Bristol NHS Trust (July 2010)

Care Quality Commission (2011) ‘Supporting life after stroke: A review of services for people who have had a stroke and their carers’ January 2011


Epilepsy Society (2013), incidence and prevalence: 
http://www.epilepsysociety.org.uk/AboutEpilepsy/Whatisepilepsy (last accessed 23.07.13)


Joint Epilepsy Council (JEC) of the UK and Ireland (2011): ‘Epilepsy prevalence, incidence and other statistics’.


The MS Society (2009), ‘Strength in Numbers’ (London)

The MS Society (2013 - in progress): The MS Society is currently working with Plymouth University School of Health Professions on a research project looking into social exclusion and insolation and how it is experienced by people living with MS and a severe impairment.

The MS Society, Parkinson’s UK, MND Association and Ataxia UK (2010) ‘Quality Neurology: a Neurological Service Audit Tool’, August 2010. The Quality Neurology tool was created collaboratively by the Motor Neurone Disease Association, Parkinson’s UK, the Multiple Sclerosis Society and Ataxia UK, with support from York University Research and Social Policy Unit, and funding assistance from the Department of Health.

Motor Neurone Disease Association, ‘MND Year of Care Pathway’, 2008


National Audit Office (2011) ‘Services for people with neurological conditions’. 
Norwich TSO


National Social Care Intelligence Service (NSCIS) (2013). ‘Provisional Data’ published 10th July 2013, Health and Social Care Information Centre, copyright © 2013


August 2013) – statistics demonstrate an estimated population of 63.7 million in mid 2012; this has been rounded up to 64 million for UK population estimates within this report.

Parkinson’s UK, ‘Get it on Time Campaign’
http://www.parkinsons.org.uk/content/get-it-time-campaign (last accessed 14.08.13)

Parkinson’s UK: ‘Parkinson’s (Get it on Time) hospital medicines management audit guidelines’ (London: 2010)

Parkinson’s UK (2009), ‘Parkinson’s prevalence in the United Kingdom’, pp7-9

Parkinson’s UK (2013), ‘What is Parkinson’s?’
http://www.parkinsons.org.uk/content/what-parkinsons (last accessed 14.08.13)


(The) Royal College of Nursing, 'Catheter Care: RCN Guidance for Nurses' (London: 2008)

Sampson FC et al (2000), ‘The effectiveness of Intrathecal Baclofen in the management of patients with severe spasticity’. Trent Institute for Health


Somerset LINk (2013), ‘Views of patients and carers affected by Parkinson’s Disease: Views of services in Somerset - Report and Recommendations’ (Somerset: March 2013)

(The) Southwest Alliance of Neurological Organisations (SWANO) (2013): http://services.swano.org/index.htm (last accessed 20.08.13)

SUDEP Action (‘Sudden Unexpected Death in Epilepsy’) ‘Epilepsy Life Project’ funded by Kt’s fund 2013: https://www.sudep.org/article/cornwall-epilepsy-life-project-findings (last accessed 10.09.13)


Thomas. S, et al (2002) ‘A New Approach to Disease Management in Multiple Sclerosis’, The Royal College of Nursing, the Multiple Sclerosis Research (Charitable) Trust, the Multiple Sclerosis Society and the Association of British Neurologists

# Appendices

## Overview

Overview: services across the Southwest

### Table 3: Regional Neurological Alliances in the Southwest

<table>
<thead>
<tr>
<th>RNA</th>
<th>Area covered</th>
<th>Details of chair (where available)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Cornwall Alliance of Neurological Domain Organisations (CAN-DO)</td>
<td>Cornwall and the Isles of Scilly</td>
<td></td>
</tr>
<tr>
<td>The Somerset Neurological Alliance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The Gloucestershire Neurological Alliance (GlosNA)</td>
<td>Gloucestershire (entire)</td>
<td>David Stokes <a href="mailto:carol.dave007@yahoo.co.uk">carol.dave007@yahoo.co.uk</a></td>
</tr>
<tr>
<td>The Swindon and Wiltshire Neurological Alliance (SWNA)</td>
<td>Swindon and Wiltshire</td>
<td>David Wray <a href="mailto:chairman@swna.org.uk">chairman@swna.org.uk</a></td>
</tr>
<tr>
<td>The West of England Neurological Alliance (embryonic)</td>
<td>Bristol, South Gloucestershire and North Somerset</td>
<td>Hilary Fairfield, 0845375 1828 or <a href="mailto:hilary.fairfield@mndassociation.org">hilary.fairfield@mndassociation.org</a></td>
</tr>
<tr>
<td>The Bath and north-east Somerset Neurological Alliance (just started)</td>
<td>BANES</td>
<td>Jayne Pye <a href="mailto:jayne.pye@gmail.com">jayne.pye@gmail.com</a></td>
</tr>
</tbody>
</table>
Table 4: CCGs with relevant neurology focus or strategies in place

<table>
<thead>
<tr>
<th>CCG</th>
<th>Relevant information</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS Bath and North East Somerset CCG</td>
<td>End of life strategy group chaired by Corinne Edwards ensures the needs of people with a neurological condition are considered when looking at end-of-life care initiatives. Neurology is referred to in the JSNA.</td>
</tr>
<tr>
<td>NHS Bristol CCG</td>
<td>Nothing specific to note.</td>
</tr>
<tr>
<td>NHS Gloucestershire CCG</td>
<td>End of life strategy group chaired by Dr Simon Smith ensures that the needs of people with neurological conditions are taken into account. NCS conducted a review of neurological services in 2010 and 2012 (NCS: 2010; NCS: 2012)</td>
</tr>
<tr>
<td></td>
<td>The Gloucestershire Neurological Alliance has developed close links with Dr Hein Le Roux, CCG lead for Neurology, and there are regular meetings to discuss progress with the action plan.</td>
</tr>
<tr>
<td>NHS Kernow CCG</td>
<td>Neurology is referred to in the JSNA.</td>
</tr>
<tr>
<td></td>
<td>NCS ran a full-scale mapping and audit of neurology services in 2012 (NCS: 2011)</td>
</tr>
<tr>
<td>NHS North Somerset CCG</td>
<td>Neurology is referred to in the JSNA. There is a named CCG member at the Somerset Neurological Alliance</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>---------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>NHS Northern, Eastern and Western Devon CCG</td>
<td>Nothing specific to note.</td>
</tr>
<tr>
<td>NHS Somerset CCG</td>
<td>Nothing specific to note.</td>
</tr>
<tr>
<td>NHS South Devon and Torbay CCG</td>
<td>Nothing specific to note.</td>
</tr>
<tr>
<td>NHS South Gloucestershire CCG</td>
<td>Nothing specific to note.</td>
</tr>
<tr>
<td>NHS Swindon CCG</td>
<td>Neurology is referred to in the JSNA. Chair of the Swindon &amp; Wilts NA, David Wray, also sits on the Swindon Health and Wellbeing Board.</td>
</tr>
<tr>
<td>NHS Wiltshire CCG</td>
<td>The Swindon and Wiltshire Neurological Alliance is active in making links with the CCG.</td>
</tr>
<tr>
<td></td>
<td>A meeting of the neurology stakeholder group was convened for July 2013 to take forward extensive work ongoing over the past few years, led by a consultant in Public Health with CCG representation.</td>
</tr>
<tr>
<td>CCG</td>
<td>Relevant information</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>NHS Bath and North East Somerset CCG</td>
<td>Ruth Grabham, service lead for end-of-life care &amp; LTCs. (Also relevant may be Jim Hampton (elective care) and Liz Hersch (non-elective care) service leads.)</td>
</tr>
<tr>
<td>NHS Bristol CCG</td>
<td>Dr Gill Jenkins is the clinical lead for LTCs and is likely to cover neurological conditions within this.</td>
</tr>
<tr>
<td>NHS Gloucestershire CCG</td>
<td>Dr Hein le Roux leads on clinical programmes for older people (and dementia), neurology and end of life</td>
</tr>
<tr>
<td>NHS Kernow CCG</td>
<td>N/a (although website contains a specific section on neurology)</td>
</tr>
<tr>
<td>NHS North Somerset CCG</td>
<td>Dr Miriam Ainsworth is the clinical lead for community care and LTCs. (Also relevant may be Dr Kevin Haggerty (urgent care) and Dr John Heather (planned care).)</td>
</tr>
<tr>
<td>NHS North, East and West Devon CCG</td>
<td>Split into three localities, the lead for LTCs (and unplanned care) in the western locality is Sharon Matson, northern locality is Dr Stephen Miller. The eastern locality is yet to be filled at the time of writing.</td>
</tr>
<tr>
<td>NHS Somerset CCG</td>
<td>Within their clinical operations groups, Dr David Rooke is the chair and focussing on integration, while Dr Matthew Dolman is the clinical lead</td>
</tr>
<tr>
<td>CCG</td>
<td>Lead for flexible healthcare and will be focussing on pathway design.</td>
</tr>
<tr>
<td>----------------------------</td>
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</tr>
<tr>
<td>NHS South Devon and Torbay CCG</td>
<td>Dr David Greenwell is the clinical lead for integration, while Dr Adam Morris is the clinical lead for commissioning.</td>
</tr>
<tr>
<td>NHS South Gloucestershire CCG</td>
<td>Dr Jonathan Evans is the clinical lead for long-term conditions while Dr Peter Bagshaw leads for mental health and dementia. It is not clear which will lead on neurology within this, yet.</td>
</tr>
<tr>
<td>NHS Swindon CCG</td>
<td>Gill May is the Executive Nurse and felt to be the most relevant person for LTC-related queries.</td>
</tr>
<tr>
<td>NHS Wiltshire CCG</td>
<td>Clinical leads for neurology are Dr Simon Burrell and Dr Jonathan Rayner.</td>
</tr>
</tbody>
</table>

n/a refers to where no clear leads have been publically denoted. Many of these have allocated leads by locality rather than clinical area.
CQuIN related information

1. Cornwall & Isles of Scilly
   C&IOS PCT drew up a Quality Handover Document for Kernow CCG, which was finalised in March 2013. Although all CQuIN targets have a potential impact on all conditions, details of those set for the year 2012/13 most likely to affect patients with a neurological condition generally are as follows:

   Royal Cornwall Hospitals Trust
   - Improve responsiveness to personal needs of patients
   - Improve collection of data
     - in relation to pressure ulcers, falls, urinary tract infection
     - in those with a catheter, and VTE
   - Achieve progress against indicators relating to avoidable emergency admissions
   - Achieve progress on indicators relating to avoidable elective admissions

   Peninsula Community Health
   - Implement the nursing metric system across community hospitals to include patient survey showing an improvement in patient experience
   - Improve collection of data
     - in relation to pressure ulcers, falls, urinary tract infection
     - in those with a catheter, and VTE
   - Improve outcomes for 2 specific conditions (to be defined) by 10%
   - Assistive Technologies (High Impact Innovation) Increase the Telehealth install and coaching
   - Reduce the length of stay at Liskeard Hospital

   Cornwall Partnership NHS Foundation Trust:
   - Improve patient experience of community mental health services
   - Improve composite indicator on responsiveness to personal needs for inpatient service
   - Improve collection of data
     - in relation to pressure ulcers, falls, urinary tract infection
     - in those with a catheter, and VTE
   - Routine use of national mental health clustering tool (HoNOS) PbR) to establish baseline data, in preparation for activity based contracting including Improving the quality and timeliness of care clustering
Bodmin Treatment Centre:
- Improve responsiveness to personal needs of patients
- Ensure that not more than 10% of patients felt that more should have been done to manage pain more effectively
- Comply with World Health Organisation (WHO) Surgical Safety checklist

Duchy Hospital:
- Improve responsiveness to personal needs of patients
- Improve collection of data
  - in relation to pressure ulcers, falls, urinary tract infection
  - in those with a catheter, and VTE
- Reduce clinical risk to patients by undertaking Medical Early Warning Assessments

Probus Surgical Services:
- Patient Experience: Improve responsiveness to personal needs of patients.
- Comply with World Health Organisation (WHO) Surgical Safety checklist

Kernow CCG
Kernow CCG has published ‘An Integrated Plan for Cornwall & the Isles of Scilly: 2013 to 2016’ (see below) in which the following priorities have been set for long term conditions:
- Strategy development
- Improving wellbeing & prevention
- Improving early detection/ diagnosis & intervention
- Improving case management & care planning (including disease-specific management)
- Supporting ‘Living well’, peer support and encouraging self-management
- Improving palliative care and end of life pathways

See also [An Integrated Plan for Cornwall & the Isles of Scilly: 2013 to 2016](Kernow CCG website)
See also [NHS Kernow Outcomes Benchmarking Support Pack](NHS England website)
See also [Cornwall LA Outcomes Benchmarking Support Pack](NHS England website)
2. NHS Devon, Plymouth & Torbay
In its **Quality Handover Board Paper** NHS Devon, Plymouth & Torbay outlined key quality and safety themes for each of the four localities making up the PCT Cluster of Devon, Plymouth and Torbay, which has since been handed to the two new Clinical Commissioning Groups of Northern, Eastern and Western (NEW) Devon and South Devon and Torbay. Local CCG published CQuINs have been agreed as:

- Discharge notification
- Frail elderly
- Stroke
- Medicines management
- Planned care sustainability
- Improved communication with primary care

South Devon and Torbay CCG has published ‘An Integrated Plan for 2013 to 2016’ (see below) in which the following three commissioning priorities have been set:

- promoting self-care, prevention and personal responsibility
- developing joined-up, patient-centred community services (including mental health services) closer to home
- leading a sustainable health and care system, encompassing workforce.

- See also [South Devon & Torbay CCG’s Integrated Plan for 2013 to 2016](CCG website)
- See also [South Devon & Torbay Joint Strategic Needs Assessment](CCG website)
- See also [NHS North, East & West Devon Outcomes Benchmarking Support Pack](NHS England website)
- See also [NHS South Devon and Torbay Outcomes Benchmarking Support Pack](NHS England website)
- See also [Devon LA Outcomes Benchmarking Support Pack](NHS England website)

3. NHS Somerset
NHS Somerset drew up a Quality Handover Document for Somerset CCG, which was finalised in March 2013. A copy of the document can be viewed here: [NHS Somerset Quality Handover](NHS Somerset website).

Somerset CCG has developed a local CQuIN framework for quality improvement in a number of priority areas where current service delivery isn’t achieving required
outcomes for patients, or where it’s thought that further progress can be made. Priorities have been identified from the Joint Strategic Needs Assessment and the quality assurance framework for foundation trusts. Although all may have some relevance to any condition, of the local CQUIN framework’s nine priorities, the following are particularly relevant:

- improve the experience of end-of-life care
- communication of test results with patients and outpatient communication to GPs
- improving outcomes for secondary care psychological therapies *

* This CQUIN may be helpful to service commissioners in addressing the virtual absence of a neuropsychology service for people with a neurological condition in Somerset

- See also Somerset CCG Commissioning Plan 2013/14
- See also NHS Somerset’s Joint Strategic Needs Assessment (2011)
- See also NHS Somerset’s Outcomes benchmarking Support Pack (NHS England)
- See also Somerset LA Outcomes Benchmarking Support Pack (NHS England website)
Overview: specialist service provision
Within the overview of neurology services for the Southwest, there is a reference to the national best practice deep brain stimulation (DBS) pathway developed by NCS as part of some integrated care pathway development work in Norfolk, Great Yarmouth and Waveney (NCS: 2013). This is depicted here for information:
Overview: variation in social care
Table 6: Measures from the Adult Social Care Outcomes Framework (ASCOF) 2012/13

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Bath and North East Somerset</th>
<th>Bristol</th>
<th>Cornwall</th>
<th>Devon</th>
<th>Gloucestershire</th>
<th>North Somerset</th>
<th>Plymouth</th>
<th>Somerset</th>
<th>South Gloucestershire</th>
<th>Swindon</th>
<th>Torbay</th>
<th>Wiltshire</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Social care-related quality of life score, 2012-13 (1a)</td>
<td>18.8</td>
<td>18.5</td>
<td>19.2</td>
<td>18.7</td>
<td>19.4</td>
<td>19.1</td>
<td>19.4</td>
<td>19.3</td>
<td>19.6</td>
<td>18.5</td>
<td>18.6</td>
<td>18.8</td>
<td>18.8</td>
</tr>
<tr>
<td>2. The Proportion of adults with learning disabilities in paid employment, expressed as a percentage (1e)</td>
<td>7.7%</td>
<td>6.2%</td>
<td>0.6%</td>
<td>8.6%</td>
<td>12.1%</td>
<td>12.1%</td>
<td>4.3%</td>
<td>4.7%</td>
<td>13.4%</td>
<td>3.6%</td>
<td>7.2%</td>
<td>14.1%</td>
<td>7.2%</td>
</tr>
<tr>
<td>3. The proportion of permanent admissions to residential and nursing care homes for younger adults (18-64), per 100,000 population, 2012/13 (2A part 1)</td>
<td>12.7</td>
<td>20.0</td>
<td>11.1</td>
<td>19.2</td>
<td>15.4</td>
<td>14.3</td>
<td>14.7</td>
<td>14.9</td>
<td>16.7</td>
<td>10.4</td>
<td>14.9</td>
<td>16.2</td>
<td>14.9</td>
</tr>
<tr>
<td>Indicator</td>
<td>Bath and North East Somerset</td>
<td>Bristol</td>
<td>Cornwall</td>
<td>Devon</td>
<td>Gloucestershire</td>
<td>North Somerset</td>
<td>Plymouth</td>
<td>Somerset</td>
<td>South Gloucestershire</td>
<td>Swindon</td>
<td>Torbay</td>
<td>Wiltshire</td>
<td>England</td>
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</tr>
<tr>
<td>The proportion of permanent admissions to residential and nursing care homes for older people (65 and over), per 100,000 population, 2012/13 (2A part 2)</td>
<td>1004</td>
<td>834.6</td>
<td>575.1</td>
<td>649.4</td>
<td>823.8</td>
<td>752.7</td>
<td>721.5</td>
<td>709</td>
<td>820.0</td>
<td>612.3</td>
<td>744.8</td>
<td>634</td>
<td>709</td>
</tr>
<tr>
<td>The proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services, expressed as a percentage 2012/13 (2b part 1)</td>
<td>86.2%</td>
<td>82.5%</td>
<td>89.7%</td>
<td>87.7%</td>
<td>71.6%</td>
<td>84.5%</td>
<td>89.3%</td>
<td>81.5%</td>
<td>83.9%</td>
<td>80.0%</td>
<td>81.3%</td>
<td>83.6%</td>
<td>81.5%</td>
</tr>
<tr>
<td>Indicator</td>
<td>Bath and North East Somerset</td>
<td>Bristol</td>
<td>Cornwall</td>
<td>Devon</td>
<td>Gloucestershire</td>
<td>North Somerset</td>
<td>Plymouth</td>
<td>Somerset</td>
<td>South Gloucestershire</td>
<td>Swindon</td>
<td>Torbay</td>
<td>Wiltshire</td>
<td>England</td>
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</tr>
<tr>
<td>6. The proportion of older people (65 and older) who were offered reablement services following discharge from hospital, expressed as a percentage 2012/13 (2b part2)</td>
<td>3.2%</td>
<td>1.1%</td>
<td>0.3%</td>
<td>1.7%</td>
<td>3.9%</td>
<td>1.3%</td>
<td>6.3%</td>
<td>3.5%</td>
<td>3.0%</td>
<td>1.6%</td>
<td>3.4%</td>
<td>10.8%</td>
<td>3.5%</td>
</tr>
<tr>
<td>7. Delayed transfers of care from hospital, per 100,000 population, 2012/13 (2c)</td>
<td>12.5</td>
<td>11.4</td>
<td>11.5</td>
<td>12.5</td>
<td>6.6</td>
<td>10.0</td>
<td>13.2</td>
<td>8.5</td>
<td>11.7</td>
<td>8.4</td>
<td>2.7</td>
<td>13.8</td>
<td>8.5</td>
</tr>
<tr>
<td>8. Delayed transfers of care from hospital attributable to adult social care, expressed as a percentage, 2012/13</td>
<td>6.9%</td>
<td>1.5%</td>
<td>5.5%</td>
<td>3.3%</td>
<td>2.9%</td>
<td>0.3%</td>
<td>5.3%</td>
<td>3.3%</td>
<td>2.9%</td>
<td>4.5%</td>
<td>1.0%</td>
<td>8.3%</td>
<td>3.3%</td>
</tr>
<tr>
<td>9. Overall satisfaction of people who use services with their care support, expressed as a percentage, 2012-13 (3A)</td>
<td>63.2%</td>
<td>63.2%</td>
<td>64.3%</td>
<td>67.7%</td>
<td>64.1%</td>
<td>65.0%</td>
<td>68.5%</td>
<td>64.5%</td>
<td>65.9%</td>
<td>63.2%</td>
<td>72.6%</td>
<td>61.3%</td>
<td>64.5%</td>
</tr>
<tr>
<td>Indicator</td>
<td>Bath and North East Somerset</td>
<td>Bristol</td>
<td>Cornwall</td>
<td>Devon</td>
<td>Gloucestershire</td>
<td>North Somerset</td>
<td>Plymouth</td>
<td>Somerset</td>
<td>South Gloucestershire</td>
<td>Swindon</td>
<td>Torbay</td>
<td>Wiltshire</td>
<td>England</td>
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<tr>
<td>10. Overall satisfaction of carers with social services, expressed as a percentage, 2012-13 (3B)</td>
<td>47.6%</td>
<td>43.6%</td>
<td>49.0%</td>
<td>48.6%</td>
<td>46.1%</td>
<td>46.2%</td>
<td>47.5%</td>
<td>42.7%</td>
<td>41.2%</td>
<td>35.5%</td>
<td>45.9%</td>
<td>42.1%</td>
<td>42.7%</td>
</tr>
<tr>
<td>11. The proportion of people who use services and carers who find it easy to find information about services, expressed as a percentage, 2012-13</td>
<td>71.6%</td>
<td>71.5%</td>
<td>71.2%</td>
<td>73.1%</td>
<td>73.6%</td>
<td>73.5%</td>
<td>72.8%</td>
<td>74.7%</td>
<td>71.9%</td>
<td>65%</td>
<td>75.2%</td>
<td>67.2%</td>
<td>74.8%</td>
</tr>
</tbody>
</table>

**Key**
- England Average
- Above
- Below
Condition-specific reporting

Multiple sclerosis (MS)

Summary of telephone audit research for Brams MS Nurses
The audit covers a two week period between 05/07/10 and 16/07/10 and captures data relating to the received telephone calls of three full-time MS nurses. A total of 253 calls were analysed over the two week period.

Call lengths:

- 71% of calls lasted less than 5 minutes
- 2% of calls lasted for more than 20 minutes
- 2% of calls lasted more than 26 minutes
- The average length of call on a Thursday was 22 minutes
- The weekly average call duration is 8 minutes

Reasons for calling
The majority of calls (66%) were concerning appointments, and either changing, making or confirming an appointment date relating to the consultant, MS nurse or clinical assistant

Other reasons for calling included:

- social – blue badge, equipment, carers, relationships, housing, benefits, suicide or depression, other including work issues, CHC funding, support, help around home, community OT, moving to area, wound management
- test results – infections, bloods or urine
- medication – changing medication, clarification, side effects, dosage, suggestions on medication
- symptoms – relapse, pain, bladder, falling, fatigue, visual, spasm, diet, bowel
- GP/community health care calls – referral, general advice, appointment/follow up, medication advice
- clinic prep – requesting notes for appointments
- clinical trials
- other – meetings, putting patient on system, physio, prescriptions, transport, education, requesting contact/fax numbers, info leaflet, returning call, advice for family, colleague, community OT referral, community physio, counselling, DART referral, chasing results, infection control, IV steroids, mental health, ordering lunch box, ordering dry ice, pharmacy, NABs testing, stopping smoking, wheelchair services
Conclusions

- Each MS nurse takes an average of 44 calls per week or 2,288 per year.
- That’s 6,864 calls in total potentially being diverted away from GPs or other healthcare staff in the community/primary care.
- The average call length is just over 8 minutes.
- This equates to 352 or 5.86 hours per week spent on the telephone.
- If an average GP appointment costs £43.00 then, if every call would otherwise have resulted in a GP visit, this would amount to £295,152 in one year.

Motor neurone disease (MND)
Charity-run hospices in the Southwest

1. St Peter’s Hospice, Bristol (covers Bristol plus north of North Somerset area)
2. Dorothy House Hospice, Winsley (covers Bath, West Wiltshire, North Wiltshire)
3. Weston Hospicecare (covers most of North Somerset)
4. Prospect Hospice, Wroughton (covers Swindon and E Wilts)
5. Salisbury Hospice (covers the South Wiltshire area)
6. Sue Ryder Care, Leckhampton (covers Gloucestershire)
7. Cotswold Care Hospice – a day hospice for S and E Gloucestershire
8. Great Oaks Hospice – a day hospice for the Forest of Dean
9. St Margaret’s Hospice, Yeovil
10. The North Devon Hospice, Barnstable
11. St Margaret’s Hospice, Taunton
12. Hospiscare, Exeter
13. Rowcroft Hospice, Torquay
15. St Julia’s Hospice, Hayle
16. Mount Edgcombe, St Austell
Carer’s associations in the Southwest

- Bath and North east Somerset - www.banescarerscentre.org.uk
- Bristol and South Gloucestershire - www.prtcarerscentre.org.uk
- Wiltshire - www.carersinwiltshire.co.uk
- Gloucestershire - www.carersgloucestershire.org.uk
- North Somerset - www.crossroadscare-ns.org.uk
- Swindon - www.swindoncarers.org.uk
- Cornwall and Isles of Scilly - www.cornwallcarers.org.uk
- Devon - www.unite-carersinmiddevon.org.uk
- Plymouth - www.colebrookhousing.co.uk (Carers Champions, Plymouth)
- Torbay - www.crossroads.org.uk/southwest
- East Somerset - www.carersukeastsomerset.org/

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QOF data is taken from the English Quality and Outcomes Framework (QOF) produced by the Information Centre for Health and Social Care (www.hscic.gov.uk/qof)

Net Ingredient Cost data is taken from the GP Practice Prescribing Chemical-level Data provided by the Information Centre for Health and Social Care (www.hscic.gov.uk/prescribing)

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