WM QRS West Midlands Quality Review Service

NHS

Services for People with Chronic Neurological Conditions

Pathway Report

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INTRODUCTION

1.1 Care of Adults with Long-Term Conditions: West Midlands Overview Report

Care of people with long-term conditions was chosen by Trust and Primary Care Trust Chief Executives as the West Midlands Quality Review Service (WMQRS) review programme for 2012/13.The *'Care of Adults with Long-Term Conditions: West Midlands Overview Report'* summarises:

- The aims, scope and structure of the review programme
- WMQRS and its role
- The development of the Quality Standards and their structure
- The number of reviews and the reviewers who were involved
- The findings of the review programme across all the pathways reviewed
- The evaluation of the review programme
- Next steps, including responsibility for follow-up and action

The '*Care of Adults with Long-Term Conditions: West Midlands Overview Report'* and the full text of all visit reports are available on the WMQRS website www.wmqrs.nhs.uk

This pathway report on the care of people with chronic neurological conditions is a supplementary report to the '*Care of Adults with Long-Term Conditions: West Midlands Overview Report'* and summarises findings which relate only to the care of people with chronic neurological conditions. Appendix 1 gives the free text sections of relevant visit reports. These extracts are taken out of the context of their health economy reports, available on the WMQRS website, and are supported by information on compliance with Quality Standards given in the health economy reports. Appendix 2 gives compliance with each of the Quality Standards and can be used by individual services to compare their progress with others. The *'Care of Adults with Long-Term Conditions: West Midlands Overview Report'* includes comparison of compliance with other specialist teams caring for people with long-term conditions.

1.2 Review Visits

The WMQRS 2012/13 review programme covered 17 pathways of care for people with chronic neurological conditions. A minimum of 29 services for people with chronic neurological conditions were reviewed, of which 12 were rehabilitation services. In some areas, compliance was combined across several services, for example, in Worcestershire nine separate services were reviewed as one pathway. Primary care, acute Trust-wide and commissioning Quality Standards were also reviewed, some of which specifically related to the care of people with chronic neurological conditions.

All West Midlands services for people with chronic neurological conditions were reviewed except those in Dudley and those provided by University Hospital Birmingham NHS Foundation Trust.

FINDINGS

Review visits findings are categorised as good practice (GP), for 'further consideration' (FC), concern (C), serious concern (SC) or immediate risk (IR). The number of services and the categorisation of the issue are shown in brackets, for example, (C:4) indicates that the issue was of concern in four of the services reviewed. The illustrations of good practice mentioned in this Overview Report are illustrative and similar examples may be found in other services.

This review programme found that the care available for people with chronic neurological conditions varied significantly depending on their condition, where they lived and, if a service was available, whether individual members of staff were at work, on holiday or away for some other reason. Concerns were raised about the lack of guidelines on referral to a specialist service of people with a suspected chronic neurological condition, including

those with a first seizure, which were present in only three of the 16 primary care areas reviewed. Incomplete implementation of NICE guidance on the care of people with epilepsy was a particular problem and identified as a concern in eight of the 14 health economies. In others, arrangements for cover for staff absences may not be robust. Specialist nurses for people with Parkinson's disease or multiple sclerosis were available in some areas but not others. Specialist nurse support for people with other chronic neurological conditions, including epilepsy, was often not available, although services in Walsall and Worcestershire would accept people with other neurological conditions. Two health economies were identified as being particularly short of consultant neurologists. The links between consultants and specialist nursing teams were often not robust (C:**4** FC:**3**). Other than at University Hospitals of North Staffordshire NHS Trust and University Hospitals Coventry and Warwickshire NHS Trust (and University Hospital Birmingham), people with chronic neurological conditions who needed acute hospital admission were usually admitted to general medical wards. Sometimes, such as in Shrewsbury and Telford Hospital NHS Trust, there were good arrangements for specialist advice and daily review by a consultant neurologist whereas in other acute hospitals these arrangements were less clearly defined.

The West Midlands Rehabilitation Service provided a very good specialist rehabilitation service for the region and local rehabilitation for Birmingham. Local rehabilitation was in place in some areas, but some parts of the region had no local rehabilitation, and in others, access depended on where you lived and the type of condition. Care for people with motor neurone disease was usually overseen by the team at University Hospitals Birmingham NHS Foundation Trust with, sometimes, good links with local palliative care services.

Access to acute and domiciliary non-invasive ventilation was identified as a general concern. Further detail on this issue is given in the '*Care of Adults with Long-Term Conditions: West Midlands Overview Report'.*

Commissioning of services for people with chronic neurological conditions was not well-developed in any of the areas reviewed, although both Worcestershire and Coventry and Warwickshire had undertaken reviews. The following recommendations are made to commissioners:

Recommendations:

1 West Midlands Clinical Commissioning Groups and NHS England (Specialist Commissioning – West Midlands) should develop collaborative commissioning arrangements for the care of people with chronic neurological conditions, recognising that un-coordinated commissioning will be unlikely to achieve the necessary improvements, in particular:

- Reducing the variability in the availability of services
- Ensuring full implementation of NICE guidance in all parts of the West Midlands
- Ensuring appropriate acute, rehabilitation (specialist and local) and ongoing care is available to patients irrespective of their condition and postcode
- Ensuring appropriate condition-specific sub-specialisation and care for people with less common neurological conditions
- Implementing robust arrangements for cover for absences
- Improving multi-disciplinary working and communication within specialist services caring for people with chronic neurological conditions through the development of integrated teams.

2 NHS Health Education England should review the availability of staff specialising in the care of people with chronic neurological conditions with the aim of ensuring the supply of sufficient staff to provide care for this group of patients.

3 NHS England (Specialist Commissioning Team) should review its commissioning of domiciliary non-invasive ventilation to ensure appropriate care is available across the West Midlands.

4 All acute Trusts should review their provision on acute non-invasive ventilation to ensure this provides appropriate access for patients who may benefit from this intervention.

APPENDIX 1 HEALTH ECONOMY REPORTS - CARE OF PEOPLE WITH CHRONIC NEUROLOGICAL CONDITIONS

Given below are the free text sections of visit reports which specifically relate to the care of people with chronic neurological conditions. These extracts are taken out of the context of their health economy reports, available on the WMQRS website, and in the visit reports are supported by information on compliance with Quality Standards. Health economy, primary care and commissioning sections of the visit reports may include general findings about the care of people with long-term conditions which also apply to people with chronic neurological conditions. The full visit reports will need to be accessed for this information.

SHROPSHIRE AND TELFORD & WREKIN HEALTH ECONOMY

SPECIALIST CARE OF PEOPLE WITH CHRONIC NEUROLOGICAL CONDITIONS

Name of Service	Provider	Geographic area covered
Neurology Service	The Shrewsbury and Telford Hospital NHS Trust	Shropshire and Telford & Wrekin
Shropshire Enablement Team	Shropshire Community Health NHS Trust	Shropshire and Telford & Wrekin

PATHWAY OVERVIEW

Care of people with chronic neurological conditions was provided by two services, the Neurology Service at The Shrewsbury and Telford Hospitals NHS Trust and the Shropshire Enablement Team. A social worker with specific responsibility for people with brain injury had previously been in post but this post no longer existed. Both teams were enthusiastic but working under considerable pressure. Pathways were not yet clearly defined and reviewers were not always clear where responsibility lay for a particular aspect of care. Carers who met the reviewers said that they were well supported although some patients were not clear about the services available to them, sometimes because services had changed since they were diagnosed.

Further consideration: See commissioning section of this report in relation to the lack of neurological rehabilitation for people aged over 65.

NEUROLOGY SERVICE – THE SHREWSBURY AND TELFORD HOSPITAL NHS TRUST

General Comments and Achievements

The Neurology Service comprised four consultants (3.1 wte) who were based at both Royal Shrewsbury Hospital and Princess Royal Hospital, specialist nurses for epilepsy, motor neurone disease, Parkinson's Disease, multiple sclerosis and spasticity management, and administrative support. Specialist nurses were nurse prescribers and worked across hospital and community services, although the balance between these varied. Access to telephone advice, clinics and some home visiting was available for those who were aware of the specialist nursing services. An in-patient EEG service was provided for patients who were too unwell to travel. Most patients were referred for neurophysiology at North Staffordshire (UHNS), Birmingham (UHB) or Wolverhampton. Patients needing neurosurgery were referred to North Staffordshire (UHNS) or Birmingham (UHB) and a surgeon from UHNS provided one clinic per month at both Princess Royal and Royal Shrewsbury Hospitals.

Considerable progress had been made on the development of this service. Neurologists worked on a shared care model with admitting consultants and were able to review acute admissions at both sites within 24 hours of

admission. Education programmes were in place for patients with multiple sclerosis, including a stress and fatigue management course.

Good Practice

1 Information for patients on how to access the Multiple Sclerosis team and services available was very clear and concise.

Immediate Risks: No immediate risks were identified.

Concerns

1 Guidelines and protocols were generally not documented. Reviewers were told that the care provided was based on NICE guidance and staff were aware of relevant processes. It was not clear that patients were receiving consistent care and support and this was reflected in some of the feedback from patients.

2 There was no cover for absences of the clinical nurse specialists working with people with epilepsy, Parkinson's disease or motor neurone disease. Reviewers were also told that future funding for the Parkinson's disease specialist nurse post was uncertain. There was also some concern whether the specialist nurses would have to take on general roles taking them away from their specialist service.

3 The criteria and arrangements for referral to clinical nurse specialists were not clear and it appeared that some patients were not offered the support that was available.

Further Consideration

1 The sustainability of the medical staffing model may benefit from review. An additional post for a general neurologist had been advertised but reviewers considered that appointment to this post may be difficult - because those completing consultant training are likely to have sub-specialised.

2 Arrangements for ensuring all patients received appropriate information at diagnosis and at later stages of the pathway may benefit from review to ensure consistency of information offered. It may also be helpful to review with previously diagnosed patients whether they have all the information that they need. Some patients who met the visiting team had not received information about the services available and how to access them.

SHROPSHIRE ENABLEMENT TEAM - SHROPSHIRE COMMUNITY HEALTH NHS TRUST

General Comments, Achievements and Good Practice

The Shropshire Enablement Team, a specialist community neuro-rehabilitation team, provided a multi-disciplinary approach to the rehabilitation of patients with long-term neurological conditions, including those with acquired brain injuries, stroke and chronic fatigue syndrome. The team was enthusiastic and caring, although working under considerable pressure. Patients who accessed the enablement service met reviewers and were very appreciative of the help, support and individualised care available to them.

Reviewers were told that some GPs were not aware of the service, although some work with primary care had taken place some years previously and some GP training and development was still undertaken.

The team had received 168 referrals for acquired brain injury and neurology in the previous year. Only 13 of these referrals were considered inappropriate and 60% of the team's activity was caring for people with chronic neurological conditions. The service was located at the Harlescott Centre in Shrewsbury. This facility had recently been upgraded, which had enabled consolidation of the service. The environment was welcoming and friendly and included lots of clinic rooms. Since the consolidation of the service the number of home visits had been reduced and, when appropriate, patients were encouraged to attend the Harlescott facility.

This team had been through two management reorganisations in the last year. The previous manager was no longer in post and, at the time of the review visit, the management of the service was the responsibility of the lead psychologist who also had clinical responsibilities.

Immediate Risks: No immediate risks were identified.

Concerns

1 Guidelines and protocols were generally not documented. Reviewers were told that the care provided was based on NICE guidance and staff were aware of relevant processes. It was not clear that patients were receiving consistent care and support and this was reflected in some of the feedback from patients. Reviewers were particularly concerned about the management of exacerbations in the absence of clear guidelines.

2 Waiting times to access an initial assessment for psychology and physiotherapy had increased significantly due to staff vacancies. Waiting lists for psychology were up to 12 months and for physiotherapy up to five months.

Further Consideration

1 Arrangements for discharge from the service were not clear and it appeared that patients could stay with the team for long periods of time. Reviewers suggested that more formalised discharge criteria and arrangements would be helpful, in order to ensure that the team's resources are used most appropriately.

2 People aged over 65 years were not able to access the Shropshire Enablement Team and discussion with commissioners on this issue is needed.

3 The psychologist was also acting as manager for the service and plans for the future of the manager post were not clear. This issue should be considered in the light of the waiting times for access to psychology assessment.

COMMISSIONING

TELFORD AND WREKIN AND SHROPSHRE CLINICAL COMMMISSIONING GROUPS

Further Consideration

1 Some services were not yet commissioned including:

   a. Neurological rehabilitation for people aged over 65.

2 There were differences in access to Long term Oxygen Therapy services across the county which were creating operational difficulties.

3 The care of people with more common chronic neurological conditions is described in this report. Less common neurological problems, when considered together, affect a significant number of people. Services for this group of patients are usually less well organised than those for people with more common conditions and further consideration should be given to whether local services are meeting their needs.

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SOUTH STAFFORDSHIRE (WEST) HEALTH ECONOMY

SPECIALIST CARE OF PEOPLE WITH CHRONIC NEUROLOGICAL CONDITIONS

MID STAFFORDSHIRE NHS FOUNDATION TRUST

General Comments and Achievements

Mid Staffordshire NHS Foundation Trust provided acute services for people with chronic neurological conditions at Stafford Hospital and rehabilitation services were based at Cannock Hospital. The team was enthusiastic and teamwork and communication between team members and services was good. Reviewers were impressed by the environment and facilities available to patients and carers at the Rehabilitation Day Unit at Cannock. Communication with GPs was well organised, including communication about the outcomes of rehabilitation sessions. The services were generally very well organised, including producing good annual reports. There was strong leadership, especially from the Parkinson's and rehabilitation nurse specialists.

A small community rehabilitation service was provided by Staffordshire and Stoke on Trent Partnership NHS Trust for patients from Stone and Eccleshall. This service was not reviewed in detail, but they were integrated with services provided elsewhere. This team was very motivated and had plans to further develop their services to meet the needs of their patient group, including lifestyle initiatives around weight management and smoking cessation.

Patients who met the visiting team were positive and enthusiastic about the services that they received

Epilepsy: A nurse-led service for people with epilepsy had strong links with neuropsychiatry and neurology services in Birmingham as well as other services that were provided locally. A fast-track 'first seizure' service was in place and weekly multi-disciplinary team meetings were held to discuss the care of more complex patients. Cognitive behavioural therapy was access by GP referral. Clear guidelines for the care of women of child-bearing age with epilepsy were available and the epilepsy nurse specialist chaired the non-medical prescribing group.

Parkinson's disease: Patient information and support were well organised with patients receiving copies of all letters about their care and good arrangements for peer support. Specific clinics for people with Parkinson's disease were run at the rehabilitation centre at Stone. Eight additional weekly clinics and a home visiting service were also provided. The team had good links with mental health services and there was access to rehabilitation programmes for younger patients. There was good leadership of the service by the clinical nurse specialist.

Multiple Sclerosis: A nurse-led service with links to the multiple sclerosis nursing service at University Hospital of North Staffordshire NHS Trust (UHNS). Patients were seen in clinic and disease modifying therapies commenced locally which prevented the patients having to attend services at UHNS. There was a range of patient information available including a guide to the MS Nursing service and who to contact in and out of hours. An annual report was also available which identified plans for the next 12 months.

Spasticity: Good services were available for people with spasticity, although reviewers suggested that further audit of outcomes may be helpful to demonstrate the effectiveness of services provided. Documentation of guidelines and protocols was generally good and showed compliance with national standards for the organisation of care.

Rehabilitation: Staff were very enthusiastic at all levels and there was very good leadership for this service with evidence of good teamwork and communication throughout. There was a range of very good information displayed on the walls as well as artwork from participants of the various rehabilitation programmes. The service also carried out small local audits.

Good Practice

1 An impressive and imaginative range and variety of rehabilitation activities was offered by the services with rehabilitation tailored to individuals' needs. The service had been able to utilise their facilities for real

lifestyle rehabilitation for those using the service such as forestry, woodwork, metal work, baking, specialist cookery, flower arranging, art and crafts and use of 'Wii fit' activities. For some of the produce and work produced, the rehabilitation service had started to provide 'orders' for local communities.

2 Rehabilitation programmes included consideration of basic numeracy and literacy skills and, when appropriate, these skills were included in the rehabilitation programme.

3 Living after Rehabilitation (LARF) was a loyal and very actively supportive patient group, who met regularly and were active in ensuring that patient and carer involvement was embedded in any service improvement and development.

4 The service provided 'outreach' care for people in prison who lived with long term neurological conditions.

5 Communication to patients and GPs accessing the Parkinson's service was very good. There was a very detailed checklist for patient reviews, which was then communicated to all with a comprehensive letter detailing any updates in treatment plans.

Immediate Risks: No immediate risks were identified.

Concerns

1 One consultant neurologist post was filled by a locum consultant. The arrangements for recruitment to a substantive post were not clear and reviewers were told of delays in approval and recruitment.

2 The overall pathway for patients with chronic neurological conditions was not documented and several of the clinical guidelines expected by the Quality Standards were not yet in place.

3 Patients did not have easy and timely access to psychological support services.

4 Reviewers were told that only 1.5 wte community speech therapist was available to support all community services. This caused particular problems for patients of the neurological rehabilitation service.

5 Arrangements for cover for the epilepsy nurse specialist and the rehabilitation specialist nurse were not formalised. Future funding for the multiple sclerosis nurse specialist post was unclear.

Further Consideration

1 Rehabilitation was organised in eight week programmes at the Day Unit with no outreach or follow up after the programme was completed. It may be helpful to consider arrangements for patients unable to attend the Day Unit and arrangements for ongoing support and further rehabilitation, if required.

2 Once the substantive neurology consultant has been appointed, developing a 'clinical champion' role to ensure the quality of and development of services for **all** long term chronic neurological conditions, in the context of the acute trust, may be helpful.

3 Links between the consultants and specialist nurses may benefit from review to ensure that all appropriate patients are receiving specialist nurse support.

4 As part of the work on documenting guidelines and policies it may be helpful specifically to consider: a) arrangements for documenting and recording of care plans, b) making the arrangements for education and self-management more formalised, c) criteria for home visiting and d) reviewing the policy of following up those patients with epilepsy who did not attend their appointments following completion of the audit.

5 Reviewers suggested that the rehabilitation service may want to widen the use of peer support within the patient self management and patient education frameworks.

COMMISSIONING

STAFFORD AND SURROUNDS CLINICAL COMMISSIONING GROUP and CANNOCK CHASE CLINICAL COMMISSIONING GROUP

Further Consideration

1 The care of people with more common chronic neurological conditions is described in this report. Less common neurological problems, when considered together, affect a significant number of people. Services for this group of patients are usually less well organised than those for people with more common conditions and further consideration should be given to whether local services are meeting their needs.

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NORTH STAFFORDSHIRE HEALTH ECONOMY

SPECIALIST CARE OF PEOPLE WITH CHRONIC NEUROLOGICAL CONDITIONS

UNIVERSITY HOSPITAL NORTH STAFFORDSHIRE NHS TRUST – ACUTE SERVICE

General Comments and Achievements

University Hospital of North Staffordshire provided an acute neurology service, with in-patient and day case facilities, out-patient clinics and outreach on a 'hub and spoke' model into Cheshire and to Stafford Hospital. The services were well organised and staff were enthusiastic and well informed. Team-work was good and the quality of support from the specialist nurses was commended by all of the patients who met the visiting team. There was a culture of working to improve the services offered and particular developments at the time of the review visit were the use of tele-medicine for patients with chronic neurological conditions and the waiting times for new out-patient referrals were three weeks and very nearly reaching the NICE guidance of two weeks.

Good Practice

1 Portable video-telemetry was being used for the diagnosis of epilepsy. This provided a cost-effective approach to reducing the mis-diagnosis of epilepsy.

2 Service improvement had been effectively used to manage out-patient capacity and demand. In particular a 'zero backlog' approach had been used for out-patient follow-up. This was actively monitored and managed. Data on the shortfall in capacity had led to the recruitment of two part-time consultants.

3 Good arrangements were in place to enable people with severe disabilities to attend out-patient appointments, including good coordination with the ambulance service and availability of pressure-relieving mattresses.

4 The 'nurse call' system had been adapted with a specialised pressure switch system so that it could be used by people who were severely neurologically impaired.

5 The layout of the neurological infusion suite was well-planned, with a private nurse assessment area which led into a treatment delivery area.

6 All the clinical nurse specialists were independent prescribers.

Immediate Risks: No immediate risks were identified.

Concerns

1 There were delays in telephone access to advice with some patients reporting that they were not called back for up to three weeks. Patients who met with the visiting team commented that this had occurred since the changes to the reduction in specialist nursing hours.

2 Accessibility for wheelchair users was difficult with no automated doors in the out-patient or ward area. Also the self check-in machines in the out-patient department were not at a height suitable for people in wheelchairs.

3 See also the commissioning section of this report about care of people with epilepsy.

Further Consideration

1 Some patients had neurological conditions that were not covered by the clinical nurse specialists available at the time of the review and so did not have access to the same level of support. Approaches to providing specialist nursing support for these patients may benefit from further consideration. Also, at the time of the review, specialist nurse activity appeared to focus on pharmacological interventions. It may be helpful to review, with patients and carers, whether holistic support needs are being met.

2 The rooms allocated for out-patient clinics varied which made it difficult for staff to have all the appropriate educational material available.

3 Links with primary care and community nursing services may benefit from further consideration in order to maximise the use of the skills in primary care services, ensure good handover from specialist services and easy routes to re-access more specialist advice and care if this is required. This was specifically raised with reviewers in relation to the care of people with epilepsy.

STAFFORDSHIRE AND STOKE ON TRENT PARTNERSHIP NHS TRUST – COMMUNITY AND IN-PATIENT REHABILITATION

General Comments and Achievements

Staffordshire and Stoke on Trent Partnership NHS Trust provided a Rehabilitation Medicine Service and a Community Rehabilitation Team which together formed the North Staffordshire Rehabilitation Centre. The North Staffordshire Rehabilitation Centre was a regional resource covering Staffordshire, Shropshire, Cheshire and a small area of North Wales. The Community Rehabilitation Team covered part of North Staffordshire (around the Newcastle Under Lyme area). Specialist rehabilitation was available in both in-patient and community settings. Facilities were geared to provide support for those patients with an acquired brain injury and severe and complex neurological conditions, as well as for those with long term conditions.

Reviewers were impressed by the range of services available and the highly personalised care aimed at enabling service users to maintain and increase their independence and participation in society. Feedback from patients and carers, especially about the in-patient care, was excellent. The service took a holistic approach to meeting patients' needs. There was good patient involvement in the running of the service, including in the design of patient information.

Good Practice

1 Carers support at the Haywood Hospital was particularly good. Carers felt that their needs were assessed and taken into account. Flexible visiting was available for Carers with relatives who needed to stay for long periods of time and the service also provided respite care.

2 There were excellent relationships developed by both teams with adult social services.

Immediate Risks: No immediate risks were identified.

Concerns

1 Psychological support was not available on the rehabilitation ward. At the time of the review, physiotherapy and occupational therapy was insufficient for the number of patients being cared for by the service, partly due to staff vacancies.

2 See commissioning section of this report about care of people with epilepsy.

Further Consideration

1 Patients who met with the visiting team commented that there were often delays in communicating prescription changes between specialists and GPs.

COMMISSIONING

STAFFORD AND SURROUNDS CLINICAL COMMISSIONING GROUP and CANNOCK CHASE CLINICAL COMMISSIONING GROUP

Concerns

1 **Care of People with Epilepsy**

The chronic neurological conditions strategy and service specifications did not include care of people with epilepsy (although an epilepsy specialist nurse was in post at University Hospital of North Staffordshire NHS Trust). Commissioners should ensure that appropriate specialist services are commissioned for people with epilepsy.

Further Consideration

1 The care of people with more common chronic neurological conditions is described in this report. Less common neurological problems, when considered together, affect a significant number of people. Services for this group of patients are usually less well organised than those for people with more common conditions and further consideration should be given to whether local services are meeting their needs.

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HEREFORDSHIRE HEALTH ECONOMY

HEALTH ECONOMY

Concerns

1 **Care of People with Chronic Neurological Conditions**

Despite the serious problems facing local services (see below), care of people with chronic neurological conditions did not appear to be a priority for Herefordshire Clinical Commissioning Group or for Wye Valley NHS Trust. The shortage of consultant neurologists was not on the Trust risk register and neither commissioners nor the Trust seemed to be aware of the limited care available for people with epilepsy.

SPECIALIST CARE OF PEOPLE WITH CHRONIC NEUROLOGICAL CONDITIONS

WYE VALLEY NHS TRUST

General Comments and Achievements

An enthusiastic, committed team was working in a multi-disciplinary way, especially caring for people with Parkinson's disease and multiple sclerosis. A specialist nurse for each of these conditions worked closely with a consultant neurologist from Birmingham and a local consultant geriatrician with a particular interest in Parkinson's disease. Some occupational therapy support (0.4 w.t.e.) was also available. Palliative care services provided local leadership and support for people with motor neurone disease.

Hospital and community-based services had integrated well. Clinics were undertaken at several community locations as well as in the hospital. The Expert Patient Programme was working well locally.

Good Practice

1 Local palliative care service provided good support for patients with chronic neurological conditions and multi-disciplinary working with the neurological team was well-established. A palliative care consultant provided local leadership for the care of people with motor neurone disease.

2 The service had excellent links with Parkinson's disease UK and the Multiple Sclerosis Society and staff were involved in several aspects of national work.

Immediate Risks: No immediate risks were identified

Concerns

1 **Low Staffing Levels**

Several aspects of staffing for the care of people with chronic neurological conditions were of concern to reviewers:

a. Reviewers were seriously concerned about the low level of consultant neurologist staffing available for people with chronic neurological conditions in Herefordshire. Consultant neurologist time in Herefordshire at the time of the review was 0.4 whole time equivalent with no cover for absences. An appointment had been made to an additional post but the person appointed was not due to start for some months and reviewers were told that only 0.2 whole time equivalent (ie one day per week) would be spent in Herefordshire. These staffing levels were inappropriately low for the number of patients with chronic neurological conditions and did not provide adequate support to local acute services, sufficient cover for absences or time for input to multi-disciplinary discussions about the care of patients. This issue would have been identified as an immediate risk but reviewers visited the acute medical admissions ward and met junior medical staff who were clear about the need to contact neurologists at University Hospitals Birmingham NHS Foundation Trust if they had queries and about the arrangements for making contact.

b. Two clinical nurse specialists provided care for people with Parkinson's disease and multiple sclerosis respectively. Because of the disease-specific nature of their roles, there was no cover for absences and no specialist nurse support for people with other chronic neurological conditions. The caseloads held by each specialist nurse were large with each nurse caring for 400 to 500 patients (although see below in relation to arrangements for discharge from their care).

c. Specialist psychological support for patients with chronic neurological conditions was not available.

d. Specialist occupational therapy support for patients with chronic neurological conditions was limited (0.4 w.t.e.) and there was no cover for absences.

e. Because of low staffing levels, access to rehabilitation for people with chronic neurological conditions was limited.

2 **NICE Guidance on Care of People with Epilepsy**

NICE guidance on care of people with epilepsy was not yet implemented. There was no specialist nurse support for people with epilepsy and no multi-disciplinary support. People with more complex epilepsy and related problems were referred to the consultant neurologist.

Further Consideration

1 Long-term management and follow up of people with chronic neurological conditions other than Parkinson's disease, multiple sclerosis and motor neurone disease appeared to rely entirely on GPs and on consultant neurologists who had very little time in Herefordshire. In taking forward service improvements, consideration should be given to the most appropriate approach to supporting all patients with chronic neurological conditions.

2 The criteria for discharge from the care of the specialist nurses were not clear and it appeared that patients were not being actively discharged.

3 Data collection arrangements were not robust and data were not used routinely to review the performance of the service. The service contributed to national Parkinson's disease and multiple sclerosis audits but a rolling programme of audit of implementation of local guidelines was not yet in place. Service-level arrangements for review and learning were also not yet in place. This issue would have been classified as a concern but, given the low staffing levels, staff could not reasonably be expected to undertake this work at the moment.

4 Reviewers were told that some patients needing non-invasive ventilation were referred to Birmingham. It may be helpful to consider whether these services could be provided locally.

COMMISSIONING

HEREFORDSHIRE CLINICAL COMMISSIONING GROUP

Concerns

1 Care of People with Chronic Neurological Conditions

Despite the serious problems facing local services (see above), care of people with chronic neurological conditions did not appear to be a priority for Herefordshire Clinical Commissioning Group or for Wye Valley NHS Trust. The shortage of consultant neurologists was not on the Trust risk register and neither commissioners nor the Trust seemed to be aware of the limited care available for people with epilepsy.

Further Consideration

1 From the data seen by reviewers, the prevalence of multiple sclerosis in Herefordshire appeared high. It may be helpful for commissioners to review whether this is the case and, if so, to understand the reasons for this.

2 The care of people with more common chronic neurological conditions is described in this report. Less common neurological problems, when considered together, affect a significant number of people. Services for this group of patients are usually less well organised than those for people with more common conditions and further consideration should be given to whether local services are meeting their needs.

COVENTRY AND WARWICKSHIRE HEALTH ECONOMY

HEALTH ECONOMY

General comments about the health economies' approach to the care of people with long-term conditions, including those with chronic neurological conditions, are given in the main North Warwickshire, Coventry & Rugby, and South Warwickshire long-term conditions review reports.

PRIMARY CARE

General comments about the Clinical Commissioning Groups' approach to the primary care of people with long-term conditions, including those with chronic neurological conditions, are given in the main North Warwickshire, Coventry & Rugby, and South Warwickshire long-term conditions review reports.

Specialist Care for People with Chronic Neurological Conditions

Table 1 seeks to summarise the services available for people with chronic neurological conditions in Coventry and Warwickshire at the time of the review visit.

Table 1 Services for Coventry and Warwickshire People with Chronic Neurological Conditions

	Parkinson's Disease	Epilepsy	Multiple Sclerosis	Motor Neurone Disease	Other chronic neurological conditions
Community support	Coventry and Warwickshire-wide service, based at UHCW. Staff employed by UHCW, SWFT (Warwickshire) & CWPT (Coventry). Day-rehabilitation Unit at UHCW for Coventry patients.	Coventry and Warwickshire-wide service, based at UHCW. All staff employed by UHCW.	**Coventry and Warwickshire:** Team based at UHCW. Staff employed by UHCW. **S. Warwickshire:** Community neurological rehabilitation team (CNRT) comprising physiotherapist, OT, S&LT, neuro-psychologist, dietician based at Leamington Spa Rehabilitation Hospital. Staff employed by SWFT. **North Warwickshire:** Some referrals accepted by both UHCW and South Warwickshire CNRT services but, in practice, North Warwickshire patients had little access to community support, especially home visits.	Some patients were referred to services provided from UHB. One of the local neuro-rehabilitation consultants did some ongoing monitoring and a two monthly meeting of interested allied health professionals was held.	No community support available
Out-patient clinics and out-patient rehabilitation					**Coventry:** Neurology and neuro-rehabilitation out-patient service at UHCW. **S. Warwickshire:** Neuro-rehabilitation out-patient service at Leamington Spa Rehabilitation Hospital (HDU) and neurology out-patient service at Warwick Hospital. **N. Warwickshire:** Neurologist out-patient clinics at George Eliot Hospital and Hospital of St. Cross, Rugby.
Allied health professionals	Patchy access with availability of specialist expertise varying in different localities (Coventry, Rugby, Stratford, Warwick, Leamington, North Warwickshire) and varying for different AHPs. Services provided by CWPT, SWFT, GEH and UHCW.				
In-patient rehabilitation	**Coventry:** UHCW (12 beds) **Warwickshire:** Leamington Spa Rehabilitation Hospital (30 beds)				
Acute care	UHCW (24 beds)				
Home ventilation	Initial assessment and then support service provided by University Hospital of North Staffordshire NHS Trust or University Hospitals Leicester NHS Trust.				
Other	**South Warwickshire:** A multi- therapy unit at Stratford did provide some general rehabilitation for patients with chronic neurological conditions. This service was not reviewed.			Palliative care support provided locally	Chronic fatigue syndrome service based at GEH.

Abbreviations:

AHP	Allied Health Professional
CNRT	Community Neurological Rehabilitation Team
CWPT	Coventry & Warwickshire Partnership Trust
GE	George Eliot Hospital NHS Trust
HDU	Hitchman Day Unit
OT	Occupational Therapist
S&LT	Speech & Language Therapist
SWFT	South Warwickshire NHS Foundation Trust
UHB	University Hospitals Birmingham NHS Foundation Trust
UHCW	University Hospitals Coventry & Warwickshire NHS Trust

ALL SERVICES

General Comments and Achievements

Providers and commissioners were cooperating to improve care for people with chronic neurological conditions through a voluntary sector-led *Coventry and Warwickshire Progressive Neurological Conditions Network.* This Network had undertaken a good gap analysis, conducted focus groups with a wide range of service users and made recommendations for improving services across Coventry and Warwickshire. The work of the Network had concentrated on Parkinson's disease, multiple sclerosis and motor neurone disease, while recognising that many of the issues would be common to other chronic neurological conditions.

Concerns

1 **Access to Services**

The care available for people with chronic neurological conditions in Coventry and Warwickshire varied depending on the patient's condition and where they lived. Although some services in some locations were excellent, appropriate cover for absences was often not available. In other parts of Coventry and Warwickshire, or for other conditions, patients were not able to access appropriate support and care. Particular problems were identified with access to community support for people with multiple sclerosis in North Warwickshire. Reviewers found some evidence that GPs were not aware of the services for people with chronic neurological conditions and that referral routes were not clear. Reviewers were also told that this variability was leading to delays in discharge from acute care for up to a third of patients.

2 **Access to Therapies**

Access to physiotherapy, speech and language therapy, occupational therapy and dietetics was variable. Several of the services reviewed did not undertake home visits and home circumstances, aids and adaptations may therefore not be fully considered as part of their care planning. General therapy services could be accessed but these staff would not have specialist expertise in the needs of people with chronic neurological conditions.

3 **Access to Neuro-Psychology Support**

In both Coventry and Warwickshire reviewers were told of long waiting times for, or limited access to, neuro-psychology. In South Warwickshire there was a neuro-psychology service for the Hitchman Day Unit and an out-patient service for those with multiple sclerosis. Access to psychology assessments was available but patients were then waiting up to 12 months for treatment. As a result, some patients were accessing the Warwick clinical health psychology service which did not have specialist neurological expertise. South Warwickshire NHS Foundation Trust had commissioned an external review to look at psychological support for people with chronic neurological conditions. In Coventry, reviewers were told of long waiting times or limited access to neuro-psychology.

Further Consideration

1 **Local Care for People with Motor Neurone Disease**

People with motor neurone disease were experiencing long waits for specialist assessments in Birmingham or Oxford and did not have access to local specialist nursing support. A recent patient survey had shown that six of the fourteen patients surveyed had waited six months or more for a consultant appointment for specialist assessment (at Birmingham or Oxford). Although one of the local neuro-rehabilitation consultants did some ongoing monitoring of people with motor neurone disease and a two monthly multi-disciplinary team meeting involving interested allied health professionals was held to discuss patient care, the patients did not all have a 'care coordinator'. The Birmingham–based specialist nurse covered the whole West Midlands and so was able to provide only limited support to individual patients. Although Coventry and Warwickshire had a relatively low prevalence of motor neurone disease, with 38 patients known at the time of the visit, patients and carers commented that accessing services in Birmingham or Oxford became more difficult as their disease progressed.

2 **Future Strategy**

Coventry and Warwickshire did not have a strategy for the development of services for people with chronic neurological conditions and there was no plan for the improvements needed. In developing and implementing this strategy, reviewers suggested that consideration should be given to:

a. Addressing the variation in access to services identified in this report so that availability of care does not depend on the patient's condition and where they live.

b. Ensuring arrangements for cover for absences are robust so that availability of services does not depend on who is on duty on a particular day.

c. Individual services for people with chronic neurological conditions in Coventry and Warwickshire were working in relative isolation from each other. In taking forward the development of services, reviewers considered that greater cooperation and integration between services and across Coventry and Warwickshire would support the development of robust, high quality services. Staff were employed by four different Trusts which may not be helping the effective integration of services.

d. Ensuring clinical leadership and care is available for patients with chronic neurological conditions other than those specifically mentioned in this report which, together, add up to a significant number of patients.

3 Difficulties and delays in accessing social care for people with chronic neurological conditions was mentioned but reviewers did not have sufficient time to explore this issue in detail.

SERVICES BASED AT UNIVERSITY HOSPITALS COVENTRY AND WARWICKSHIRE NHS TRUST

As summarised in table 1, the following services were based at University Hospitals Coventry and Warwickshire NHS Trust:

- Acute in-patient, specialist nurse and out-patient service for people with Parkinson's Disease, covering Coventry and Warwickshire
- Acute in-patient, specialist nurse and out-patient service for people with epilepsy, covering Coventry and Warwickshire
- Acute in-patient, specialist nurse and out-patient service for people with multiple sclerosis, covering Coventry and Warwickshire.
- Acute in-patient and out-patient services for other chronic neurological conditions, covering Coventry and Warwickshire
- In-patient and out-patient rehabilitation service for Coventry

General Comments and Achievements

Patients who met the visiting team were very appreciative of the care they received from the services based at University Hospitals Coventry and Warwickshire NHS Trust. Patients appreciated particularly the support available from clinical nurse specialists. Patients had nothing but praise for care they received on the in-patient and rehabilitation units, including some patients who had had quite extensive stays on the rehabilitation unit. All patients were given copies of GP letters detailing changes to their care plans.

In one year, the epilepsy specialist nurse had trained 160 carers or family members of patients with epilepsy in the administration of buccal Midazolam liquid. This was a notable achievement and should reduce admissions for these patients.

Physiotherapists at UHCW had undertaken an audit of contractures and had demonstrated the need for additional therapy support on ITU in order to reduce contractures.

The consultant, with the MND Association and a Warwickshire MND Association Group, had delivered three days training in the last year for staff and patients about how to care for patients with motor neurone disease.

The services had a strong focus on rehabilitation with four neuro-rehabilitation consultants working across Coventry and Warwickshire. Reviewers were also impressed by the links with palliative care, especially for the care of people with motor neurone disease.

Good Practice

1 There was a good training programme for carers on actions to take for people with epilepsy when they had seizures.

2 The Parkinson's disease specialist nurses ran a daily two-hour helpline (Mondays to Fridays) when patients could phone with queries or to discuss any problems.

3 The multiple sclerosis specialist team ran weekly 'telephone clinics' when staff were available and patients could phone with queries or to discuss any problems.

Immediate Risks: No immediate risks were identified.

Concerns

1 **Epilepsy Specialist Nurse Staffing**

Epilepsy specialist nurse staffing levels were insufficient for the population served. There was one epilepsy specialist nurse covering Coventry and Warwickshire who had a high workload and no cover for absences. In addition to telephone advice for a large number of patients (helpline twice a week), she was running a regular women in epilepsy clinic, two treatment monitoring clinics each week, providing education for primary care and running an active training programme on the use of buccal Midazolam.

2 **Swallow Screening**

A member of staff with competence in swallow screening was not on duty at all times on the acute neurology unit. As a result, patients waited until a speech and language therapist was available which sometimes resulted in delays, especially at weekends. Also, the swallow screening protocol was not clear about which members of staff should carry out the screening.

3 **Therapy Support**

The in-patient rehabilitation ward had physiotherapy time allocated to work with patients on the ward on only two days a week and this time was shared with the neuro-surgical unit. Physiotherapists had a high caseload and patients were not always able to use the gym (see below) because of pressure on physiotherapists' time. No speech and language therapist had time allocated for work with patients with chronic neurological conditions in out-patients or on the in-patient rehabilitation unit. Physiotherapy, occupational therapy, psychology and speech and language therapy were not easily available for patients

with epilepsy, although referrals could be made to these services. Reviewers were also told of difficulties and delays in accessing community physiotherapy for patients in Coventry and up to 16 week wait for access to the UHCW rehabilitation service.

4 **Speaking Valves for Patients with Tracheostomies**

The acute in-patient and rehabilitation units at UHCW did not put in speaking valves for patients with tracheostomies because staff had not been trained to do this. As a result, patients were not able to communicate as effectively as they could if they had had a speaking valve and no specialised/adaptive call system on the ward.

Further Consideration

1 A 'Mapping Day' had been held in July 2011 which had discussed the possible development of a monthly motor neurone disease clinic providing integrated care from hospital, community and Myton Hospice services. There did not appear to be a clear action plan resulting from this 'Mapping Day'.

2 There were 10 doors between the in-patient unit and the physiotherapy rehabilitation gym at University Hospital Coventry. Because of the length of time taken to reach the gym and the low staffing levels (see above) this facility was not always used for patients who may have benefited from it. Also oxygen and suction were not available in the physiotherapy rehabilitation gym and so patients with tracheostomies could not use the facility

3 At the time of the review visit, 1.6 w.t.e. consultants were involved in the care of people with multiple sclerosis. Reviewers suggested that this may be insufficient for the future needs of local patients, especially considering the need for spacisity management and prescribing and monitoring of new therapeutic agents including (Fingolimod and Natalizamab)

4 Patients reported that they were often waiting up to an hour for a car parking space at University Hospital Coventry and the associated stress was causing them problems.

5 Some of the available patient information was out of date and no longer accurate.

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SERVICES BASED AT SOUTH WARWICKSHIRE NHS FOUNDATION TRUST

As summarised in table 1, the following services were based at Leamington Spa Rehabilitation Hospital (South Warwickshire NHS Foundation Trust):

- In-patient rehabilitation service on Campion Ward for patients from Coventry and Warwickshire and other areas.
- Hitchman Day Unit out-patient rehabilitation service for Warwickshire
- Community Rehabilitation Service (CNRT) providing community and out-patient care for people with multiple sclerosis, covering South Warwickshire. Some North Warwickshire referrals were accepted but limited support was provided for these patients

A general AHP neurology team at Stratford had previously provided care for musculo-skeletal conditions but was taking on more patients with chronic neurological conditions. This service was not reviewed, though reviewers were told that referral was via the GP and patients waited several months to be seen.

General Comments and Achievements

Services for people with chronic neurological conditions based at Leamington Spa Rehabilitation Hospital were provided by dedicated, caring staff. The three services had come under the same management 18 months before the review. The hospital had also gone through a major re-building programme. Patients were very appreciative of the care they received. Links with palliative care were good.

Campion Ward was well-staffed with good equipment and enthusiastic leadership. Facilities were good, including adapted call buttons and good pressure relieving mattresses. Patients were encouraged to eat their meals together. A discharge coordinator was in post and there was good support for discharge from the ward. Carers were regularly involved in multi-disciplinary team meetings. Cooperation between therapists, nursing staff and health care assistants had improved and all were key worker roles. The ward had a lot of work in progress to improve the quality of care, including work on electronic discharge. Medical cover for the ward was provided by a rota of two consultants (who also worked in UHCW) and two Trust grade doctors.

Hitchman Day Unit had excellent gyms and therapy areas. There was a good 'activities of daily living' unit used by the occupational therapists.

Community Neuro-Rehabilitation Team (CNRT) was a small team which offered good support for people with multiple sclerosis in South Warwickshire, including a Fatigue Programme and a Weight Reduction Programme. Ward admissions had reduced since the team had started work. The team used a good form for helping patients to monitor their own progress.

There was good access to wheelchair and orthotics services which were based on the same site. One speech therapist undertook augmented communications assessments for the whole of Warwickshire.

Good Practice

1 The single assessment sheet used by the Community Neuro-Rehabilitation Team was comprehensive, covering both health and social care, and including information on home circumstances.

2 Good information for carers of people in low awareness states was available.

3 Campion Ward had a 'Tea for Two' programme where staff were encouraged to sit and have tea with patients who did not have visitors.

4 A rolling audit of the discharge processes was in use which 'RAG-rated' progress. This led to active management of discharge.

Immediate Risks: No immediate risks were identified.

Concerns

1 **Hitchman Day Unit Staffing Levels**

The Day Unit had insufficient staffing for the service provided. Staffing each week comprised 25 hours of administrative support; four sessions of occupational therapy; six sessions of speech and language therapy, ten sessions of physiotherapy and four sessions of neuro-psychology. There was no regular medical input to the work of the Day Unit although one of the consultants did attend if required. Although activity levels were not clear, reviewers were not clear how the reported number and frequency of patients attending could be achieved with the staffing resources available.

2 **Regular Reviews**

Other than in the CNRT, processes for review of patients were not robust. It was not clear which patients were being followed up, at what frequency and by whom. Some patients who met the visiting team said that they did not have care plans and were not clear about their plan of care.

3 **Guidelines and Protocols**

Documented clinical guidelines and protocols were not evident in any of the three services reviewed.

4 **Provision of Specialist Treatments**

Access to some specialist treatments was limited (especially botulinum toxin, spasticity and contractures). Botulinum injections were commissioned only for patients following stroke and for wrist and finger flexors. Other patients or limbs which may benefit from this treatment could not access it. Also, post-injection physiotherapy and occupational therapy treatment was not available. Splinting was available for spasticity

and contractures but therapists were not available to provide support. Reviewers were told that some patients were being admitted when this could have been avoided if these treatments had been more easily available.

Further Consideration

1 Campion Ward had several new staff and the service should ensure that these all have appropriate competences for their work with people with chronic neurological conditions.

2 Relatively little patient information was available, including little information on the ward. The patient information and CNRT care plan did not include much about 'Looking to the future' and it may be helpful to give this aspect some further consideration.

3 The length of stay on the in-patient ward appeared long at an average of 160 days. Reviewers were told that this had reduced recently and considered that there may be the potential for further reductions.

4 Reviewers saw relatively little data about the work of the in-patient and Day Unit services. The Trust and commissioners should ensure that appropriate data are being collected and used by staff managing these services

GEORGE ELIOT HOSPITAL NHS TRUST

George Eliot Hospital provided a specialist service for people with chronic fatigue syndrome. This service was not reviewed in detail as part of this review visit. The work of this service should, however, be taken into account in the development of Coventry and Warwickshire strategy for the care of people with chronic neurological conditions.

COMMISSIONING

General comments about the Clinical Commissioning Groups' commissioning of services for people with long-term conditions, including those with chronic neurological conditions, are given in the main North Warwickshire, Coventry & Rugby, and South Warwickshire long-term conditions review reports.

Concerns

1 **Strategy for the Care of People with Chronic Neurological Conditions**

See 'All Services' section of this report about the need for a clear Strategy for the Care of People with Chronic Neurological Conditions.

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NORTH EAST BIRMINGHAM & SOLIHULL HEALTH ECONOMY

HEALTH ECONOMY

Concerns

1 **Care of people with chronic neurological conditions**

The care of people with chronic neurological conditions did not appear to be a priority for commissioners or providers. Out-patient care, a small rehabilitation service and some input to in-patient care was provided by neurology services at Heart of England NHS Foundation Trust. Specialist nursing support for people with multiple sclerosis or Parkinson's disease was provided by Birmingham Community Healthcare NHS Trust. Some patients, especially from Solihull, were referred to neurologists at University Hospitals Birmingham NHS Foundation Trust. Services for people with epilepsy did not meet NICE guidance (see section of this

report relating to care of people with chronic neurological conditions for further detail). There was no overall strategy for the development of services and no clarity about future commissioning intentions. As a result, some patients from the health economy had access to only a limited range of services. Pathways of care were not clear and mechanisms for integrated working between the services that were available were not defined. (See chronic neurological conditions section of this report for more detail on this issue.)

Specialist Care of People with Chronic Neurological Conditions

HEART OF ENGLAND NHS FOUNDATION TRUST: GOOD HOPE HOSPITAL, BIRMINGHAM HEARTLANDS HOSPITAL. SOLIHULL HOSPITAL and BIRMINGHAM COMMUNITY HEALTHCARE NHS TRUST

General Comments and Achievements

Specialist services for people with chronic neurological conditions were provided by a team at Heart of England NHS Foundation Trust, linking with Birmingham Community Healthcare NHS Trust staff and services at University Hospitals Birmingham NHS Foundation Trust. Consultant staffing at the time of the review was 4.2 w.t.e., which included one locum consultant on 0.2 w.t.e. provided from University Hospitals Birmingham NHS Foundation Trust through a service level agreement. Twenty seven out-patient clinics per week were run. A specialist nurse for people with multiple sclerosis was available from UHB who ran a monthly clinic at Solihull Hospital. Four Parkinson's disease specialist nurses from Birmingham Community Healthcare NHS Trust covered the whole of Birmingham, including running community clinics. 'The Hub', a small rehabilitation service for people with chronic neurological conditions, was based at Birmingham Heartlands Hospital.

At the time of the review, waiting times for a consultant neurologist out-patient appointment were six weeks at Birmingham Heartlands Hospital, six to eight weeks at Solihull Hospital and 13 weeks at Good Hope Hospital. Capacity and demand work had indicated the need for additional out-patient sessions at Good Hope Hospital. Some patients, especially from Solihull, were referred to neurologists at University Hospitals Birmingham NHS Foundation Trust. Neuro-physiology was accessed at City Hospital (Sandwell and West Birmingham NHS Trust) and UHB although a business case for an in-house service was being developed.

Patients needing in-patient care were admitted onto general medical wards. Urgent review by a neurologist was available Monday to Friday 9am to 5pm. Reviewers did not visit medical wards as part of this review.

Staff providing the services were enthusiastic and committed. There was good awareness of the difficulties facing the service. GPs were able to requests investigations via the radiology electronic referral system with the imaging department making some decisions about the most appropriate investigation to perform. A hydrotherapy pool staffed by physiotherapists was available on each hospital site.

Patients who met the visiting team appreciated the care they received and commented that they had seen improvements in the services available at Heart of England NHS Foundation Trust, and improved liaison with services at University Hospitals Birmingham NHS Foundation Trust.

Good Practice

1 A prescribing pharmacist attended clinics for people with Parkinson's disease. Good links with social care and voluntary organisations were also evident in the community clinics run by the Birmingham Community Healthcare NHS Trust.

2 The 'Hub' rehabilitation facility was providing good multi-disciplinary support for people with chronic neurological conditions.

3 Clinics for people with multiple sclerosis in Solihull were run by a nurse from University Hospitals Birmingham NHS Foundation Trust and a support worker from the Multiple Sclerosis Society was also available in the clinic.

Immediate Risks: No immediate risks were identified

Concerns

1 **NICE Guidance on Care of People with Epilepsy**

NICE guidance on the care of people with epilepsy was not being followed. Guidelines and information for primary care encouraging referral of people with their first seizure was not in place. A Trust protocol for referral to the neurology department was in place in the A&E departments for people presenting with their first seizure. Specialist nurse support for people with epilepsy was not in place across the health economy and there was a limited amount of information available for patients and carers although reviewers were told that information was given to patients and carers as part of their out-patient appointments.

2 **Care Planning and Review**

Robust arrangements for personalised care planning and review of patients at least annually were not in place although individual care plans were incorporated into clinic letters. Reviews may have taken place in primary care but, if so, information from these reviews was not communicated to the specialist team. Little patient information was available. The pathway of care for people with multiple sclerosis or Parkinson's disease was fairly clear but there was no clear pathway of care for people with epilepsy or those with other chronic neurological conditions, although arrangements for referral for neurophysiology and neuro-radiology were covered in clinic letters.

3 **Clinical Guidelines**

Clinical guidelines expected by the Quality Standards were not documented. Overall, the pathways of care for patients with Parkinson's disease or multiple sclerosis were clear but pathways for other chronic neurological conditions, including epilepsy, were not clearly defined, other than A&E guidelines for referral of people with first seizure.

4 **'Out of Hours' Cover**

Consultant neurologists were not on call outside normal working hours. Patients were cared for in general medical beds and arrangements for accessing advice in an emergency outside normal working hours were not clear. There was a service level agreement with University Hospitals Birmingham NHS Foundation Trust for neurology referrals covering the provision of advice and support outside normal working hours. Reviewers were told, however, that this functioned effectively only for patients who had been seen by a neurologist and not for referrals from general medical teams.

5 **Data Collection**

The number and types of patient for whom the service was commissioned, the activity being delivered, and the extent of unmet need were not clear.

6 **Service Strategy**

The strategy for the future development of the service was not clear. Individual members of staff had ideas about developments they wished to make but it was unclear if these were supported by the Trust or by commissioners. A clear service specification was not available and robust monitoring arrangements were not in place.

Further Consideration

1 Only three patients were in 'The Hub' day hospital at the time of the review although reviewers were told that sessions for people with Parkinson's disease were more fully utilised. It may be helpful to review whether more patients would benefit from this service.

2 Information about patients did not appear to be being shared between community and hospital-based staff, and so the latest information may not always be available when a patient is seen.

3 Arrangements for liaison with the multiple sclerosis specialist nurse from University Hospital Birmingham NHS Foundation Trust may benefit from further discussion in order to resolve operation problems, such as lack of notification about cancellation of patients.

COMMISSIONING

NHS BIRMINGHAM CROSSCITY CLINICAL COMMISSIONING GROUP
NHS BIRMINGHAM SOUTH CENTRAL CLINICAL COMMISSIONING GROUP

Concerns

1 **Services for people with chronic neurological conditions**

Service for people with chronic neurological conditions were not fully reviewed. There did not appear to be an overall commissioning strategy for these services. An extensive service was commissioned from University Hospitals Birmingham NHS Foundation Trust (UHB). A more limited service, with no in-patient provision, was commissioned from Heart of England NHS Foundation Trust (HEFT). Parkinson's disease specialist nurses were commissioned from Birmingham Community Healthcare NHS Trust and linked in different ways with hospital-based services at UHB, HEFT and Sandwell and West Birmingham Hospitals NHS Trust. Patient pathways and waiting times varied depending on the provider to whom patients were referred. There were no specialist nurses for people with epilepsy. Reviewers were told that times to be seen after a first seizure varied from six to thirteen weeks and ongoing care of people with epilepsy was largely the responsibility of primary care.

Specialist rehabilitation was commissioned from Birmingham Community Healthcare NHS Trust. Operational links with services in the rest of the West Midlands were in place, but there were no formalised pathways or arrangements for shared care. Whether services were meeting the needs of populations across the West Midlands was not clear and activity levels at different services, related to need, did not appear to have been analysed. Non-specialist rehabilitation was not specifically commissioned and it appeared that access depended on whether the patient's GP thought to refer them.

Ensuring services met the needs of people with chronic neurological conditions, and that NICE guidance was fully implemented, did not appear to be a priority for commissioners.

Further Consideration

1 The care of people with more common chronic neurological conditions is described in this report. Less common neurological problems, when considered together, affect a significant number of people. Services for this group of patients are usually less well organised than those for people with more common conditions and further consideration should be given to whether local services are meeting their needs.

NHS SOLIHULL CLINICAL COMMISSIONING GROUP

Concerns

1 See health economy section of this report in relation to the care of people with chronic neurological conditions.

Further Consideration

1 The care of people with more common chronic neurological conditions is described in this report. Less common neurological problems, when considered together, affect a significant number of people. Services for this group of patients are usually less well organised than those for people with more common conditions and further consideration should be given to whether local services are meeting their needs.

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SOUTH AND CENTRAL BIRMINGHAM HEALTH ECONOMY

SPECIALIST CARE OF PEOPLE WITH CHRONIC NEUROLOGICAL CONDITIONS – REHABILITATION

BIRMINGHAM COMMUNITY HEALTHCARE NHS TRUST

General Comments and Achievements

The neurological rehabilitation service provided by Birmingham Community Healthcare NHS Trust was a highly specialist service, commissioned by specialised commissioners to serve the whole of the West Midlands. The service provided out-patient, in-patient and vocational rehabilitation. There were good links with related services in the Trust, including orthotics, prosthetics and electronic equipment, wheelchair services, assistive technology, and posture and mobility services. The 32-bedded in-patient unit at Moseley Hall Hospital was a designated level 1 rehabilitation unit with strong links with the Major Trauma Centre at University Hospitals Birmingham NHS Foundation Trust. A specific multiple sclerosis rehabilitation service was available. Out-patient clinics for people with Parkinson's disease were held at a variety of locations across Birmingham. A weekly multi-disciplinary meeting reviewed all referrals and allocated them to the most appropriate part of the West Midlands Rehabilitation Service – or referred back to local services if this was appropriate. Pathways for referral between different parts of the specialist rehabilitation service were clearly defined and appeared to work well. A transition service supported young people needing neurological rehabilitation in their transfer to adult care.

A rehabilitation coordinator provided liaison with specialist neurology services at University Hospitals Birmingham NHS Foundation Trust. The specialist rehabilitation service also linked with local rehabilitation in-patient units in Wolverhampton, Stoke and Leamington Spa. Consultants from the service undertook out-reach work in Burton and Worcestershire.

Patients who met the visiting team were highly appreciative of the care they received. Carers had access to a carer support service and good information was available for both patients and carers. Patient transport was available for all patients attending the West Midlands Rehabilitation Service. Clinical psychology support was also available. Staff were generally enthusiastic and welcoming. Some new approaches to rehabilitation were being tried, including a Tai Chi class.

Good Practice

1 Multi-disciplinary input to out-patient clinics was very good with all clinics having at least a consultant, nurse, physiotherapist or occupational therapist available. Patients who met the visiting team greatly appreciated this holistic approach to their care.

2 Self-referrals to the service were accepted. The service reviewed all referrals and then directed them appropriately.

3 A good Intrathecal Baclofen service was available, with good service user involvement. This included the option for a meeting with a representative of the service user group prior to the patient's operation.

4 The spasticity clinic had a clear, well-structured process of care planning, goal setting and review.

5 Out-patient clinic times were appropriate for the complexity of patients' needs, with one hour allocated for new patients and 30 minutes for a follow-up attendance.

6 The patient pathway for people with motor neurone disease was clear and appeared to work well. In particular, patients had good support for PEG feeding.

7 Arrangements for vocational rehabilitation were very good with a highly experienced team providing this service. The service was actively working with employers, with particularly good links when an individual relapsed or their condition deteriorated. There was a robust process of measuring achievement of goals and high patient satisfaction.

8 Liaison between Parkinson's disease specialist nurses and palliative care services were well organised and ensured continuity of care for individuals.

Concerns

1 **Care Planning**

The process for communicating the latest care plan to the patient and their GP was not robust. The latest care plan for outpatients was not always easily identifiable in the patient notes seen by reviewers. Patients who met the visiting team said that they did not always receive written confirmation of changes to their care plan.

2 **In-Patient Service**

a. Dietician support for the in-patient service was insufficient. Only 0.2 w.t.e. dietician support was available for up to 32 patients, some of whom may have PEG feeds.

b. Reviewers were told that patients were often transferred from University Hospitals Birmingham NHS Foundation Trust for in-patient rehabilitation without a discharge letter or other appropriate transfer of clinical information.

Further Consideration

1 Arrangements for involving patients and carers in service improvement activity and in decisions about the management of the service may benefit from review. Some feedback mechanisms were in place.

2 Active use of individualised expected date of discharge was not evident and, at the time of the review, the average length of stay was 60 days. Reviewers considered that there may be the potential to reduce length of stay.

3 The out-patient service was commissioned for a number of contacts per year. It may be helpful to review activity levels for different parts of the region and how this relates to the services available in each locality.

4 Although the service linked operationally with other in-patient and community rehabilitation services in the West Midlands, the role of each service and arrangements for shared care were not clearly defined. Neither providers nor commissioners seemed to have an understanding of whether services were meeting needs across the West Midlands.

5 The development of collaborative audit arrangements with other specialist neurological rehabilitation services may be helpful. This could enable the service to compare outcomes with similar services.

6 The BNRT service provided time-limited community-based rehabilitation for people with chronic neurological conditions, including stroke. Reviewers commented that younger patients with stroke may benefit from access to a longer period of rehabilitation.

7 The occupational therapist had limited space for the storage of equipment and, as a result, equipment was stored in the meeting room.

8 Parkinson's disease nurses were linking well with voluntary organisations in some parts of Birmingham but these links did not appear to be in place in south and central Birmingham areas.

9 Service-level website information was felt to be useful by the users and carers but they commented that it was not easy to navigate to service information and that some aspects appeared to be out of date.

10 A community nutrition support team was available, specialising in the care of people with Parkinson's disease, motor neurone disease and multiple sclerosis. Consideration could be given to whether this team could also support in-patient care.

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SOUTH STAFFORDSHIRE (EAST) HEALTH ECONOMY

SPECIALIST CARE OF PEOPLE WITH CHRONIC NEUROLOGICAL CONDITIONS

BURTON HOSPITALS NHS FOUNDATION TRUST and STAFFORDSHIRE & STOKE ON TRENT PARTNERSHIP NHS TRUST

General Comments and Achievements

Specialist care for people with chronic neurological conditions was provided by two rehabilitation teams, the Adult Ability Team in Burton was an interdisciplinary team including two specialist nurses, one for people with Parkinson's Disease and the other for people with multiple sclerosis and the General Rehabilitation Service serving Lichfield and Tamworth, a consultant-led service at Queen's Hospital, Burton. Both rehabilitation services cared for people with a wide range of chronic neurological conditions. Good leadership was evident in the rehabilitation teams and the services worked hard to keep patients out of hospital. There were two specialist nurses, one for people with Parkinson's disease and the other for people with multiple sclerosis or motor neurone disease who covered the South East Staffordshire area. Patients who met the visiting team were pleased with the services and appreciative of the care they received.

The Adult Ability Team provided an impressive, innovative service. Patients with progressive neurological conditions were supported well and there was particular focus on fatigue management and research. Patients could access respite beds at Barton. Multiple sclerosis and Parkinson's disease specialist nurses were integral to the team and had good links with the acute trust.

The South East Staffordshire service was a general rehabilitation service based at Sir Robert Peel (Tamworth) and Samuel Johnson (Lichfield) Community Hospitals. This was an integrated service involving physiotherapy, occupational therapy and speech and language therapy. One of the physiotherapists had specific expertise in the care of people with neurological conditions. Links with specialist nurses for people with chronic neurological conditions were also in place and the rehabilitation team provided cover when the specialist nurses were away. The community falls team was also based at Sir Robert Peel Hospital which helped communication with this team and links with the consultant in care of frail older people. The service also linked with the early discharge team for the Burntwood, Lichfield and Tamworth area and with voluntary sector organisations. A good range of education and self-management programmes was offered and the service was able to be very flexible in meeting patients' needs. A good, clear pathway was in place. Staff had experience of caring for people with neurological conditions and people with a wide spectrum of conditions were accepted. (Only adults with cerebral palsy were not covered by the referral criteria.) Reviewers were told that 75% of patients referred to the service had a neurological problem.

The consultant-led neurology service at Queen's Hospital, Burton, comprising two consultant neurologists, a Trust specialty doctor and secretarial support, was working hard to meet the needs of patients with limited resources. Clear pathways of care were being developed and there was a strong focus on patient-orientated goals. A monthly multi-disciplinary clinic was held, involving specialist nurses and staff from the Adult Ability team. Rehabilitation service staff were able to easily put patients on the list for multi-disciplinary team discussion. One session of neuro-radiology was available, provided from University Hospitals Leicester. Patients needing consideration of disease modifying therapy were referred to Queen's Medical Centre, Nottingham.

Good Practice

1 A good 'Epilepsy First Fit Flow Chart' was used in the Emergency Department. This was very clear and set out well the responsibilities of Emergency Department staff.

2 A very clear pathway for ambulatory care for people with recurrent seizures was in use.

3 The Adult Ability Team provided good, integrated care for people with progressive neurological conditions. There was a strong focus on keeping people out of hospital and good links with the hospital-based service for discussion of patients' needs. Vocational support and home visits were also provided.

4 The South East Staffordshire Rehabilitation Service provided a holistic multi-disciplinary approach to meeting the needs of the local population and good, integrated working with other local community-based services was evident.

Immediate Risks: No immediate risks were identified.

Concerns

1 **Care of People with Epilepsy**

No specialist nurse was available to support people with epilepsy and NICE guidance on the care of people with epilepsy was therefore not fully implemented.

2 **Guidelines and Protocols**

Clinical guidelines and protocols were not yet documented in the hospital-based service. Staff said they referred to NICE guidance but this had not been localised to show how it would be implemented locally. New pathways were, however, being developed.

Further Consideration

1 Support for people with other chronic neurological conditions was not always available.

2 Limited evidence of the competences of staff providing services for people with chronic neurological conditions was available. Staff appeared to have undertaken appropriate training but there was not a clear framework of competences expected and whether these were achieved.

3 It may be helpful to consider whether nurse prescribing would be a useful addition to the range of services offered.

4 The rehabilitation services did not have access to medicines management advice which could enhance the multi-disciplinary input to the care offered.

5 Reviewers did not see much use of activity data and caseload numbers for management and planning improvements to the services offered. For example, the Adult Ability Team was regularly doing urgent visits which impacted on routine activity – but this activity and its implications did not appear to be being analysed.

6 Carers who met the visiting team were not clear about the support available in different areas of the health economy, including for carers of people with cerebral palsy.

7 A large number of separate teams and services were involved in the care of people with chronic neurological conditions, including two rehabilitation services, two specialist nursing services, a hospital-based service in Burton, support from Leicester, referral to Nottingham and some links with Birmingham for the care of people with motor neurone disease. Services were working together despite this fragmentation, especially in East Staffordshire. It may be helpful to consider whether the current organisational and managerial arrangements optimise patient care, including patient pathways, patient flow, communication and integration and whether any changes are needed.

COMMISSIONING

ALL COMMISSIONERS

Concerns:

1 Specialist Care of People with Chronic Neurological Conditions : NICE Epilepsy Guidance

WALSALL HEALTH ECONOMY

SPECIALIST CARE OF PEOPLE WITH CHRONIC NEUROLOGICAL CONDITIONS

WALSALL HEALTHCARE NHS TRUST

General Comments and Achievements

Specialist care for people with chronic neurological conditions was provided by a hospital-based neurology team and a Community Neurological Rehabilitation Team (CNRT) based at Dartmouth House. The hospital-based service provided predominately out-patient care. There were no specific in-patent beds for people with chronic neurological conditions although the consultant neurologist (0.8 w.t.e.) provided advice on the care of in-patients. A consultant based with the rehabilitation teams with a particular interest in the care of people with Parkinson's disease was also available to provide some advice. The epilepsy specialist nurse was based in the hospital because previous work had shown a high rate of presentation with acute admission for people with epilepsy. Joint antenatal clinics were held with the epilepsy specialist nurse and the lead obstetric consultant for the care of people with long-term conditions.

The Community Neurological Rehabilitation Team was an enthusiastic team providing a very good, comprehensive community service. Three continuing health care coordinators were based in Dartmouth House and acted as case coordinators for the continuing health care funded clients, including piloting personalised budgets. Specialist nurses caring for people with Parkinson's disease or multiple sclerosis were based with the Community Neurological Rehabilitation Team. There was good liaison with the hospital-based consultants for the care of people with these two conditions, including arrangements for people with multiple sclerosis who experienced relapses to phone Dartmouth House in order to access a 'walk in' clinic. One of the elderly care consultants had a particular interest in the care of people with Parkinson's disease. A neurological rehabilitation consultant (a joint appointment with The Royal Wolverhampton NHS Trust) was part of the Dartmouth House team. Bi-monthly multi-disciplinary meetings to discuss the care of people with motor neurone disease were held, involving the community neuro-rehabilitation team, palliative care services, the Motor Neurone Disease Association and the specialist nurse for people with motor neurone disease from University Hospitals Birmingham NHS Foundation Trust.

Patients who met the reviewing team were very appreciative of the support and care received from all parts of the service.

Good Practice

1 The intermediate care team was able to provide intravenous steroid therapy in patients' homes.

2 The community rehabilitation team received email alerts when one of their patients was admitted to hospital.

3 Arrangements for transition from children's services were well-organised. The child development centre notified the specialist team when young people reached age 12 so that planning for transition to adult services could begin.

4 Comprehensive and user-friendly single assessment process documentation was being used effectively (although not yet used by the epilepsy specialist nurse)

5 There was a good multi-disciplinary approach to the diagnosis of Parkinson's disease. A multi-disciplinary assessment formed part of the diagnostic process, involving the consultant, specialist nurse, speech and language therapist and physiotherapist. As a result, patients met members of the team early in their 'patient journey'.

6 The Community Neurological Rehabilitation Service provided comprehensive, coordinated care for all people with chronic neurological conditions. The co-location of rehabilitation, specialist nurse, case

managers and social work staff supported and enabled a holistic approach to the patient care. The team supported people with all chronic neurological conditions. Direct access to the team was available through a specific telephone number for queries; this was answered by a member of the team and patients' queries could therefore often be resolved quickly. A range of education and self-management programmes were available, including a cognitive group and access to hydrotherapy provided by therapy staff. Newly diagnosed patients were also offered specific education courses.

Immediate Risks: No immediate risks were identified.

Concerns

1 **Staffing Levels**

Staffing levels were low for the population served and services were heavily reliant on key individuals, in particular:

a. Only 0.8 w.t.e consultant neurologist time was available in the hospital-based service with no on-site cover for absences.

b. Urgent review within 24 hours by a specialist was not available on Friday's or weekends.

c. Due to a vacancy, the neurological rehabilitation consultant was also covering the Wolverhampton neurological rehabilitation service and at the time of the visit, there was no cover for his absences.

d. There was no cover for any of the specialist nurses. The epilepsy specialist nurse was answering telephone calls when not on duty. Case management support for people with neurological conditions other than epilepsy, Parkinson's disease, multiple sclerosis and motor neurone disease was not available.

e. The rehabilitation service was heavily dependent on a small, highly committed team with limited administrative support. The service appeared to rely on the goodwill of staff rather than on a robust staffing establishment with appropriate arrangements for cover for absences.

f. Neuro-psychology staffing had been reduced to 0.5 w.t.e as part of cost efficiencies within the Quality, Innovation, Productivity and Prevention programme (QIPP) and capacity was now insufficient to meet the current caseload.

2 **IT Systems and Care Records**

The hospital and rehabilitation services had different IT systems and different case notes. It was therefore not clear that staff had all the necessary clinical information when they saw patients.

3 **Clinical Guidelines and Protocols**

Few of the expected clinical guidelines and protocols were documented. Staff said that they used NICE guidance but this was not localised to show the local implementation.

4 **Clinical Leadership**

The pathway of care for people with chronic neurological conditions in Walsall did not have a lead clinician with responsibility for coordination and driving service improvements. A lead clinician was identified for the rehabilitation service and for the hospital-based service but no-one had overall responsibility for the patient pathway.

Further Consideration

1 There was regular contact between individuals working in the community rehabilitation and hospital-based services but no formalised communication. The services did not meet together to discuss operational problems or for review and learning. Reviewers considered that there was the potential for greater integration between the services and improvements to the patient pathways through more collaboration

and communication. Also, there was no health economy-wide mechanism for driving improvements to the pathway of care for people with chronic neurological conditions.

2 The service was not yet able to offer urgent review within 24 hours. Urgent review was available on Mondays to Thursdays.

3 The hospital-based service did not receive email alerts when their patients were admitted. Further consideration should be given to the benefit of linking consultant neurologists to this system.

4 Hospital-based and rehabilitation services did not come together in order to undertake review and learning. The rehabilitation service did have an annual review day. Bringing the teams together for review and learning may be helpful.

5 Arrangements for prescribing oral steroids for management of relapse for people with multiple sclerosis may benefit from review as reviewers were told of some problems with the current arrangements.

6 Arrangements for developing care plans for all patients could be more robust. Some patients had the single assessment proforma completed, some had the proforma but it was not completed, some had copies of clinic letters and some did not.

7 Audit of the multi-disciplinary diagnosis process for Parkinson's disease may help to confirm that all clinicians involved were using the same diagnostic criteria.

8 Patients who met the visiting team were concerned about possible changes in the location for the rehabilitation service. Additional communication with patients about any proposals may be helpful.

9 The 'walk in' clinics appeared to be a useful approach but may increase the pressure on staff. Review of working practices may be helpful to ensure time is freed up for this initiative.

10 The social worker within the community rehabilitation service was being allocated more general social work referrals. As a result, some patients who may have benefitted from her specialist expertise were being allocated to generic social workers. Given the complex needs of some of these patients, re-consideration of arrangements for allocation of referrals may be helpful so that best use can be made of the specialist expertise available.

11 The service was only commissioned to provide botulinum toxin treatment for a small number of patients. As a result, some patients needing complex spasticity management had to be referred out of area or required special funding on a case by case basis. Reviewers considered that the service had the ability to deliver this service locally if this was commissioned.

COMMISSIONING

WALSALL CLINICAL COMMISSIONING GROUP

Further Consideration

1 The pathway of care for people with chronic neurological conditions was not as well developed as for other long-term conditions (see chronic neurological conditions section of this report). A Strategic Transformation and Redesign (STAR) group for this pathway and the identification of a clinical lead for the whole pathway may be helpful.

Other Concerns Identified:

1 Specialist Care of People with Chronic Neurological Conditions : Staffing Levels; IT systems and care records; Clinical Leadership

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WOLVERHAMPTON HEALTH ECONOMY

HEALTH ECONOMY

Concerns

1 **Services for people with chronic neurological conditions**

The section of this report relating to specialist care for people with chronic neurological conditions identifies several issues which will require the attention of primary care, The Royal Wolverhampton NHS Trust and Wolverhampton City Clinical Commissioning Group. These issues include ensuring compliance with NICE guidance on the care of people with epilepsy and the need to develop clear pathways of care for all people with chronic neurological conditions.

SPECIALIST CARE OF PEOPLE WITH CHRONIC NEUROLOGICAL CONDITIONS

THE ROYAL WOLVERHAMPTON NHS TRUST

General Comments and Achievements

Services for people with chronic neurological conditions in Wolverhampton comprised an acute neurology service and a specialist inpatient rehabilitation ward plus a community neurological rehabilitation team based at West Park Rehabilitation Hospital. People with spinal injuries were referred to Robert Jones and Agnes Hunt (Orthopaedic) Hospital, Oswestry. Those with motor neurone disease were generally cared for by the neurology service and referred to the tertiary service at University Hospitals Birmingham NHS Foundation Trust as required. Those needing more complex specialist rehabilitation (ACT, FES, IBT pump) were referred to the West Midlands Rehabilitation Service in Birmingham.

The acute service was staffed by 2.6 w.t.e. consultants, which included a 1.0 w.t.e. vacancy, and a locum consultant neurophysiologist. The neurophysiology service supported Shropshire and Dudley as well as Wolverhampton. Clinical nurse specialists (1.6 w.t.e. – including 0.6 w.t.e. vacancy) provided care of people with multiple sclerosis, providing home visits as well as acute support. A Parkinson's disease specialist nurse was also available but did not meet the reviewing team. One consultant specialising in care of older people also had a special interest in Parkinson's disease but did not meet the reviewing team. Acute neurology beds were not available in Wolverhampton. Consultants were employed by University Hospitals Birmingham NHS Foundation Trust and worked in Birmingham on Fridays in order to take part in multi-disciplinary and other meetings. Advice was available from Birmingham at all times. The multiple sclerosis nurse linked with the 'Hospital at Home Team' for the provision of intravenous steroid therapy. Patients commented positively on the support they received from the multiple sclerosis specialist nurse and the neuro-psychologist.

In 2012/13 a total of 469 people were referred for neurological rehabilitation and the ongoing caseload of the community neurological rehabilitation team (CNRT) was 408 at the time of the review. Staff were highly committed and enthusiastic and patients were very appreciative of the care offered by the team. The establishment of the community neurological rehabilitation team included 1.0 w.t.e. consultant covering the services at Walsall and Wolverhampton. The post covering Wolverhampton was vacant at the time of the review and the Walsall consultant was covering the whole service with one Trust doctor at West Park Hospital. The 10 bedded in-patient rehabilitation unit at West Park Rehabilitation Hospital admitted approximately 60 patients per year and was achieving the standards for a level 2a in-patient specialist rehabilitation service. A 0.4 w.t.e. neuro-psychologist and 0.5 w.t.e. psychology assistant was available, covering in-patient and out-patient rehabilitation services. A service for people with chronic fatigue was also run from West Park Hospital. Specialist clinics were provided for people with spasticity, brain injury and amputations.

Good Practice

1 Reviewers were particularly impressed by the neurological rehabilitation service. A good multi-disciplinary team was available including a social worker and neuro-psychologist. The team had a holistic approach to rehabilitation including management of symptoms and drug therapy, vocational rehabilitation, support for leisure pursuits and personal dignity. The team cared for people with a wide range of conditions, including those with stroke, head injuries and chronic fatigue syndrome. A multi-disciplinary meeting was held weekly to discuss the care of in-patients. This meeting was well-organised with a comprehensive approach to assessment against internationally validated outcome measures. 'Live' data collection to the UK Rehabilitation Outcomes Collaborative (UKROC) database was in place. This service had recently been commissioned to provide care for people in the Seisdon area as well as Wolverhampton.

2 A good wheelchair service was available with short waiting times for all patients and the capacity to see urgent referrals more quickly. Wheelchairs could also be supplied for people with a short-term need as well as those needing longer-term equipment.

3 Patients with Guillain-Barré Syndrome were jointly managed with the respiratory service with good arrangements for liaison and communication about all aspects of the patients' care.

4 The neurophysiology service had access to a portable EEG machine which could also be used for home-based investigations.

Immediate Risks: No immediate risks were identified.

Concerns

1 **Consultant Staffing Levels**

The rehabilitation consultant was covering both Walsall and Wolverhampton services. The second post had been advertised. There was also 1.0 w.t.e. consultant neurologist vacancy in the acute service. This situation was particularly difficult because of the low level of middle grade medical staff in the acute service. GPs who met the visiting team were concerned about long waiting times for an out-patient appointment.

2 **Implementation of NICE Guidance for People with Epilepsy**

There was no specialist nurse available to support people with epilepsy. Guidelines on the management of epilepsy were not in place. An audit of care in the Accident and Emergency department showed that people with epilepsy were not being treated according to NICE guidance, including patients not being referred to a neurologist. Consideration was being given to using the acute consultant vacancy to recruit a consultant with a particular interest in epilepsy.

3 **Local Availability of Services**

Out-patients seen by a consultant neurologist who needed a diagnostic lumbar puncture were required to attend the Queen Elizabeth Hospital, Birmingham for this investigation. Patients with multiple sclerosis who required dose-modifying therapy were referred to Birmingham for assessment and then referred back to Wolverhampton for treatment. They then had to go to Birmingham again for annual reviews. Patients therefore had to travel to Birmingham for services which could be provided locally.

4 **Guidelines and Protocols**

Few local clinical guidelines and protocols were documented. Access to NICE guidance was available but this guidance had not been localised to show how it would be implemented locally.

5 **Care Planning and Reviews**

Robust arrangements for care planning and holistic annual review were not evident in the acute service. In the acute service, patients seen as out-patients did not have care plans and were not copied into clinic letters. Arrangements for annual review of patients seen in the acute service were not clear and reviewers

were told that a formal review process was not commissioned. (Patients in the rehabilitation service did have personalised goal-setting and received very clear, well-worded clinic letters from the consultant.)

6 **Patient Information**

Little written patient information was available in the acute service although patients were verbally told about websites where they could access relevant information. This was of particular concern for people with epilepsy where no specialist nurse was available to provide support.

Further Consideration

1 Although reviewers were told that one clinical lead and one manager had responsibility for the services, effective clinical and managerial coordination of the acute and community parts of the service was not yet evident. Improving links and communication between acute and community parts of the service may benefit from further attention.

2 There was no competence framework or training plan detailing the competences expected for staff in the service. Staff who met the reviewers had had appropriate training.

3 A user and carer group to provide feedback on the service was not yet in place. Patients could feedback via the Patient Advice and Liaison Service (PALS). Carers who met the reviewing team commented that they would welcome additional support and a forum specifically to discuss carers' needs.

4 Work was taking place on developing links with local palliative care services for people with motor neurone disease. Reviewers supported continuation of this work.

5 Follow-up of the recommendations of the audit of first seizures will need to be taken into account as part of work on implementation of NICE guidance for care of people with epilepsy

6 The rehabilitation service may be able to make greater use of the UKROC data which are being collected. Exploring the use of the 'live' data collection for service management and service improvement could be an exemplar to other services.

COMMISSIONING

WOLVERHAMPTON CLINICAL COMMISSIONING GROUP

Concerns

1 Services for people with chronic neurological conditions: See health economy section of this report.

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WORCESTERSHIRE HEALTH ECONOMY

SPECIALIST CARE OF PEOPLE WITH CHRONIC NEUROLOGICAL CONDITIONS

WORCESTERSHIRE HEALTH AND CARE NHS TRUST and WORCESTERSHIRE ACUTE HOSPITALS NHS TRUST

General Comments and Achievements

A wide range of services was available for people with chronic neurological conditions in Worcestershire:

Consultant-led services:
Provided by Worcestershire Acute Hospitals NHS Trust through visiting consultants from University Hospitals Coventry and Warwickshire NHS Trust (UHCW), University Hospitals Birmingham NHS Foundation Trust (UHB)and Birmingham Community Healthcare NHS Trust (BCHC).

Service	W.t.e.	Head-count	Based at	Clinics
Consultant neurology out-patient clinics (UHCW)	0.6	3	Alexandra Hospital	Clinics held at Bromsgrove and Redditch
Consultant neurology out-patient clinics (UHB)	0.9	2	WRH	Clinics held at Worcester, Malvern and Kidderminster
In-patient and out-patient neuro-rehabilitation (BCHC)	0.4	1	Evesham Hospital (in-patient beds)	Clinics held at Evesham and Worcester

Community rehabilitation services:
Worcestershire Health and Care Trust

Team		W.t.e.	Head-count	Based at	Care for people with	Care for people from
Complex physical neuro-disability	Nurse consultant Specialist nurse Administration	1.0 0.8 1.0	3	Evesham	Mostly ABI & spinal injury	All SW
Multiple sclerosis	Specialist nurse Specialist nurse (Shared admin.)	1 1	2	Evesham Kidderminster	MS	SW NW
Parkinson's Disease	Specialist nurses Administration	1.4 1.6	4	Bromsgrove (POWCH)	PD	All
Acquired Brain Injury	OT S&LT Rehab assistant	1.0 P/T 1.0	3	Headway, Worcester	ABI	SW All All
Chronic neuro-rehabilitation (Wyre Forest)	Specialist nurse OT Physiotherapist Admin. (shared)	0.4 0.4 0.6 0.5	4	Kidderminster	All CNC	WF
Chronic neuro-rehabilitation (Bromsgrove & Redditch)	Specialist nurse OT Physiotherapist Rehab assistant Administration	0.6 0.9 0.6 1.0 1.0	4	Bromsgrove (POWCH)	All CNC	B&R

Other Services					
Neuro-physiology			WRH	All CNC	
Consultant neuro-psychologist	1.0	1	WRH	All CNC	
Out-patient physiotherapy			WRH	All CNC	SW
Epilepsy specialist nurse for people with learning disabilities				Epilepsy & LD	All

Staffing Summary:

Role	W.t.e.
Consultant neurologist	1.4
Consultant in neuro-rehabilitation	0.4
Consultant neuro-psychologist	1.0
Nurse consultant & specialist nurses (excluding epilepsy & LD specialist nurse)	6.2
Occupational therapy	2.3
Speech and language therapy	P/T
Physiotherapy (excluding WRH out-patient physiotherapy)	1.2
Rehabilitation Assistant	2.0
Administration (excluding consultants' secretaries)	4.1
Note: This table excludes any staff with specialist competences in the care of people with chronic neurological conditions who are supporting the in-patient rehabilitation beds at Evesham Hospital.	

Key:

ABI	Acquired Brain Injury	PD	Parkinson's Disease
CNC	Chronic Neurological Conditions	POWCH	Princess of Wales Community Hospital
LD	Learning Disabilities	S&LT	Speech and Language Therapist
NW	North Worcestershire = Wyre Forrest and Redditch and Bromsgrove.	SW	South Worcestershire
MS	Multiple Sclerosis	WRH	Worcestershire Royal Hospital (Worcestershire Acute Hospitals NHS Trust)
OT	Occupational Therapist	WF	Wyre Forrest

A good range of specialist nurses was available, with a range of specialist expertise, and this support was appreciated by some patients who met the visiting team. Good patient information and contact leaflets had been developed by the community rehabilitation services. Care plans were evident in the community notes and all parts of the services were undertaking annual reviews of patients' neurological conditions. The community services had developed good patient surveys.

A consultant neuro-psychologist was available for patients with acquired brain injury (although there was no cover for absences). A transition clinic for young people with epilepsy was in place, attended by the paediatric consultant, paediatric learning disabilities specialist nurse, specialist nurse for adults with learning disabilities and epilepsy, and a consultant neurologist.

A good county-wide review of care of people with chronic neurological conditions was undertaken in 2010 but the actions being taken as a result of this review were not clear. The WINRS (Worcestershire Integrated Neurological

Rehabilitation Service) was beginning to bring people together and bi-monthly meetings of all the services involved were scheduled.

Good Practice

1 A very good neuro-physiology service was available. Facilities were good and patients were usually seen within six weeks of referral. GPs had direct access to the service which also provided support to in-patient, out-patient and community services within Worcestershire and beyond. The service was well-organised, providing a single point of access for county-wide care.

2 Data collection and monitoring information in the community services was meticulously collected and well-used, including data on trends over time.

3 Specialist nursing support was available for people with all chronic neurological conditions except epilepsy. The three generic teams ensured that people with rarer chronic neurological conditions had access to support.

4 The acquired brain injury team provided specialist support for this group of patients and linked well with the voluntary sector, including being based in the *Headway* day centre.

Immediate Risks: No immediate risks were identified.

Concerns

1 **Service Integration**

Ten separate services plus two county-wide services (neuro-physiology and neuro-psychology) provided care for people with chronic neurological conditions in Worcestershire. Although the nurse consultant and the WINRS network were beginning to bring community rehabilitation services together, this did not include acute neurology services and the community services were still managed separately and had separate budgets. There was no cover for many of the staff in the individual teams.

Consultant neurologist and neuro-rehabilitation input was provided by six different individuals which made it very difficult to develop appropriate cooperation and liaison with these individuals – or for them to input into the management and improvement of the services in Worcestershire. Some liaison was evident, especially between the multiple sclerosis team and consultant neurologists and between the complex physical neuro-disability team and the neuro-rehabilitation consultant, and ad hoc communication about individual patients took place.

There were no systematic mechanisms for coordinating the care of patients, including annual reviews, or for medical input into the work of most of the community teams. Parkinson's disease nurses no longer attended consultant clinics because of pressures on their time and did not regularly meet with consultants (see below). IT systems did not allow for acute-based and community-based staff to see up to date clinical information about patients, although some community locations could access imaging and pathology results and discharge letters.

As a result, patients could be being cared for by several specialist services or may not be referred to them at all. Services did not have all relevant up to date clinical information about the patients for whom they were caring. There was also overlap between the generic and specialist teams with generic teams caring for people with Parkinson's disease, multiple sclerosis and acquired brain injury even though specialist teams for these groups were available.

2 **Care planning, care coordinator and support**

A mixed picture of support available to patients was evident. Some patients had an allocated care coordinator, especially those under the care of the multiple sclerosis team. Robust arrangements for allocation of a care coordinator were not in place across all the pathways of care. Some of the patients who met the visiting team were very happy with the support they received but others were less satisfied. Patients also commented that when they contacted services they sometimes talked to someone who was

clear about the services available whereas, at other times, they did not receive clear answers. One patient summed up the situation as “it’s all or nothing” and examples were given on multiple service input at a time when this was not appropriate.

3 **Insufficient Consultant Staffing**

Consultant neurologist and neuro-rehabilitation input was Insufficient for the population served. Only 15 sessions of acute neurology and four sessions of neuro-rehabilitation time was available for the Worcestershire population of approximately 575,000. North Worcestershire was particularly short of consultant time. The neurology service was provided by five different people which did not lead to effective coordination and liaison with other services. Reviewers commented that they would have expected between four and five consultant neurologists for a population of this size.

4 **Epilepsy specialist nurse**

No specialist nurse was available for adults with epilepsy, other than those who also had learning disabilities.

5 **Parkinson’s Disease Service**

The Parkinson’s disease specialist nursing service appeared to be overwhelmed by number of referrals and caseload. Reviewers were told that the team of two nurses was receiving 35 referrals per week and the team caseload had increased from 200 to 800. The referral and discharge criteria and working practices evident at the time of the review did not ensure that this caseload could be effectively managed. Parkinson’s disease nurses no longer attended consultant clinics because of pressures on their time and did not regularly meet with consultants. Clinical guidelines covering the monitoring and management of patients with Parkinson’s disease were not in place and there were no arrangements for medical supervision or medical oversight of the work of the team. The specialist nurses did contact the consultant neurologists if they had concerns but these arrangements were not formalised, for example, through clear criteria.

6 **Guidelines and Protocols**

In general, the expected clinical guidelines and protocols were not documented. NICE guidance was used but this had not been localised to show how it was to be implemented locally, including how different services should be involved. University Hospitals Coventry and Warwickshire NHS Trust guidelines were used at the Alexandra Hospital but it was not clear that these fully reflected the pathways and services available in Worcestershire. Community referral guidelines were in place but these were fairly general and, in practice, the services accepted anyone with a diagnosis of a chronic neurological condition and a Worcestershire GP.

Reviewers were particularly concerned about the lack of guidelines for the care of people with epilepsy. Some guidelines for the Clinical Decisions Unit were seen but these did not include a clear pathway for referral to neurology services. Many people with a first seizure may not be seen in the Clinical Decisions Unit. No ‘first seizure’ clinic was available. This, combined with the lack of epilepsy specialist nurse support, suggested that NICE guidance on the care of people with epilepsy was not yet fully implemented.

Further Consideration

1 A lead clinician was identified for the Worcestershire Royal Hospital neurology service and for the community services but there was no identified lead for the Alexandra Hospital service and no-one with overall responsibility for driving improvements in the pathways of care for people with chronic neurological conditions. The identification of an overall clinical lead may be a helpful part of improving pathways of care.

2 Community teams did not have regular pharmacy input. They could contact pharmacy services for advice but no regular meeting for oversight of medicines management with pharmacy. There were, however, plans to appoint additional pharmacy staff to address this issue.

7 There was no cover for absences for many of the staff, including all consultants. Neuro-physiology services were heavily dependent on one person. In practice, community teams had little or no cover for absences. Also, specialist nurses and other community staff were mostly fairly senior and there was little evidence of succession planning for community services or for neuro-physiology.

8 Some staff said that they had very good access to MRI and CT, especially at Worcestershire Royal Hospital. The patients who met the visiting team, however, reported waits of up to eight weeks for diagnostic imaging and further waits of between two and five weeks for reporting. It may be helpful to look at this issue in more detail in order to ascertain whether the patient experiences related to historic events or waits for specialist equipment, such as the scanner at Birmingham Heartlands Hospital, or whether long waits are still happening.

9 Patients who met the visiting team said that they had not received any written information but this may be because the new leaflets had been produced shortly before the review and had not yet been distributed to existing patients. Patients commented that had not been given information about support groups at the time of diagnosis and details of 'sign-posting' to support groups were not noted in any of the case notes seen by reviewers. Clinic letters were available but these were not always copied to patients. It may be helpful to review information needs with existing patients as well as distributing the new leaflets.

10 Reviewers considered that the service model, including deployment of staff and working practices, was not making best use of the resources available, in particular:

a. The six community teams were each quite small and the service model included both county-wide specialist teams and generic geographically-based teams. The responsibilities of the generic and specialist teams overlapped. As a result, resources were ‘spread very thinly’ with little cover for absences and patients may have access to differing levels of expertise. A simpler service model could make all services more robust.

b. Referral and discharge criteria from all services may benefit from review, ideally in a coordinated way across all services and in discussion with primary care. This should enable services to be targeted at those at greatest need.

c. Further development of links with primary care may be helpful, including consideration of a model whereby community teams provide more training and support to primary care and generic community-based services while maintaining a caseload of patients with more complex needs.

d. The criteria for and frequency of home visits may benefit from review. Whilst not underestimating the value of seeing patients’ home circumstances, reviewers considered that the number of home visits undertaken may not be the best use of specialist nursing time. Some of the patients who met reviewers also commented on this and said that they would have been happy to travel to the nurse.

e. Patients with multiple sclerosis were travelling out of Worcestershire for assessment for disease modifying therapies and for annual review thereafter. Some patients from the Alexandra Hospital were travelling to Coventry for neuro-physiology when this was available in Worcester. Reviewers considered that there may be potential for these patients to be cared for within Worcestershire.

f. Reviewers noted awareness of these issues and a willingness to consider alternative solutions from all the staff who they met. Although additional consultant sessions and an epilepsy specialist nurse were needed, reviewers considered services could be significantly improved within the resources available through greater coordination and integration and by introducing a different service model and different ways of working.

COMMISSIONING

BROMSGROVE & REDDITCH, WYRE FOREST and SOUTH WORCESTERSHIRE CLINICAL COMMISSIONING GROUPS

Concerns

1 Specialist Care of People with Chronic Neurological Conditions; Integration; Care planning and coordination; Staffing; Parkinson's disease Service.

Further Consideration

1 The care of people with more common chronic neurological conditions is described in this report. Less common neurological problems, when considered together, affect a significant number of people. Services for this group of patients are usually less well organised than those for people with more common conditions and further consideration should be given to whether local services are meeting their needs.

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APPENDIX 2 COMPLIANCE WITH CHRONIC NEUROLOGICAL CONDITIONS QUALITY STANDARDS

Only those quality standards that were applicable to those services caring for people with a chronic neurological condition are shown here. To view the compliance with all the quality standards covering, primary care, community and specialist services, and commissioning for adults with long term conditions please refer to the '*Care of Adults with Long-Term Conditions: West Midlands Overview Report'* available on the WMQRS website www.wmqrs.nhs.uk

Primary Care

Ref	Short Title	Met	Not	N/A	Total	% met
JA-501N	Primary Care Guidelines – Chronic Neurological Conditions	3	13	0	16	19

Specialist Neurological and Rehabilitation Services

Ref	Short Title	Met	Not	N/A	Total	% met
JN-101	Pathway Information	13	16	0	29	45
JN-102	Service Information	14	15	0	29	48
JN-103	Condition-Specific Information	21	8	0	29	72
JN-103N	Condition-Specific Information – Chronic Neurological Conditions	19	10	0	29	66
JN-104	Personalised Care Planning	0	29	0	29	0
JN-105	'Care Coordinator'	0	29	0	29	0
JN-106	Formal Review and Care Planning	9	19	1	29	32
JN-106N	Formal Review and Care Planning – Chronic Neurological Conditions	14	14	1	29	50
JN-107	Self-Monitoring and Self-Care	21	8	0	29	72
JN-108	Education and Self-Management Programmes	16	13	0	29	55
JN-109	Medication Support	21	8	0	29	72
JN-196	General Support for Patients and Carers	29	0	0	29	100
JN-197	Carers' Support	23	6	0	29	79
JN-198	Carers' Needs	29	0	0	29	100
JN-199	Involving Users and Carers	18	11	0	29	62
JN-201	Lead Clinician	24	5	0	29	83
JN-202	Staffing Levels and Skill Mix	3	26	0	29	10
JN-203	Competence Framework and Training Plan	1	28	0	29	3
JN-299	Administrative and Clerical Support	17	12	0	29	59
JN-301	Support Services	20	9	0	29	69
JN-301N	Support Services – Chronic Neurological Conditions	13	16	0	29	45
JN-302	Orthotics and Wheelchair Services	24	5	0	29	83
JN-303	Home Oxygen Therapy	27	1	1	29	96
JN-304	Pathology Services	28	1	0	29	97

Ref	Short Title	Met	Not	N/A	Total	% met
JN-305	Imaging Services	27	2	0	29	93
JN-305N	Imaging Services – Chronic Neurological Conditions	27	0	2	29	100
JN-306	Pharmacy Services	26	3	0	29	90
JN-307	Housing and Social Care	26	3	0	29	90
JN-401	Facilities and Equipment	26	3	0	29	90
JN-402	Non-invasive and Invasive Ventilation	17	9	3	29	65
JN-403	IT System	0	29	0	29	0
JN-404	Secure Transmission of Patient-Identifiable Data	29	0	0	29	100
JN-501	Diagnosis Guidelines	6	17	6	29	26
JN-501N	Diagnosis Guidelines – Chronic Neurological Conditions	5	23	1	29	18
JN-502	Self-Care Guidelines	2	27	0	29	7
JN-503	Monitoring and Management Guidelines	5	24	0	29	17
JN-503N	Monitoring and Management Guidelines – Chronic Neurological Conditions	1	27	1	29	4
JN-504	Acute Exacerbations and Acute Complications Guidelines	12	17	0	29	41
JN-505	Chronic Complications Guidelines	4	25	0	29	14
JN-506	Transition	3	14	12	29	18
JN-507	Guidelines – Women of Child-Bearing Age	3	21	5	29	13
JN-510	More Specialist Referral	4	25	0	29	14
JN-597	Discharge Guidelines	9	19	1	29	32
JN-598	Palliative Care Guidelines	22	7	0	29	76
JN-599	End of Life Care	23	3	3	29	88
JN-601	Local Pathway	6	23	0	29	21
JN-602	Multi-Disciplinary Meetings with Other Local Services	0	29	0	29	0
JN-603	Risk Stratification	1	28	0	29	3
JN-604	Service Improvement across the Local Network	7	22	0	29	24
JN-605	Annual Review Meetings	3	26	0	29	10
JN-606	Rehabilitation Services	19	5	5	29	79
JN-607	Contribution to Prevention and Early Identification Programmes	19	7	3	29	73
JN-698	Long-Term Care Training and Development	17	12	0	29	59
JN-699	Primary Care Training and Development	20	8	1	29	71
JN-701	Data Collection	5	24	0	29	17
JN-702	Audit	1	28	0	29	3
JN-798	Review and Learning	19	10	0	29	66
JN-799	Document Control	26	3	0	29	90

Commissioning

Ref	Short Title	Met	Not	N/A	Total	% met
JZ-101	Advocacy Services	10	8	0	18	56
JZ-102	Long-Term Conditions Awareness Programme	2	16	0	18	11
JZ-601	Commissioning: Services for People with Long-Term Conditions	9	9	0	18	50
JZ-602	Commissioning: Other Services	9	9	0	18	50
JZ-603	Risk Stratification	8	10	0	18	44
JZ-701	Local Network	7	11	0	18	39
JZ-702	Needs Assessment	17	1	0	18	94.
JZ-703	Strategy	12	6	0	18	67
JZ-704	Quality Monitoring – Primary Care	8	10	0	18	44
JZ-705	Quality Monitoring – Community-Based and Specialist Services	6	12	0	18	33
JZ-706	Pathway Monitoring	6	12	0	18	33
JZ-798	Pathway Review and Learning	2	16	0	18	11

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