

NHS Western Isles

Neurological Services Strategy

2011 - 2014



NHS Western Isles
37 South Beach Street
Stornoway
Isle of Lewis
HS1 2BB

Tel: 01851 702997

<http://www.wihb.scot.nhs.uk>

Authors

Elaine Mackay, Planning & Development Officer
Phil Tilley, Deputy Head Planning and Development

© Copyright NHS Western Isles 2011

The text in this document (excluding logos and copyright images) may be reproduced free of charge in any format or medium provided it is reproduced accurately and not used in a misleading context. The material must be acknowledged as NHS Western Isles copyright and the title of the document specified.

Where we have identified any third party copyright material, you will need to obtain permission from the copyright holders concerned.

For any other use of this material please write to; Communications Manager, NHS Western Isles, 37 South Beach Street, Stornoway, Isle of Lewis. HS1 2BB

NHS Western Isles

Neurological Services Strategy

2011 - 2014

Contributors

Service Users and Carers

Health Intelligence

Patient Focus Public Involvement Development Officer

General Practitioners

Neurology Services Development Group

Allied Health Professions

Healthcare Improvement Scotland

Dr. David Rigby General Practitioner – Pain Management, Neuro LES

Dr. S Razvi, Consultant Neurologist, Southern General Hospital, Glasgow

Consultation on Neurological Services Report to CMT May 2011

Board Advisory Groups

Area Medical Committee

GP Subcommittee

Area Clinical Forum

Drug and Therapeutics Committee

Surgical CMT

Consultants Committee

CONTENTS

Executive Summary	7
1. Vision for Neurological Services	9
2. Neurological Networks and Client Group	9
3. National Context	11
4. Local Context	12
5. Demographics	14
6. Current position in relation to Clinical Standards	21
7. Evidence of what works	23
8. Service User and Carer Views	25
9. Current Service Provision	27
10. Proposed Neurological Conditions Service Model	31
11. Neurology MCN	35
12. Pathway Development	36
13. Funding	39
14. Future Priorities	40
15. Learning and Development	41
- Clinical Nurse Specialist	
- Education Programmes	
- Psychological Needs	
- Pain Management	
16. Self Management	49
- Contribution of carer	
- Contribution of Service User	
17. Assistive Technology	51
- Obligate Network Development	
- Telehealth	
- Teleneurology	
- Supporting Remote and Rural Neurological Developments	
18. Appendix 1: Action Plan	57
19. Appendix 2: Patient and Public Involvement Reports	61

Executive Summary

This strategy serves several purposes. Firstly there was and is a need in the Western Isles to have a concerted focus and improve services for people with neurological conditions and their carers. Secondly the strategy has been developed around the needs and issues that were raised following a series of local consultations with service users. Thirdly it closely follows the guidelines and quality requirements that are set out in the Clinical Standards for Neurological Health Services (2009).

At this time there is no obvious clinical or operational leadership around provision of neurological services. Most patients are referred off-island by their GP for initial assessment and diagnosis either to Glasgow or Inverness but with little or no co-ordination of care on their return. Clearly the situation has to change with modernization of standards of care, improvement strategies in primary and tertiary care, improved patient pathways, reduction in travel, better access to services, care and follow up and regular reviews. Some people will also benefit from care at home packages and the use of telehealth care and home monitoring for the most vulnerable who live alone.

Alongside service improvements consideration should be given to the needs of people with a neurological condition in other strands of work for example, Care Fund, DALLAS / SALP and the work of the eHealth Programmes Board.

We aim to improve services by:

- Delivering on the quality requirements in the Clinical Standards for Neurological Conditions.
- Developing and re-designing clear pathways for people to access and move through services
- Improving access to information, advice, education and support on neurological conditions and support networks and developing information prescriptions
- Improving the patient experience and quality of life (with services personalised to meet people's needs)
- Strengthening joint working across agencies, developing new models of service provision
- To improve the service in line with evidence based research and meeting or exceeding the recommendations in relevant policies or guidelines.

- Developing an action plan and setting priorities.
- Monitoring & evaluating the impact of these changes by on-going engagement with service users and carers.
- Establishing an NHS Western Isles Neurological MCN who will have responsibility for service development, clinical leadership and implementing this strategy.

1. Vision for Neurological Services

The vision is that every patient in the Western Isles with a disorder of the nervous system experiences high quality of care that meets at least the minimum standard and that patients experience a substantial improvement in their quality of care and condition management. Where existing service models do not suite the particular geography and demographic of the Western Isles, new and innovative approaches to service development will be used to ensure that patients are not disadvantaged.

This requires that the person:

- is assessed by the right person at the right time;
- has timely access to investigations required;
- receives treatment appropriate to their needs and condition;
- is encouraged to participate in decision making on a partnership basis,
- has easy access to information and services that enhances the long term management of their condition.

Harnessing the experiences and views of patients, NHS staff, voluntary organisations and social care will be central to the success of the strategy.

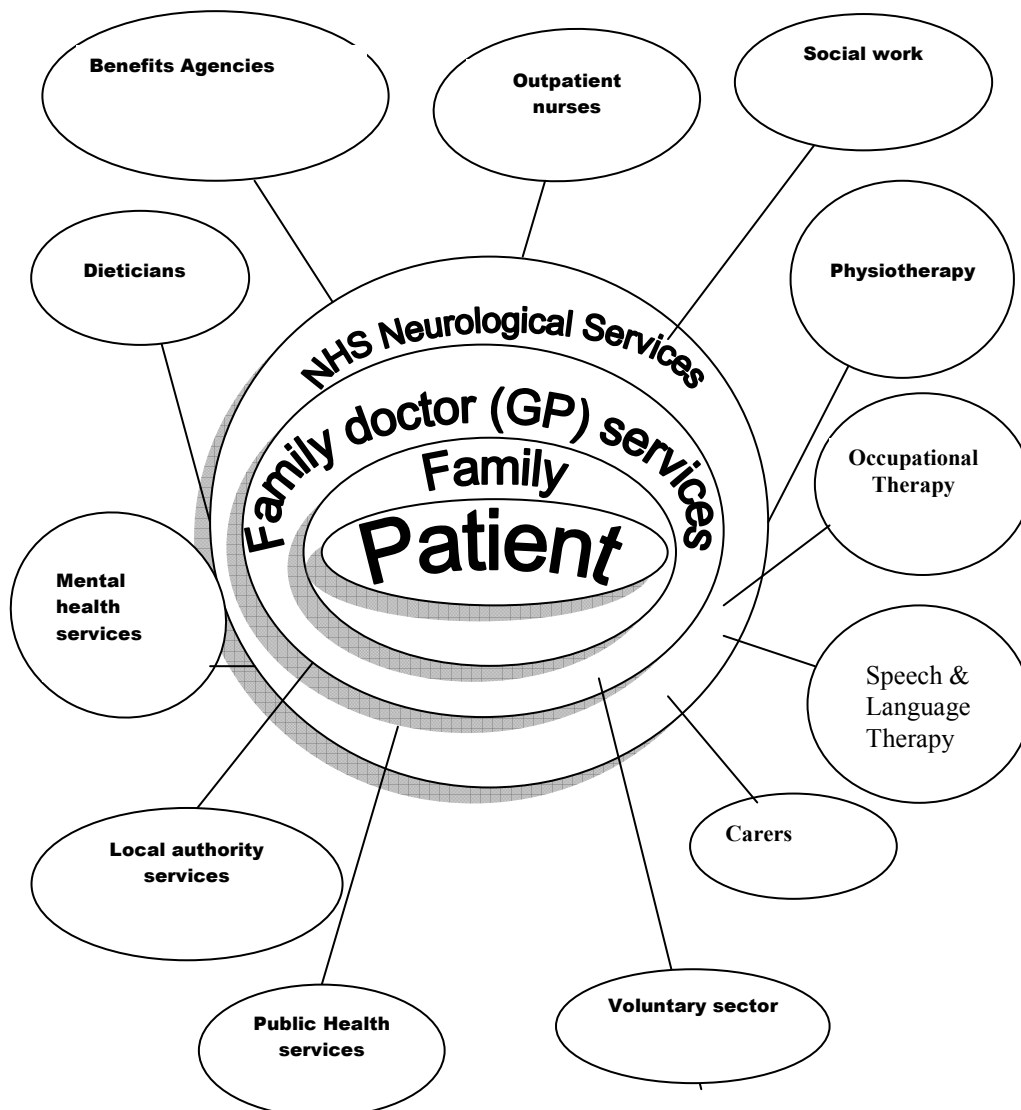
This report sets out the vision for improving the health and well being of those in the Western Isles living with any kind of neurological condition; though initially the patient groups identified in the national neurological standards; Multiple Sclerosis, Parkinson's Disease, Motor Neurone Disease, Epilepsy and Headache, will be prioritised. There are a number of specific actions that ought to be taken and which relate to long term neurological conditions:

- The emergence of telehealth care presents additional opportunities for Long Term Condition pathways, support systems and protocols
- Improving the quality, experience and safety of support for people with long term conditions by delivering services that are clinically effective and responsive to people's needs but which are also more efficient and make best use of skill mix and local resources will be of significant benefit to the whole system supporting a shift in the balance of care.
- The suggested establishment of a Managed Clinical Network (MCN) for neurological conditions in line with the NHS QIS draft clinical standards for neurological services.
- Ensuring that the MCN undertakes technical solutions in their pathways for people with long term conditions and invest in training and development to build capacity within existing workforces to meet patient's

needs, provide service and condition specific information and develop links with other care providers in local authority and third sector organisations to improve services.

- Develop integrated proactive pathways of care for common long term conditions and work closely with tertiary centres to establish an Obligate Network for Neurological Services.

2. NEUROLOGICAL NETWORKS & CLIENT GROUP



What are Neurological Conditions?

A long term neurological condition results from disease of, injury or damage to the body's nervous system (i.e. the brain, spinal cord and /or their peripheral nerve connections) which will affect the individual and their family in one way or another for the rest of their life. Long term neurological conditions can be broadly categorized as follows:

a) Sudden-onset conditions usually due to trauma, for example acquired brain injury or spinal cord injury, followed by a partial recovery (Note stroke for all ages is covered in other National Standards and not included in this strategy).

b) Intermittent and unpredictable conditions, for example epilepsy, certain types of headache or early multiple sclerosis, where relapses and remissions lead to marked variation in the care needed.

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

d) Stable neurological conditions but with changing needs due to development or ageing, for example post-polio syndrome or cerebral palsy in adults.

What these conditions have in common is the potential for causing great disability. This may be intermittent as in migraine or epilepsy, permanent as in a head injury or progressive as in multiple sclerosis or other neurodegenerative disorders. Many of these conditions are truly long term conditions which a patient will live with for many years and even decades.

See Western Isles prevalence and specific conditions in epidemiology section.

Client Group

The client group that is primarily the focus in this strategy is all adults over the age of 16. Paediatric Neurological services were excluded as services are provided separate to adult services. Similarly Stroke and Acquired Brain Injury are subject to condition specific standard and auditing arrangements.

3. National Context

The NHS Quality Improvement Scotland Clinical Standards for Neurological Health Services (October 2009) were created to address the variability of services, across Scotland, available to those with neurological conditions. The standards aim to improve the patient journey from the point of referral into the service and ensure that every patient with a disorder of the nervous system experiences a quality of care that gives confidence to the patient, clinician and carers.

In October 2009 NHS Quality Improvement Scotland (NHS QIS) published clinical standards for neurological health services aimed at improving the patient journey from the point of referral into the service. The standards focus on generic issues for the delivery of all neurological health services, and the areas of access, diagnosis and ongoing management.

In addition to the generic standards, condition-specific standards for five conditions were developed which represent a high proportion of all neurological conditions managed both in primary and secondary care.

These conditions are:

- Epilepsy
- Headache
- Motor Neurone Disease
- Multiple Sclerosis and
- Parkinson's Disease

There are 114 standards which Boards are to meet.

These standards aim to improve the patient journey from the point of referral into the service and it is hoped this will improve the care for all those suffering from a neurological condition.

The QIS report identifies 19 standards covering a range of issues including management processes, diagnosis, access to services, quality of services and ongoing care management.

Through the proposed establishment of a Neurological MCN, the progression of this work will continue against these criteria and progress will also be reported through local clinical governance structures.

4. Local Context

Neurology Improvement Leads were asked to complete a baseline self-evaluation and then identify the top ten priority standards for improvement in our board area, which are listed below:

The Ten Priority Criteria for NHS Western Isles

- The NHS board has a minimum 3-year plan for the provision of neurological health services to its population. This plan is published and subject to annual review.
- The NHS board provides accurate and current information to patients and their carers about their condition.
- The NHS board demonstrates that a minimum of 90% of outpatient demand for all neurological health services can be met by substantive resources without resorting to waiting times initiatives, reliance on temporary staffing or other short-term measures.
- The NHS board ensures that the neurology service has a communication process for discussion of urgent cases with a neurologist at all times.
- The professional development and maintenance of standards of all staff working within neurological health services is monitored by the NHS board.
- All inpatients are discharged with a printed immediate discharge summary.
- Immediate discharge information is sent to the GP electronically in at least 95% of cases.
- The NHS board provides designated rehabilitation services specifically for people with neurological symptoms.
- Patients with advanced conditions or complex needs have access to assessment and treatment in their place of residence by a member of the neurology multidisciplinary team where they are unable to access services at hospitals or clinics.
- Patients with neurological conditions are encouraged to discuss advance care planning when clinically appropriate.

The Strategy for the development of services for Neurological Conditions has been prepared jointly by a multi-agency group.

Against the background of the NHS QIS Neurology Services Self Assessment exercise, it was agreed to establish a Neurology Service Development Group with the aim of service development, establishing the framework for a Neurological Services MCN and to begin work on developing integrated care pathways across primary, secondary and tertiary care, for patients with neurological conditions; and which will in time be established as NHS Western Isles Neurological MCN.

The membership of the development group is as below:

Name	Organisation
Ella Macbain	Older Peoples Partnership, CNES
Stephen Moore	Associate Chief Operating Officer, Primary Care
Cathy Maciness	Manager, OPD Services
Sonja Smit	Occupational Therapy
Brian Michie	GP
Karen France	Dietician
Maggie Fraser	Communications Manager
Phil Tilley (Chair)	Deputy Head of Planning & Development, Public Health
Lachlan Macpherson	Capacity Planning Manager
Jon Harris	IT Manager
Christine Lapsley	Speech and Language Therapy Manager
Elaine Campbell	Planning Officer, Public Health
Finella Morrison	Community Nursing Manager
Barbara Bates	Speech Therapist
Alison Maciver	MS Coordinator
Marion Macloone	Clinical Governance Lead
Fiona Maclean	Radiology Manager
Denise Symington	PFPI Officer
Chrisanne Campbell	Associate Chief Operating Officer – Secondary Care
Sheila Nicolson	Physiotherapy Manager
Gill Chadwick	Macmillan Lead Cancer Nurse
Dr Razvi	Consultant Neurologist, Department of Neurology, Institute of Neurological Sciences, Southern General Hospital, Glasgow

5.Demographics

Approximately 10 million people across the United Kingdom (UK) have a long term neurological condition, accounting for 20% of acute hospital admissions. A long term neurological condition is the third most common reason for seeing a general practitioner.

- 1 in 5 emergency hospital admissions are related to neurological conditions
- 1 in 8 General Practitioner consultations are related to neurological conditions
- 25% of people between the ages of 16 and 64 with a chronic disability have a neurological condition accounting for a high proportion of disability, particularly severe and progressive disability, in the population. QIS neurological standards Page 3 (2009)

Referrals to neurology outpatients are also increasing and with long waits to see a specialist or to have investigations, people may wait for lengthy periods to receive a diagnosis. Once a diagnosis is given, support in the community is variable and many people are left feeling isolated knowing that their condition is 'long term' and will be with them for the rest of their lives.

There are an estimated one million people in Scotland living with a neurological condition that has a significant impact on their lives. The most common physically disabling condition affecting young people, multiple sclerosis (MS), has a particularly high prevalence in Scotland compared with the rest of the UK. Neurological conditions account for a high proportion of disability, particularly severe and progressive disability, in the population.

Within NHS Western Isles there is a significant number of patients with a wide range of neurological conditions as detailed below:

By practice area											
	EPILEPSY	MOTOR NEURONE DISEASE	MULTIPLE SCLEROSIS	POSTVIRAL FATIGUE SYNDROME	MYASTHENIA GRAVIS	PARKINSON'S DISEASE	HUNTINGTONS DISEASE	PROGRESSIVE SUPRANUCLEAR PALSY	MUSCULAR DYSTROPHY	DYSTONIA	Total by Practice
Westside	16	0	17	16	2	5	0	0	0	0	56
Broadbay	55	3	15	42	2	14	0	0	4	1	136
Group	62	2	19	56	2	27	1	1	4	1	175
North Lochs	10	0	6	7	0	0	0	0	0	0	23
Uig and Bernera	2	0	4	6	1	2	0	0	0	0	15
South Lochs	3	0	1	0	0	0	0	0	0	0	4
North Harris	8	1	3	5	1	8	0	0	0	0	26
South Harris	6	0	4	1	0	3	0	0	0	0	14
North Uist	16	1	5	6	0	9	0	0	0	0	37
Benbecula	17	1	8	21	1	3	0	0	1	0	52
South Uist	13	0	2	2	1	2	0	0	0	1	21
Barra	5	1	5	3	0	3	0	0	0	0	17
Totals	213	9	89	165	10	76	1	1	9	3	576

Neurological Conditions Epidemiology in Western Isles

Assessing the epidemiology of neurological conditions is made difficult by both the multitude and wide spectrum of conditions that are involved – neurology has the greatest number of conditions listed in the International Classification of Disease. It is made more difficult with the paucity of national data especially within the primary care setting where much of these conditions are managed – there have been estimates that nervous system diseases are the most common condition consulted upon at GP practices in UK (McCormick & Rosenbaum, 1990).

All estimates though have pointed to the large and increasing scale of the impacts of neurological conditions upon populations which has made it the focus for much health policy in recent years - it is estimated over 10 million people in the UK with a neurological condition affecting their lives (Neurological Alliance, Neuro Numbers 2003).

Prevalence within Western Isles

A survey of Western Isles General Practices found the following prevalent numbers for selected neurological conditions (Table 1).

Table 1: No. persons in Western Isles with selected neurological conditions

Neurological Condition	Southern Isles	Harris	Lewis	Total Prevalence 2011	WI
Epilepsy	51	14	148	213	
Parkinsons Disease	17	11	48	76	
Motor Neurone Disease	3	1	5	9	
ME/CFS	32	6	127	165	
Huntingdons Disease	0	0	1	1	
Myasthenia Gravis	2	1	7	10	
Progressive Supranuclear Palsy	0	0	1	1	
Muscular Dystrophy	1	0	8	9	
Multiple Sclerosis	20	7	62	89	
Dystonia	1	0	2	3	
All selected neurological conditions	126	40	406	576	

The total number of persons found with above neurological conditions was 576 though this may include persons with more than one of the identified conditions. The most common condition was epilepsy which together with ME/CFS comprised over two thirds of all selected conditions. 95% of all prevalent cases

in the islands were accounted for by the aforementioned conditions together with Parkinsons Disease and MS.

The information was provided on the level of severity of the condition. Nor was information provided on the age/gender profile of these patients which would be required to enable both projections based on population forecasts and comparisons standardised to take into account older age profile of the Western Isles population. It is recommended that further work to identify the age/gender/severity of the prevalent cases in Western Isles is undertaken to allow the above projections and comparisons and also to apportion cases to appropriate care settings based on severity profile.

Notwithstanding this comparisons of the found prevalence with expected prevalence were made based on overall UK prevalence rates and presented in the form of an indirect standardised prevalence ratios (See Table 2 below)

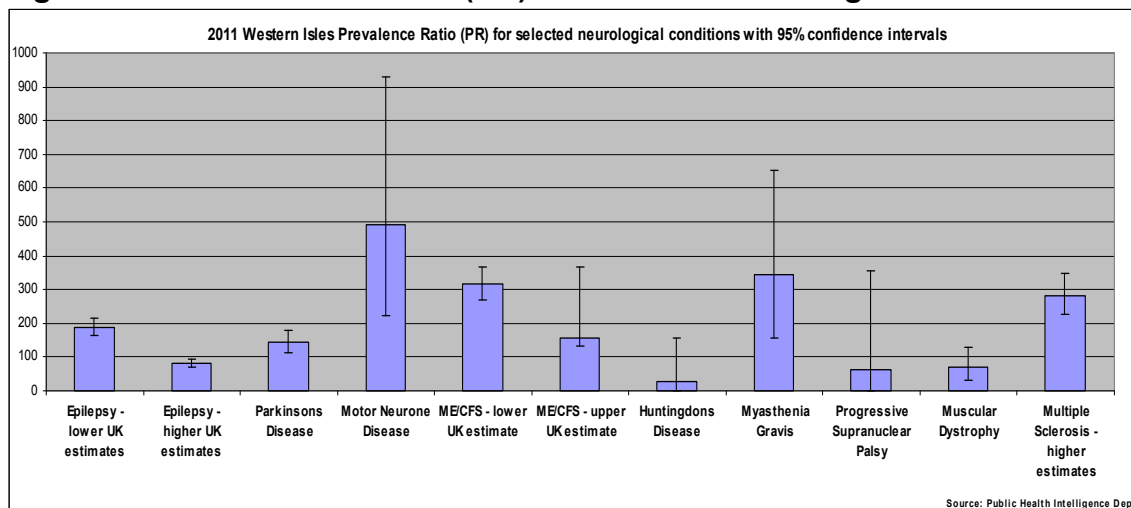
Table 2: Expected prevalence and prevalence ratio (PR) for Western Isles resident.

Neurological Condition	UK Prevalence ¹	Expected prevalence	Excess prevalence	Non-Standardised Prevalence Ratio (PR)*
Epilepsy - lower UK estimates ²	430	113	100	189.1
Epilepsy - higher UK estimates ²	1000	262	-49	81.3
Parkinsons Disease	200	52	24	145.0
Motor Neurone Disease	7	2	7	490.7
Myalgic Encephalomyelitis CFS - lower UK estimate ³	200	52	113	314.9
Myalgic Encephalomyelitis CFS - upper UK estimate ³	400	105	60	157.4
Huntingtons Disease	13.5	4	-3	28.3
Myasthenia Gravis ⁴	10	3	6	343.5
Progressive Supranuclear Palsy ⁵	6	2	-1	63.6
Muscular Dystrophy	50	13	-4	68.7
Multiple Sclerosis - higher estimates ⁶	120	31	58	283.1
All selected neurological conditions - lower estimates		272	300	
All selected neurological conditions - higher estimates		473	99	
Notes:				
* based on UK prevalence but unable to apply indirect standardisation method due to unavailability of age specific data				
UK Prevalence estimate sources				
¹ Based on 'Neuro numbers: a brief review of the numbers of people in the UK with a neurological condition' unless otherwise indicated				
² NICE guidelines, Epilepsy, 2004				
Chief Medical Officer (CMO) for England and Wales, Report of the CSF/ME Working Group, 2002				
⁴ Myasthenia Gravis Association				
⁵ Nath U et al, 'The prevalence of progressive supranuclear palsy (Steele–Richardson–Olszewski syndrome) in the UK' , BRAIN, 124(7), 2001				
⁶ NICE guideline, Multiple Sclerosis, 2003				

This resulted in 300 excess prevalent cases compared to the lower UK prevalent estimates and 99 compared to higher UK prevalent estimates. Those conditions

with PR greater than 100 have a higher prevalence than expected based on national levels though many have very wide confidence intervals due to small numbers involved (see Figure 1)

Figure 1: WI Prevalence Ratio (PR) for selected neurological conditions



Nonetheless all of those conditions with SPR above expected levels are found to be statistically significant with lower CI above 100. MND, ME/CFS, Myasthenia Gravis and MS have the greatest variance over expected levels though age standardisation to adjust for the more elderly Western Isles population should be undertaken when data becomes available. However, it is reasonable to conclude that for a majority of neurological conditions the Western Isles has levels above the national average.

There are a number of other neurological conditions which were not surveyed in the general practice survey and therefore comparisons are not possible. However, estimates based on UK levels are shown below in table 3.

Table 3: Estimates of WI prevalence for other selected neurological conditions

Neurological Condition	UK Prevalence ¹	Expected prevalence	WI prevalence
Alzheimer's disease/ dementia	1,000	262	
Ataxia (inc. Friedrich's ataxia)	5,000	1,310	
Cerebral palsy	186	49	
Dystonia	65	17	
Essential tremor	850	223	
Migraine	15,000	3,930	
Spinal cord injury	50	13	
spina bifida & congenital hydrocephalus	24	6	
Traumatic brain injury leading to long term problem	228	60	

Early onset dementia	n/k	-
Charcot-Marie-Tooth Syndrom	40	10
Post polio syndrome	n/k	-
Tourette syndrome	40	10
Tuberous sclerosis	14	4
Total expected prevalence for other neurological conditions		5,894

The overwhelming majority here are for less debilitating ataxia and migraine with the remainder comprising 654 prevalent persons.

Patient activity in specialist neurological and general secondary care services

Assessment and treatment for a neurological condition within secondary care services may occur either at specialist neurology consultant services or other general consultant services.

New outpatient attendances to see neurologist over the past 5 years have steadily risen by over a third year on year from 142 in 2006 to 192 in 2010. Over this period there has been a large shift in the patient pathway from the visiting consultant service in the Western Isles Hospital to mainland centres particularly at Southern General in Glasgow with main shift occurring in 2009 (see Table 4)

Table 4: New outpatient attendances by Hospital, 2006-10 (Source: SMR00)

Year	Mainland Hospitals	Western Isles Hospital	% Mainland
2006	41	101	28.2
2007	40	103	28.0
2008	44	108	28.9
2009	117	70	62.6
2010	149	43	77.6

The increase in mainland referrals is continued by the level of return attendance activity which has risen more than 3 fold over the 5 years.

This pattern in recent years increasingly towards mainland centres particularly Southern General occurs across all island groups with an increase over 5 years of 84 new attendances in Lewis and Harris and 12 in Southern Isles.

All hospital admissions under care of neurologist specialist occur on mainland centres mainly at Southern General Hospital which have risen by over two thirds to 119 in 2010.

For the selected neurological conditions the pattern of hospital admissions to both neurological specialty and other general specialties is shown in table 5

Table 5: 2010 Hospital Admissions for selected Neurological Conditions as main diagnosis to all specialties (SOURCE: SMR01)

<i>Neurological Condition</i>	<i>Mainland Hospital</i>	<i>Western Isles Hospitals</i>
Epilepsy	13	13
Multiple Sclerosis	12	15
ME/ CFD	1	1
Parkinson's Disease	6	7
Motor Neurone Disease	9	1
Muscular Dystrophy	0	0
Migraine	5	1
Headache	4	19
Intracranial Injury	4	5
Traumatic Brain Injury	7	10
Total Selected Conditions	61	72

This shows that more patients are admitted for care within Western Isles hospitals than mainland centres for above neurological conditions. It is likely that this will be for non-specialist general care or emergency admission prior to transfer to specialist centre which would benefit from further analysis to establish.

Summary

The Western Isles has higher than national levels of persons for a range of neurological conditions. This is concentrated in 4 main conditions (Epilepsy, ME/CFS, MS and Parkinsons Disease among those surveyed but exists across the spectrum of neurological conditions. Further work to investigate comparisons adjusted for age, project prevalent burden based on population forecasts and to profile severity levels is recommended.

Secondary care activity for specialist consultant neurologist services has risen over 5 recent years particularly in Southern General which has seen an over 3 fold increase in outpatient referrals and 68% increase in admissions.

Further work to benchmark Western Isles hospitalisation levels against other areas and national areas is recommended. Also, of value would be a more detailed analysis of the conditions seen at neurology consultant services.

Recommendations for Data/Intelligence requirements

- A Health Needs Assessment should be undertaken for people with Neurological conditions across the Western Isles;
- An agreed definition of which conditions should be considered should be developed;

- There is a need to have improved and unified systems for routine collection of data on incidence and prevalence of long term neurological conditions;
- There is a need for activity data related to the management of Neurological Conditions in the community including social services and in palliative care to complement data for secondary and tertiary services.

6. Current position in relation to standards

Locally there is no identifiable clinical leadership for neurological services and in discussion with local service leads was considered a barrier to organising and managing services and to service improvement.

The standards refer directly to general neurology and also the provision of a specialist services. If these standards are to be met a new approach to delivering neurological services must be adopted. This is especially critical in a remote and rural area where access to generalist neurology services and specialist neurology services is fragmented. It is impractical for many of the very specialised services to be commissioned locally but by engaging with other Boards it is possible to provide local access. Improved service structures would be aimed at delivering a near patient neurological service whether by the availability of qualified staff or by using technology to bring services to the patient. The aim of the service would be to ensure an agreed level of expertise and case co-ordination, as local to patients as possible, to provide a quality service to patients, families and carers and act in support of other professionals.

It is clear that with effective coordination, better team work and a greater focus on preventative strategies that enable people to stay as well as possible, not only can effectiveness be improved, but patients and their carers can experience better clinical outcomes, improved quality of life and higher levels of satisfaction.

Services need to be personalised, empowering, effective and integrated. And with these investments lead to improved service quality, more effective and efficient care provision, reduction on the dependency for hospital admission, a reduction in GP appointments and possible extended length of life could be achieved.

Key components of a neurological service should include:

- Early detection & diagnosis
- Case management & integrated care across service boundaries
- Self Management
- Access to Specialist Care
- Therapy & rehabilitation
- Palliative Care

The strategic plan will be led by the following key performance drivers:

- People developing neurological conditions will be diagnosed earlier and offered support to manage their diagnosis through medical interventions and behaviour change. Access to rapid specialist neurological advice for primary care clinicians will be improved.

- Front line staff will be trained to improve recognition of neurological symptoms, with shared care protocols for referral and assessment.
- Everyone with a neurological condition will have an individual action plan with a named point of contact to help them better manage their condition and maintain or improve their health and well-being. Those with complex needs will have their care co-ordinated by a care co-ordinator or case manager to ensure contingency plans are in place to manage need when an individual's disease changes unpredictably.
- There will be a fall in the number of admissions, and emergency bed days and intermediate care bed days for people with neurological conditions, irrespective of whether that admission is as a direct result of their neurological condition or attributed to a broader health care need.
- Services gaps for patients with neurological conditions including adults with neurological disease or damage and adults with complex and continuing care needs will be reviewed, with patient care being delivered as close to home as possible.

7.Evidence of what works

Although the Clinical Standards Framework focuses on the needs of people living with neurological conditions, it will make an important contribution to delivering the government's overall strategy to improve NHS and social care support for all people living with long term conditions.

Neurological medical conditions have an enormous impact on the whole of a person's life. Such conditions require alterations to daily life, learning new skills, and realistic planning so as to minimise the effect of the condition on individuals and families. These conditions and their treatments can affect mood, cognitive processing (thinking), self-esteem, relationships and quality of life, sometimes leading to stress, anxiety and or depression.

These illnesses not only impact on the neurological health of an individual, or on an individual by themselves but also impact on their general health and well-being, their mental health and the lives and health of their family members and carers. One of the biggest impacts is on their mental health.

These psychological changes are not only distressing in themselves, but can also affect people's ability and motivation to understand, make informed choices about and to pursue treatment regimes. Good care can help prevent the development of or reduce the impact of psychological distress associated with physical health conditions.

The management of long term conditions is complex and will involve many services. In the early stages after diagnosis these impacts will be minimal but as each person's condition progresses and they experience a greater degree of disability they will require the involvement of a multi-agency team of professionals with different skill sets and different roles.

Different models of long term conditions management are described in literature and in the Western Isles we have successfully developed a model of long term conditions management that has been deployed with Diabetes, Chronic Obstructive Airways Disease (COPD) and CHD & Stroke. It is proposed to replicate the same model for the management of neurological conditions;

- To invest in the development and training of local staff to an agreed educational level
- To ensure that there are staff trained to that level and attached to each GP practice (thereby providing near patient support and intervention)
- Develop capacity within the existing workforce to meet the needs and demands of people with neurological conditions
- To promote self management through patient education

- To link agencies to work as a single team
- To form working partnerships with other Boards through Obligate Network Structures
- To build in forward planning and mineralise the risk of single-handed services.

Professionals likely to be involved in care of a person with neurological conditions.

General Practitioner	Benefits Agency
Neurologist	Carers
MS Specialist Nurse	Neurorehabilitation specialist
District Nurse	Spasticity clinic
Continence Nurse	Ward nurses in local hospital
Physiotherapist	Ward nurses in regional centre
Occupational Therapists	Outpatient nurses
Speech and Language Therapists	Outpatient administrative staff
Dieticians	Neurologist's secretary
General practice receptionists/Admin	Social Services

This document sets out quality requirements which are derived from research and expert evidence specific to neurological conditions, but many elements of them are relevant to people with other long term conditions, for example:

- prompt diagnosis;
- providing information and support;
- person centred care and choice;
- providing information and support for the safe and effective use of medicines;
- care planning and integrated service provision involving different agencies, including closer working between health and social services;
- planning and liaison when people make transitions between services;
- supporting self care and considering health promotion needs;
- prompt access to treatment and timely referral for appropriate specialist intervention;
- rehabilitation and support in the community and vocational rehabilitation;
- providing equipment and adapted accommodation;
- providing palliative care;
- supporting carers;
- managing long term conditions effectively when in hospital (or other settings) for other problems.

8. Service User and Carer Views



Harnessing the experiences and views of patients and voluntary organisations will be central to the success of the programme. As such a number of key activities identified for the public involvement / engagement plan in regard to the development of the Neurology Services Plan have been undertaken.

Working alongside our Patient Focus Public Involvement colleagues we have begun an engagement programme to involve lay representation for this group.

A number of consultations were held with patients and carers throughout September and October. The aim was to ascertain the lived experience of carers, service users and frontline staff so that real issues are captured and addressed in developing improved services. The information obtained from the workshops will also contribute, in the future, to the development of care pathways also known as patient journeys for people with neurological conditions with the aim of improving the access and quality of services.

This is an important element of developing the Western Isles wide strategy for people with neurological conditions and their carers.

The workshops focused on key aspects of the patient journey which included: Early signs and diagnosis, Treatment and Services, Support and Follow-up, and on-going care. Below are issues that emerged from those consultations;

Early signs and diagnosis

Education for GPs and Health professionals and for patients themselves

Speedier diagnosis –Time between GP & consultation, long wait between diagnosis and treatment, no support in between.

No support directly after diagnosis
Information to be provided at an early stage

Improve communication between professionals and patients

Improve administration/communication –

Treatment and Services

Bureaucracy – assessment, repeating story

Waiting time – no movement through pathway

Need for specialist neurological team – all ranges of staff, primary and secondary care

More local knowledge and services notably around medication support particularly in following up when new medication is prescribed;

More support for carers and families

Time: issues re travel, waiting, medication, cancelling appointments

Specialist advice & information: a point of contact

More knowledge awareness of neurological conditions across all care environments

Specialist support e.g. Nurse, who to contact (key coordinator)

Local Support Group – speak to others in the same situation

People to believe you have the illness

Help with finance / benefits

Support

Neurological specialist care / team: (coordination of services) psychological support, voluntary groups, primary / secondary

Finance: Direct payments, choice flexibility

Medication: information support,

A Specialist nurse to be point of contact or coordinator and source of information

More support for patient and carers – being directed in the right direction for medical and social help

Patients want to be **listened** to properly

Currently services very „bitty“ (INFORMATION).

Accessibility: (access information).

Improvements needed for travel, parking, appointments support etc

Psychological support with adjustments.

GP should have more input into the coordination of care

More involvement of Psychologist and Social Care

Visits at home would be considered perhaps through telehealth

Follow-up / on-going care

Specialist care team (neurological) e.g. include nurses, occupational therapists etc

Support Groups – self/peer support with specialist nurse, time to discuss

wider/sensitive issues in depth. Useful to meet people of same age at same stage of disease & information support group

Someone at the end of the telephone who you can talk to – who knows what they are talking about and can advise

Services reactive not pro-active e.g. waiting for the crisis rather than daily management. More preventative work needed.

Support needs to happen sooner rather than later for getting back into the system including back into work including via a voluntary basis, more disability employment advisers

9. Current Service Provision and Resources

Tertiary Referrals

Referrals mainly go to the Southern General Hospital, Glasgow and the majority of patients will be seen in the general neurology telemedicine clinic held at the Western Isles Hospital outpatient department. Specialised investigations such as MRI scans and lumbar punctures are undertaken mainly at the Southern General Hospital, but have also been done at Raigmore Hospital, Edinburgh or Aberdeen.

The majority of patients may be followed-up by either the general neurologist or condition specific neurologists. A number of patients are discharged and can self-manage or are managed by the GPs who can refer patients to the neurologist as required.

NHS Western Isles Allied Health Professions Services

Physiotherapy

Physiotherapy is provided from two main NHS Western Isles sites: the Western Isles Hospital (WIH), Stornoway and the Uist and Barra Hospital (OUAB), Benbecula.

In WIH, there is one Band 6 Physiotherapist with responsibility for Medical and Neurology physiotherapy. The physiotherapist works between Medical Wards 1 and 2, and Erisort Ward. Treating patients admitted to the Stroke Unit is part of this physiotherapist's remit. The physiotherapist is also responsible for, and provides, an Out-patient physiotherapy service for those with neurological conditions. There is a weekly exercise class for clients with Multiple Sclerosis; patients with a diagnosis of MS attend on a six week rolling programme. The Band 6 Physiotherapist has a remit for WIH, In and Out-patients from Lewis **and** Harris, a wide geographic spread.

The physiotherapist is aided in delivery of this service by the Physiotherapy Department Support Workers as and when required. There is also a Community Physiotherapist (Band 6) who will visit neurological patients in their homes, or in any community location, including Bethesda Hospice.

WIH there is a part time Band 7 Physiotherapist with responsibility for Paediatric Physiotherapy provision. Her caseload includes paediatric clients with neurological diagnoses.

In OUAB there is no dedicated Neurological Physiotherapist; a team of 4 Physiotherapists (2 full time, 2 part time) provide a physiotherapy service to all clients referred to the Physiotherapy service. Neurological patients may be seen as In-patients or Out patients by any of the Physiotherapists working in OUAB. There is a weekly visiting physiotherapy service to Barra, once again the

physiotherapist will see Neurological patients in Barra during her time on the island. A member of OUAB physiotherapy staff has dedicated time to provide a Paediatric Physiotherapy service throughout Uist and Barra, included in her caseload are children with neurological disorders such as Muscular Dystrophy.

Occupational Therapy

Occupational therapists provide a service to adult patients with neurological conditions; In-patient interventions in the form of acute assessment and early rehabilitation of stroke patients in the specialist Stroke unit on Erisort Ward;

A similar service to those who are newly diagnosed with acquired brain injury, and rarer neurological conditions, wherever they are located in the hospital and; in-patient review of those with longer term conditions, especially discharge planning.

Out-patient and community services extend throughout the island chain for people who have been discharged from hospital following stroke, and to those with progressive neurological disorders, such as MS, MND, and Parkinson's disease. Though stroke is not included in this neurological strategy it is worth remarking on the extent of the service.

The service is led by 1 wte. Band 7 Occupational Therapist, whose caseload includes acute stroke and brain injured inpatients alongside those with complex and ongoing neurological needs in the community.

The remainder of the OT team also carry caseloads which includes Neurological patients - particularly the Adaptation and Rehabilitation Team (ART), OT's responsible for working on property adaptations to meet the needs of people with disabilities; house extensions, level access shower provision, portable hoisting equipment are examples of the focus of this work.

The OT service is currently piloting the inclusion of additional Band 6 OT protected time to provide input to people with newly diagnosed neurological conditions on wards. The plan is that this will free up time to develop community and out-patient services; the forming of out-patient groups with specific diagnoses.

There are gaps in community based rehabilitation resources, including both a workforce to deliver these service as well as facilities that can in particular cater for the needs of younger adults with acute deterioration in long term conditions which impacts on independent living as well as individuals with traumatic brain injuries who require 24 hour supervision while participating in rehabilitation. A hospital environment is not the desired option.

Speech and Language Therapy

Speech and Language Therapy is based in two main sites within NHS Western Isles: the Western Isles Hospital (WIH), Stornoway and 25 Winfield Way Balivanich, Benbecula.

In WIH there is currently one Band 7 Specialist Speech and Language Therapist [SLT] who has lead responsibility for those with a neurological diagnosis and whose caseload includes inpatients, outpatients and with patients in the community who have difficulties with communication or swallowing due to a neurological condition. The service is also supported by a Specialist SLT whose remit is to provide support for bilingual patients and guidance to staff working with patients whose first or preferred language is not English. This therapist also has specialist skills in assessment of swallowing disorders and acquired communication difficulties and may provide cover for the lead therapist on a limited basis.

There is also an SLT support worker based in WIH who has fluent Gaelic and supports the therapists working with those with neurological conditions.

In WIH we have a part time Band 8a SLT with responsibility for Speech Therapy provision for children with additional support needs and this would include those with complex neurological conditions

In the Southern Isles patients with a neurological condition are seen by the SLT Manager who is also a Specialist in this client group. Patients with neurological conditions are usually seen in their homes in order to promote self management aspects of their care and also to support family and carers. The SLT service to children with neurological conditions in the Uists would also be included in that caseload.

The Speech and Language Therapists in the Western Isles working with this client group have the specialist skills and knowledge required to assess and design rehabilitation programmes for individuals in the community.

Link with Change Fund Programme

Our local AHP teams have specialist knowledge and could gain additional specialist knowledge and skills to assess and design rehabilitation programmes for individuals in the community. However the service needs an infrastructure of rehabilitation workers to carry out treatment programmes. There are potential links with the Reablement component in the Change Fund Programme.

Recommendations

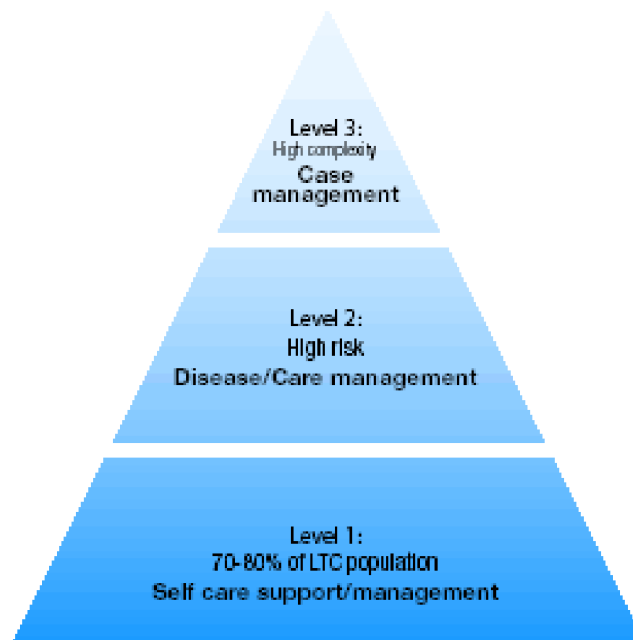
- Benchmarking needs to be undertaken across all AHP groups against local team structures and resources followed with a gap analysis and options of how this could be addressed.
- Investment in rehabilitation programmes, likely to be available through the proposed Obligate Network Development, to allow for staff to carry out treatment programmes.

10. Proposed Neurological Conditions Model

The long term conditions model below is equally applicable to neurological conditions.

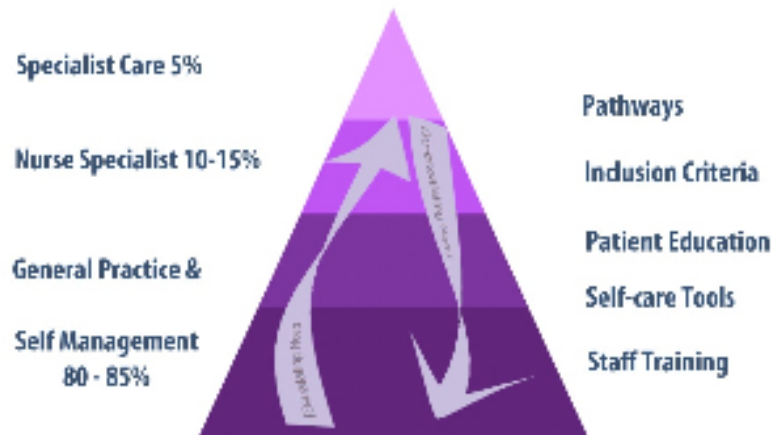
The majority of patients with a neurological condition (about 80%) will fall within level 1, with a further 15% of patients located within level 2. The majority of such patients could be managed within primary care therefore it is vital that there are locally designed and appropriate services along with adequate investment in primary care delivered services.

However there will also be 5% of those individuals with neurological conditions within level 3 and they will require specialised intensive case management and support to promote quality of life and better outcomes. The nature of neurological conditions is that patients will move between these different levels depending on illness trajectory in terms of exacerbations or relapses.

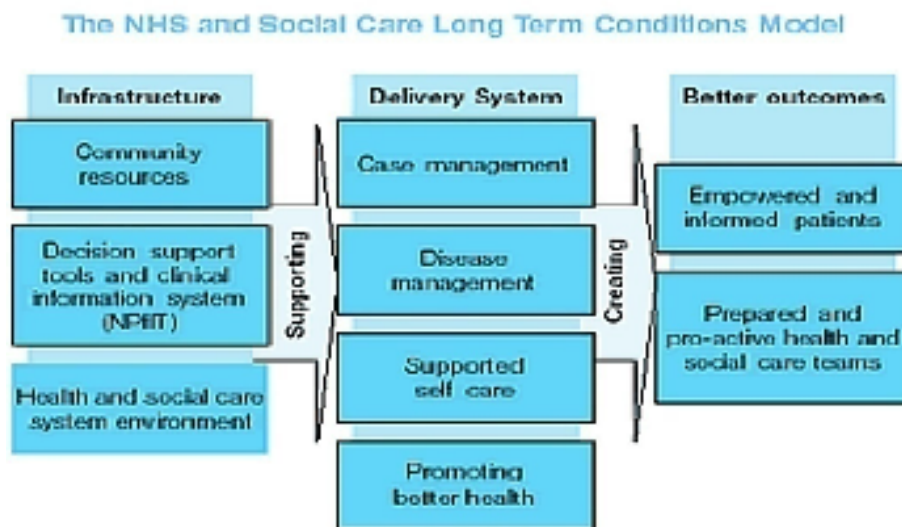


A very successful model of delivering services for people with long term conditions has been developed in the Western Isles by investing in primary and community services, equipping local health care staff with the knowledge and expertise required to deliver near-patient health care appropriate to their needs. The recommendations in this report are based on the factual evidence that this model is the most effective for meeting the needs of people living in a report and rural area. The model developed for diabetes services has also been used for Coronary Heart Disease and more recently Respiratory Management. Rather than a centralised service a local service also provides parity, equity of access and a local more personalised service.

Based on the self-management model for structuring services for people with long term conditions, the following diagram identifies the alternating dependencies of people through the course of their life from one level of care to another and where investment should occur to reduce escalation and increase de-escalation thereby maintaining people at the highest level of independence appropriate to their needs.



To maintain individuals with the maximum independence and optimal quality of life the service needs to be structured to ensure that changing dependency is provided for but that the focus is on multi-service interventions, rehabilitation and sustaining or returning people to the lowest level of intervention as possible. To achieve this clinical pathways, inclusion criteria for each type of care, patient education, self care tools and staff training are all critical areas of service development and investment.



Integrating care to reduce hospital admissions and manage chronic diseases

The most recent thinking from the Kings Fund and Care UK, suggests that evidence points to substantial benefits for patients and that reduced costs to health and social care can be achieved through developing integrated care programmes.

These proposals make greater use of managing people's health needs in their own homes or, where greater levels of nursing are involved, in residential care settings and have a relevance to how we manage services for people with Neurological conditions in the Western Isles.

The NHS is currently facing a two-pronged challenge of delivering increasing levels of health and social care services to a growing population of older people, many of whom will have complex needs whilst also responding material cost reduction.

In parallel and to achieve similar objectives, health and social care services are seeking to transform the delivery of services by giving service users greater choice, say and control over what, when and how services are delivered. These pressures demand a radical shift in the way health and social care are delivered.

The concept of integrated moves the system from the traditional NHS model of reactive 'inbound' healthcare to proactive, preventative 'outbound' healthcare. In other words: from waiting for problems to occur and then fixing the problem, to understanding what problems might occur and preventing as many of them as possible.

There is strong evidence that integrated care can deliver more effective and higher quality care and significant efficiency savings. The recent McKinsey report estimated that savings may be available from greater integration of health and social care.

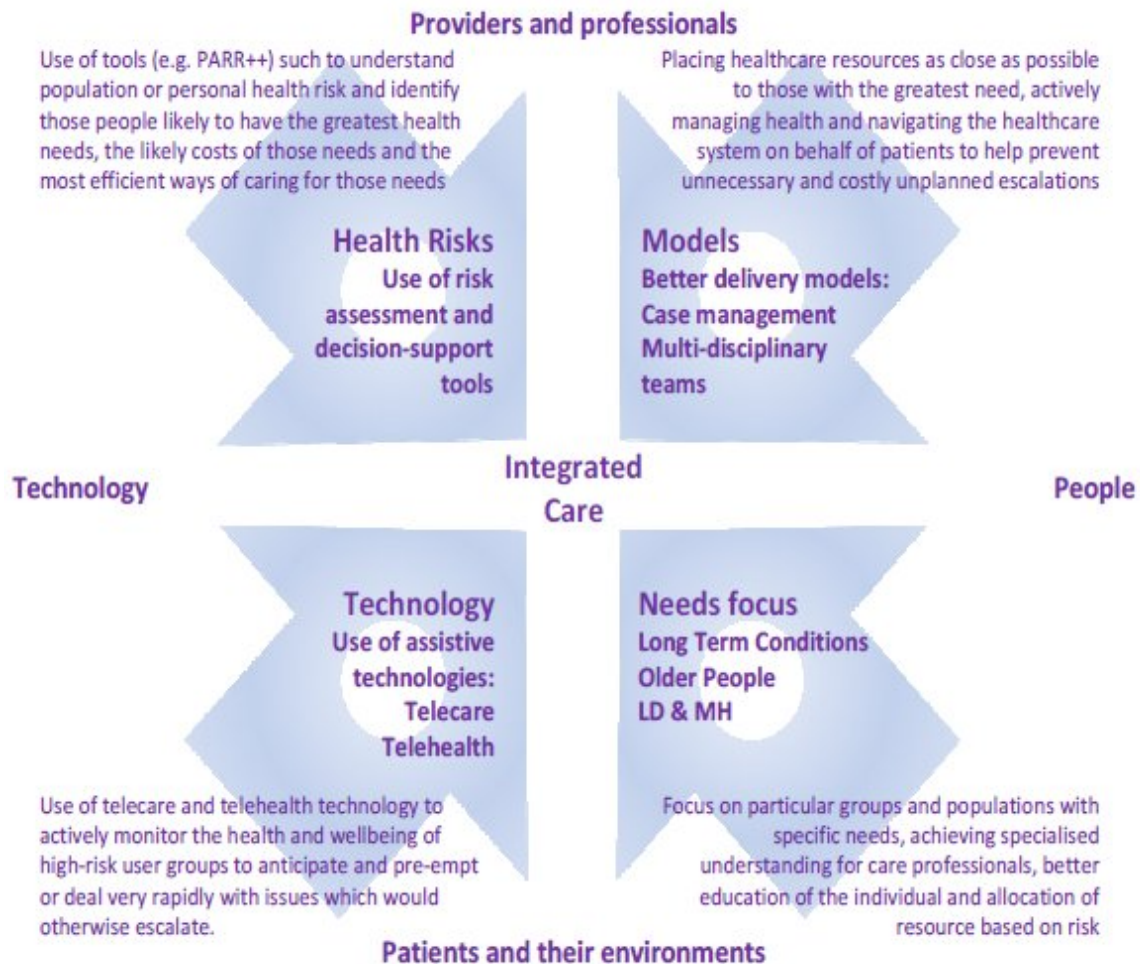
The potential for cost reduction typically focuses on reducing healthcare interactions, notably unnecessary hospital visits (especially A&E admissions) and, to an extent, GP visits, by providing alternative services to pro-actively manage the health of those people who are most likely to consume healthcare resources.

However, this view would tend to suggest that the savings from integrated care are all to be made within healthcare while much of the cost of improved services is borne by social care. In practice, one of the principle triggers for the need for social care (or escalation towards more intense social care) is hospitalisation and deterioration in health. Therefore, there is a strong likelihood that by providing better services which intervene to improve health, quality of life and self

management, which reduce demands on hospitals, that demand for social care services might also be reduced.

Since nobody wants to be hospitalised unnecessarily or to lose their independence, efforts to improve care to the end of reducing demand, also improve the quality of care.

The ability to deliver integrated care services depends on a number of critical competencies. There are four major components:



Accessing savings requires an initial recognition that basic nursing can be carried out somewhere other than in a hospital. Where nursing needs to be continuous, greater integration between health and social care pathways, would bring nursing and community support more directly and actively into the care pathway. This supports the ultimate objective of returning patients to their own home or to the maximum level of independence achievable, at the earliest practicable time. This

would require coordinated inputs from GPs, AHP's, Community Nurses and Social Care Services. .

A successful system must start and end with the needs of the patient, have the GP at the heart of the system. Implicit within this is that social care would need to share responsibility for outcomes.

The success of such systems would require far more integrated health and social care pathways to reduce inappropriate referrals and removal of boundaries between health and social care (as well as between primary and secondary care), all supported by investment in 'rehabilitation' and more proactive information systems.

This model propose solutions based on the management of cohorts of patients by providing neurological case management for the most complex cases, through medicines management for those with more manageable conditions, to maintaining the most marginal cases in patients' own homes. Such solutions should involve the patients themselves in their own care, with the results of continuous monitoring 'case managed' through GPs at the centre of the system.

Examples of other models of service are provided at Appendix 3

11. Neurology MCN Development

This model is suggested for neurological conditions. There is a strong argument for the managed clinical network approach with its frequent requirement for interface between neurology services, rehabilitation medicine services and urology services, and also of the interface with mental health services which again, may usefully be provided by a managed clinical network.

The purpose of the project is to review current service provision for adults and redesign the care pathway to deliver high quality, clinically effective and equitable services for adults with neurological conditions

The first stage of the project (early deliverables) will deliver the following work programme:

1. Identify and agree cohort of diseases/conditions to be included within the scope of the review. (Reference NHS QIS Neurological Standards).
2. Develop project group to support delivery of work programme.
3. Develop communication strategy to inform stakeholders of project brief and undertake local consultation.

4. Map and review current service provision for adults with neurological conditions across NHS, Social Care and Voluntary and Private Organisations.
5. Review requirements for known Western Isles patients whether currently provided for within or outside the Western Isles.
6. Understand current and future predictions, expected numbers and disease progression.
7. Describe treatments and interventions and their clinical effectiveness, and disease progression where known and develop clinical pathways to standardise and optimise treatment and clinical management.
8. Identify and review current location and prevalence for conditions.
9. Identify role of charitable and voluntary organisations.
10. Agree and prioritise work programme for service specification / clinical pathway redesign and development as defined by outcomes of 1-9 above.

12. Pathway Development

There is a significant lack of any formalised pathways for neurological conditions at present, with the majority of patients following a pathway based on GP or individual preference. There is the need for these pathways to be formalised and to look to the development of a good clinical framework with clear inclusion criteria.

Defining clinical pathways will be dependent upon the development and adoption of other proposals related to the service model. However these other proposals set out below have been deployed successfully for other long term conditions management in the Western Isles.

The World Health Organisation (2006) endorses that there is ample evidence that points to neurological disorders being one of the greatest threats to public health. The most promising approach for reducing the burden of neurological disorders is to develop primary care services, which are supported by secondary and tertiary care facilities, physicians and neurologists. This requires a continuing seamless care approach to handle the long term nature of neurological disorders and the ongoing care with an established referral system for management of complex cases and patients requiring access to diagnostic and technological expertise (WHO 2006 Neurological disorders: public health challenges Chapter 4).

People with neurological conditions can experience a wide range of complex physical, sensory, cognitive, psychological, emotional, behavioural and social difficulties with a broad range of needs. An integrated approach to assessment of care and support needs and to the delivery of services is key to improving the quality of life of people with long-term neurological conditions. There is evidence that:

- a. the most effective support for people with long-term neurological conditions is provided when local health and social services teams communicate; have access to up-to-date case notes and patient-held records and work together to provide co-ordinated services Social services tend to provide the greater part of support for people with relatively severe disabilities; (see Integrated Care above)
- b. an integrated system of assessment and care planning can prevent unnecessary reassessment and repetition of basic information. It also helps to ensure that case notes are complete and people are receiving appropriate services assessed against their need.
- c. broad-based and holistic assessment by health and social care services can lead to successful interventions, rehabilitation and care. These can limit the development of predictable secondary consequences of disease, increase the effectiveness of earlier rehabilitation; promote improved quality of life for people, their families and carers and improve opportunities for social participation; and
- d. people with long-term neurological conditions have improved health outcomes and a better quality of life when they are able to access prompt and ongoing advice and support from practitioners with dedicated neurological expertise, such as specialist nurses. This can cover: managing and optimising their medicines; treatment of specific symptoms; help to understand their condition and its current and future management. Specialist advice and treatment can be cost neutral and may reduce admissions and length of stay and improve wellbeing.

Integrated assessment and care planning

People with complex needs resulting from a neurological condition need an holistic approach to the management of their condition involving all professionals and agencies relevant to their care.

An integrated assessment of both health and social care needs will ensure that appropriate care can be planned from the start to enable individuals to remain as independent as possible.

An initial assessment will identify immediate needs and inform the care plan. However an individual's condition and personal circumstances may change over

time and regular reviews undertaken by a multidisciplinary and multi-agency team will anticipate and identify future needs, thereby avoiding sudden crises.

The benefits of this approach for both staff and individuals with neurological conditions include:

- One point of contact making it much easier to access the service
- A co-ordinated approach to care which means that individuals are receiving the appropriate care and support when they need it
- Other problems may be highlighted which have not previously been identified
- Peer support for staff and a greater understanding of each other's roles
- And 'fast-track' referral into services when required

Recommendations

- The role of rehabilitation, physical and emotional support, social re-integration, coping strategies and confidence building need to be built into all pathways
- Greater independence and autonomy is central to all pathways.

13. Funding

The Board is in receipt of a grant of £70,000 from NHS Health Improvement Scotland to NHS Western Isles against a planned business case that was submitted from the Board in June. The Neurological Services Development Group identified the following expenditure against priority spends.

Description	Delivery Date	Amount £
Public Consultation	Aug 2011	3,000
Pump Prime Funding MCN (inc; Attendance at National Conferences & Meetings)	Sept 2011	8,000
Fixed Term LES (6 Months)	Feb 2012 to March 2013	17,000
Advanced Diploma Level Training for Primary & Community Care Staff x 20 @ £1,000	March 2012	20,000
Advanced Neuro Rehab Training for AHPs; OT, Physio, S<, Dietetics	March 2012	6,000
Pump Prime Funding Neurological Obligate Network with partner Board	March / April 2012	4,000
Development of electronic Care Pathways	April 2012	8,000
Telehealth Development in Support of new service design.	April 2012	4,000
Total		70,000

It is likely that some of these identified spends will still be under development by March 2012.

Below is some further information regarding the priority spends.

14. Future Priorities

From the evidence available including information outlined above in this strategy and from stakeholder feedback a list of priority areas were identified. These are:

▪ The provision of current, accurate information for patients and carers	▪ Prompt diagnosis and access to treatment
▪ Person centred care and choice	▪ Integrated service provision
▪ Rehabilitation services	▪ Self Management
▪ Provision of palliative care	▪ Safe and effective use of medicines
▪ Appropriate specialist intervention	▪ Staff education and training
▪ Best use of technology	▪ Neurological Care Pathways

An action plan has been developed to address these priorities, acknowledging and identifying that the lead for delivering on these may be solely or in partnership with another agency or service or be the direct responsibility of Neurological MCN. The action plan is detailed in an appendix to this strategy.

15. Learning and Development

Staff providing services whether specialist to neurological conditions or generic, can be presented with significant challenges when dealing with the needs of people with complex neurological conditions, particularly when the individuals needs arise from behavioural and emotional problems and staff do not have the benefit of appropriate specialist advice and support.

Common issues for staff tend to centre around the following themes:

- a) managing family distress
- b) level of experience and training in dealing with these conditions
- c) assessing capacity and decision making abilities
- d) managing risk, respecting rights, addressing health & safety issues
- e) accessing appropriate services/managing in the context of absence of the required services

Some of these components listed below could be built into an Obligate Network Model which would allow for some of these issues to be addressed:

Clinical Nurse Specialists

In comparison with other island boards – Orkney and Shetland – there seems to be a shift towards the introduction of a general neurology nurse. In Orkney they have 90 patients suffering from MS – covered by an MS nurse who works 18hrs a week. However they have just undertaken scoping exercise to determine way forward for supporting other neurological conditions. Similarly in Shetland – who have 70 patients with MS and though the MS nurse was put in place to cover MS only, she does do general neurology telemedicine clinics.

In the Western Isles there are 89 people with a diagnosis of MS (GP Practice Data). With a predicted 10 to 15% of this population needing the direct intervention of specialist services at any given time would indicate a caseload of between eight and thirteen patients for an MS nurse. At a meeting of the Neurological Services Development Group Dr. Razvi, Consultant Neurologist made the following observation;

“A proportion of neurological patients need to be seen on a regular basis and they could be seen by a Specialist Nurse or a Consultant. Having a Specialist Nurse in place would help and give the patient easier access to the service.. it would be better to have a general neurological nurse rather than an MS Specialist Nurse as due to the low numbers involved. It would be difficult for an

MS Specialist Nurse to maintain their skills. A general neurological nurse would be able to see a broad range of patients and a broader workload would be better.”

The view is that in order to make provision for all people with a neurological condition the most appropriate recommendation is for the appointment of a General Neurological Nurse. There are examples of this approach in England and it is the option that is currently being considered by NHS Shetland.

Specialist nurses add value to patient care, while generating efficiencies for organisations through new and innovative ways of working.

The cost benefits generated by specialist nurses include:

- reduced waiting times
- avoidance of unnecessary hospital admission/ readmission (through reduced complications post-surgery/enhanced symptom control/ improved patient self-management)
- reduced post-operative hospital stay times
- the freeing up of consultant appointments for other patients
- services delivered in the community/at point of need
- reduced patient treatment drop-out rates
- the education of health and social care professionals
- the introduction of innovative service delivery frameworks
- direct specialist advice given to patients and families.

Clinical specialist nurses have undertaken this type of role and have run nurse led services which have been shown to be effective (Appleton & Sweeney 1995, De Broe et al 2001 and Hurwitz et al 2005) However, generally these have been disease specific i.e. Parkinson’s disease, Multiple Sclerosis, Motor Neurone Disease and Epilepsy and in the main they have been either hospital or community based with limited working relationships between both sectors.

In the field of neurology it has been identified that there are similar generic issues seen in all patients with chronic neurology illnesses and disability. These generic issues could be dealt with by a Generic Neurology Nursing Service. Patients with neurological symptoms who do not fall into the more common categories (i.e. MS, Parkinson’s disease and MND) where there are well established nurse led services often do not routinely receive services from a neurology nurse. It is envisaged that such a service could cross the boundaries of primary and secondary care, be working in both settings and additionally provide an educative role for the hospital general medical and surgical teams. Linked with a proposal to establish a Neurology Obligate Network this role would be supported and augmented by more specialised nursing and consultant specialists based in another board but working as a ‘single’ team.

Furthermore, it is anticipated that the Generic Neurology Nursing Service would provide faster access to specialist intervention and support resulting in service improvements for patients, their families and carers. Additionally support would be available for community and hospital teams in the care of neurology patients.

General Practitioners

The following passage is extracted from 'Action on Neurology, Improving Neurology Services – a practical guide'.

“Many doctors would rate their understanding of the brain and nervous system as less good than other organ systems. This is most unfortunate, since although some neurological diseases do require special diagnostic and therapeutic skills, many are common disorders which are straightforward and easy to diagnose and treat.”

When they are in training, doctors often receive limited formal neurological teaching. What training they do receive has often focused on the relatively rare disorders seen in teaching hospital neurology wards rather than the common conditions seen in the community.

It is not surprising that many doctors confidence in the diagnosis and general management of neurological conditions is not great. However, the skills of a well trained general practitioner and their team are crucial in managing long term conditions. Their communication and networking skills, together with a real understanding of the psychological and social impact of these diseases on individuals and their family and carers make them a crucial link in patient care.

During the PFPI consultation meetings it was clear from people's description of their experiences that the level of support received from their General Practitioners was variable. There should be an agreed plan agreed across primary care as to how practice can be improved and standardised.

There would be a need for them to be enabled to empower the rest of the team who care for people with neurological conditions particularly Parkinson's Disease and Multiple Sclerosis. This would take the form of developing education programmes.

Educational Programmes

There is a need for staff to expand and improve access to self care educational programmes for people with neurological conditions. As explored above, the development group have considered that an LES with primary care would enable some of these educational needs to be met.

The LES gives primary care the opportunity to share in the development of an increased local knowledge base relating to the broad spectrum of neurological conditions. The Development Group are aware of the time constraints placed on primary care staff and have developed an LES that allows practices to work in their own time to achieve an enhanced knowledge base which can be shared with colleagues throughout the Health Board area.

Locally Enhanced Service (LES)

INTRODUCTION

In October 2009 Quality Improvement Scotland (now Health Improvement Scotland-HIS) published standards for neurological services within NHS Scotland. Following on from this a local Neurological Services Development group has been established with pump priming funding from SGHD. The development group are keen to see as many local practitioners as possible develop their own skills in the provision of services relating to various neurological conditions for the benefit of this patient population.

There is much local activity relating to neurological conditions at present with the recent decision to employ a local nurse specialising in MS care. Whilst this is to be applauded, there are several other neurological conditions of equal importance and it is hoped that the LES will build a degree of local specialism in these areas also.

Recent LES's for COPD and LD have concentrated on set training programmes to engage clinicians. Whilst these have proved successful clinicians in primary care have commented that the set time commitment for these is becoming too onerous due to competing pressures within the primary care team. With this in mind we have developed an alternative model for this LES that we feel will be more flexible for primary care and allow a 'virtual' community of skilled practitioners with enhanced knowledge.

The format still requires practices to provide a named lead for the practice but gives choice and flexibility around the route to enhanced knowledge as outlined below.

START DATE: 01/02/12

END DATE: 31/03/13

CONDITIONS COVERED BY THE LES

In line with the HIS standards practitioners are encouraged to look at their own patients with the following neurological conditions and to choose one area for further study, funded by the LES:

- Epilepsy
- Headache
- Multiple Sclerosis
- Motor Neurone Disease
- Myasthenia Gravis (not included in the HIS standards)
- Parkinson's

Disease

REQUIREMENTS OF THE LES (See Appendix for detail)

The LES aims to accomplish the following:

1. Completion of practice **registers** with approved codes for the following conditions:
 - a. Epilepsy (already covered by QOF, no additional work anticipated)
 - b. Headache (Migraine, Cluster headache etc)
 - c. MS
 - d. MND
 - e. Myasthenia Gravis
 - f. Parkinson's Disease
2. Identification of a **lead health professional** from each practice.
3. Completion by each lead of an approved **educational commitment** (from the options listed in Appendix A)
4. Provide a **summary of the study completed** by the end of the LES to the neurological services development group with a willingness to share the acquired knowledge with the rest of the cohort.

FUNDING

Funding will be provided as follows:

1. Engagement *payment*
All practices who sign up to the LES by 01/02/12 will receive a payment of £250 plus £100 per thousand registered (5.1k total)
2. Education *allowance.*
All practices will be given an allowance of £1000 to spend on one of the approved courses in Appendix A. This allowance is designed to cover the costs of the education course as well as providing a contribution towards any backfill required in the completion of the training programme. All participants will be asked to sign an agreement to complete their chosen course in line with WIHB policy. (10k total or 14k if a candidate is identified for UCL diploma)

Appendix A: Options for self-directed study

COURSE TITLE	DURATION	PROVIDER	FEE	STUDY LEVEL
Professional Diploma in Epilepsy	45 weeks (3x 15 week modules online)	NeuroEducation (Leeds Metropolitan University)	£800	Level 6 45 CAT points total
Professional Diploma in Parkinsons	45 weeks (3x 15 week modules online)	NeuroEducation (Leeds Metropolitan University)	£800	Level 6 45 CAT points total
Professional Diploma in Multiple Sclerosis	45 weeks (3x 15 week modules online)	NeuroEducation (Leeds Metropolitan University)	£800	Level 6 45 CAT points total
Professional Diploma in Stroke Care	45 weeks (3x 15 week modules online)	NeuroEducation (Leeds Metropolitan University)	£800	Level 6 45 CAT points total
Diploma in Neurology	18 months variable (12-36 months)	UCL	£5000*	120 points (Medical Qualification Required for Entry)

* Only one place can be accommodated for the UCL diploma. Acceptance will be decided by interview. There is a requirement for any candidate wishing to undertake this course to commit to providing regular input to the neurological services development group and any subsequent MCN that may be formed. The course will be fully funded by the LES (i.e. £5000 instead of £1000)

The above list is not exhaustive, if a candidate can identify another appropriate course then funding support will be considered by the neurological services development group.

Further Educational Needs

Psychological Health Needs

Psychological therapies have an important place amongst the range of treatments available as part of a comprehensive service for people with neurological conditions. Psychology and Health Medical conditions, especially those with a neurological component have an enormous impact on the whole of a person's life. Such conditions require alterations to daily life, learning new skills, and realistic planning so as to minimise the effect of the condition on individuals and families. These conditions and their treatments can affect mood, cognitive processing, self-esteem, relationships and quality of life, sometimes leading to stress, anxiety and/or depression. These psychological changes are not only distressing in themselves, but can also affect people's ability and motivation to understand, make informed choices about and to pursue treatment regimes. Good psychological care can help prevent the development of or reduce the impact of psychological distress associated with physical health conditions.

Pain Management

A recent programme for pain management was piloted locally with the involvement of Pain Association Scotland. The programme demonstrated a very effective method of pain management which was cited in the Kerr Report. The following is an extract from the report on the local programme and which this strategy advocates should be deployed in the management of chronic pain associated with neurological conditions and in particular 'Headache' which is one of the national standards target groups.

PAIN ASSOCIATION SCOTLAND: SELF-MANAGEMENT PROGRAMME

During the last months of the Long Term Condition Collaborative (LTCC) the group worked closely with the Pain Association Scotland to develop a local programme for pain management.

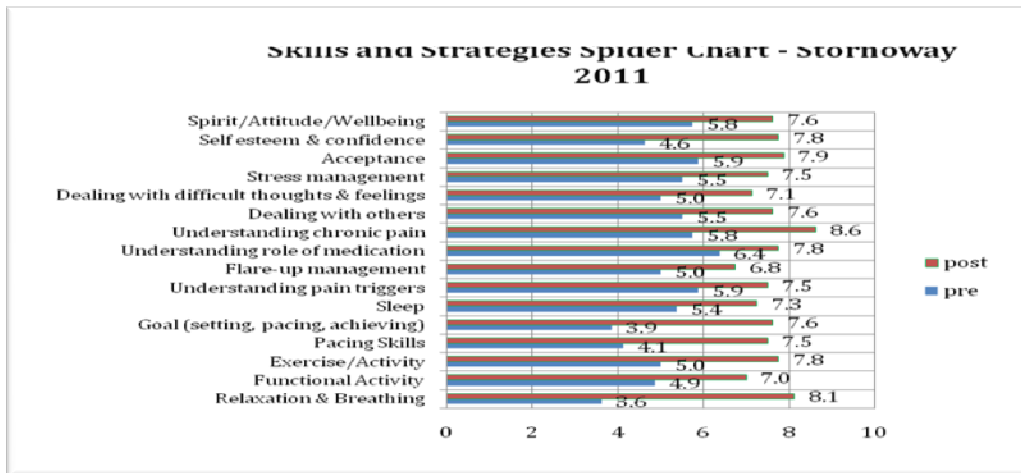
The Pain Association has a well-established and respected programme of self-management of chronic pain. The Kerr report (Scottish Executive 2005) made specific reference to the Pain Association as " a pioneer in Scotland developing professionally led-management programmes". In addition, it highlighted the fact that there is "...research evidence on the effectiveness of the Pain Association's approach especially when implemented in collaboration with health and social care professionals. This is reflected by the partnership they have with many of the NHS Boards in Scotland". The intended audience for these programmes includes all those living with chronic pain from whatever cause. The skills taught in the course aim not to eliminate pain but rather to allow patients to live with their pain without it ruling their lives. Western Isles Health Board already has a well established pain clinic run by one of the local anaesthetists; this programme is designed to compliment that approach in teaching self management skills

With funding from the LTCC the first course has been successfully run from March to May 2011. The course consisted of five sessions one of which is run each Friday at St Martin's church hall. The venue being specifically chosen to 'de-medicalise' the atmosphere around the course. Twelve participants have completed the five sessions and will now continue over the next 3 months to attend monthly 'maintenance and review' sessions.

The feedback from the course has been very positive with several GP's reporting that patients who have attended the course have shown benefits in the understanding and management of their pain. In addition, the Pain Association has collated feedback from the participants, which shows improvement in all areas covered.

The future provision of the self-management programme is now under review. The intention is to allow more professionals to refer patients into the programme and, in addition, to allow patients to self refer. It is hoped to run two full courses each year as well as providing maintenance and review sessions on a regular basis, which, in time, will be facilitated by local staff.

Overleaf is a summary of the patient feedback provided after the first course.



Patient information

Information about their condition, services and how to access them, products and how to gain the best from them and self management skills; is essential for patients to achieve greater levels of awareness and self manage and also to understand and comply with medication regimes in order to gain the most health benefit from them. Information needs to be developed to ensure that the most appropriate patients who will gain the most benefit are aware and offered choices. This will require multidisciplinary clinical input in conjunction with patients to ensure the information is usable and relevant.

Patient support

Prescribing the medicines is only one facet of the management of a condition. Some patients and carers require practical support in terms of provision of a plan that ensures a patient can actually take the medication. This element of care could be addressed through other work streams in community pharmacy contract development and older peoples support. Neurology patients must form part of the patient groups being considered for these services.

16. SELF MANAGEMENT

Most people self manage their long term conditions with help from family, community and voluntary sector and with some support from health and community care services. Community Health and Social Care Partnerships (CHASCPs) and MCNs need to fully involve service users and their carers if they are to promote a culture of change that empowers supported self management and access to community-led health.

It is recognized that people with a long term neurological condition have improved health outcomes and a better quality of life if they can access prompt advice and support from relevant practitioners with neurological expertise, such as specialist nurses. This can cover managing medicines; treatment of specific symptoms and help to understand their condition.

Specialist advice and treatment can be cost neutral and may reduce admissions and length of stay and improve well being.

The majority of individuals with long term neurological conditions will self manage and will follow the long term conditions triangle fluctuating at times of crises and relapse. A number will require complex case management during these times and when moving into the palliative stage ensuring that their care is coordinated, symptoms managed and needs met.

People with long term neurological conditions require a coordinated, seamless approach to delivery of care and support, avoiding fragmentation, confusion and duplication of effort.

Coordination is required to ensure better outcomes for patients with these conditions by having:

- The right skills, knowledge and competencies
- Good networks in place
- Effective partnerships and strong multi-disciplinary working
- Integrated working across agencies
- Case management
- Effective care planning
- Strategies to promote self management

Whilst there are numerous long term neurological conditions a feature they have in common is that the number of professionals and agencies involved is high and services provided are generally specialized and interdependent. Individuals needs are often complex and fluctuate along the disease pathway, but without exception they need tailored and responsive services, whether the condition is newly diagnosed or something they have lived with for a number of years.

Benefits to patients:

- Improved Self Efficacy
- Improved communication with Health Care Professionals
- Better fatigue control
- Lower levels of depression
- Improved symptom control
- Less isolated/ meeting people who understand how they feel
- Better awareness of the community and health resources available.

Benefits to GP Practice and wider NHS agenda:

As a consequence of attending a lay led self management course many patients gain sufficient insight, commitment and energy to:

- Act as advocates for their patient group
- Support the PPI agenda
- Increase volunteer capacity
- Formal care and support, when required, is largely delivered at home through services provided by primary care teams together with social care and housing partners.

The capability and potential of community-based services is maximised through an effective extended primary and community team that in turn collaborates well with more specialist services. This extended community team and its specialist support has a key contribution to the delivery of care in community hospitals and in care homes.

This model requires an integrated approach to skills mapping, workforce development and support for ongoing education and development of the multi-professional team. It also requires defined pathways that support effective care, avoid needless delays, duplication and waste, reduce inappropriate variance in practice and improve access, coordination and continuity of care across teams, agencies and settings.

From reviewing the available literature, several themes have emerged regarding the value of the specialist neurology nurse for patients and their carers. This included the increased knowledge and self management of the condition and potential financial savings.

Increased Knowledge and Self Management

The specialist nurse being effective in increasing patient knowledge and in facilitating self management of care is clearly identified in the literature. Furthermore, to facilitate self management, communication and information, the services must be effective (Appleton & Sweeny 1995, Scambler et al 1996, Risdale et al 1997 Shaw et al 2007, Mills et al 1999, Mills et al 2002, AAPG 2007, De Broe et al 2009).

Risdale et al (1997) found that specialist nurse clinics demonstrated significant improvements in the level of advice recorded that was given to patients. This is also supported by Mills et al (2002), they reported that patients felt able to effectively communicate with the specialist nurses and that the information and advice given to, or by, the specialist nurses was valued highly by patients.

17. ASSISTIVE TECHNOLOGY

Obligate Network Development

While patients access Neurology Services on the mainland, there is no formal mechanism for managing or controlling how and when these services are accessed or provision for monitoring the outcome of mainland services.

In order to ensure continuity between local services and continuity in the patient experience it is proposed that the option of developing an Obligate Network arrangement with tertiary Neurology Services is explored. This model has been applied successfully with other LTC Services and is currently being developed with Mental Health Services.

The benefit of an obligate network is that it provides for highly specialist services to link with local services, provides a quality development framework for services, links peers for clinical supervision and professional development and fast-tracks access to specialist care.

Supported by telehealth the Obligate Network brings the very specialist services into the local service structure, reduces the need for people to travel to the mainland except in exceptional circumstances and reduces to risk of operating single-handed local services.

Telehealth

This model has already been shown to be effective within the Western Isles taking into account the general neurology telemedicine clinic and the tele-neuropsychology clinic both in conjunction with the Southern General Hospital.

Empirical research supports the use of technology for self monitoring and remote sensing within the field of neurological conditions. It empowers the patient, supports the delivery of better care and enables a more proactive service, allowing resources to be better allocated and planned. The introduction of telemedicine in neurology has reduced the need for clinicians and patients to travel long distances to clinics or meetings. This has not only increased capacity but has also meant that people can be seen at relatively short notice for emergencies. This resulted in:

- Reduced average waiting time between referral and first consultation;
- An increase in the number of clinic slots available, by reduction in wasted travel time;
- An emergency service being created
- Better use of resources: by reduction in consultant hours spent travelling and travel expenditure;
- Better communication links between members of the dispersed team (Action on Neurology 2005 Page 28) and between patients and the clinical team.

Telehealth solutions have the capability of resolving many of the current workflow issues, reducing travel, improving access to patient records, shortening response times, avoiding critical incidents, driving up the quality of care and improving the patient's experience. These solutions would enable the service to become proactive and able to respond to patients needs before their condition becomes critical requiring a rapid reactive response. The deployment of technology will provide a significant improvement across every stage of the work flow.

Teleneurology

Teleneurology enables neurology to be practiced when the clinician and patient are not present in the same place and possibly not at the same time. The two main techniques are videoconferencing and email. Specific problems that can be solved by teleneurology include:

- Patients admitted to hospital with acute neurological symptoms can access a consultant neurologist
- Delayed treatment for acute stroke
- Non-optimum management of epilepsy
- Unproductive travel time for neurologists
- Poor access to neurologists for clinicians/patients
- Long waiting times to see a neurologist

Technology Supporting Remote and Rural Neurological Developments

A successful pilot was undertaken in the North of Scotland (NHS Grampian and NHS Shetland) to improve access for patients attending neurology outpatient clinics using innovative IT. At the time of the pilot waiting times for neurology outpatient services were lengthy. The following benefits were identified as part of the project:

- Improved access to consultant neurologists
- Reduced waiting times for outpatient appointments
- Reduced travel times for patients in remote area
- Increased patient satisfaction due to reduced referral times
- Email triage has the potential to significantly reduce the number of patients requiring neurological appointments.

Further benefits for staff included in the pilot included:

- The opportunity to develop telemedicine skills
- Increased contact with the department of neurology for remote clinicians
- Increased clinical and educational opportunities in neurology
- Opportunities to develop further links with specialist staff
- An experienced practitioner assisting during consultation reduced the length of the appointment by approximately five minutes.

The Neurology Service has the usual requirements of a service being provided within a remote and rural demographic, and in addition has the requirements specific to the client group, and the services that both that group and the service depends upon to deliver a quality service.

Tele-neurology is the use of modern communication technology to enable neurology to be practiced when the doctor and patient are not present in the same place and possibly time. This can improve patient care in terms of quality, access and appropriates regardless of geography resulting in timely care delivery.

This section draws on the lessons learnt and gives ideas for implementing the Clinical Standards Framework for Neurological Conditions requirements and suggestions as to how to go about making changes to improve neurology services.

A Person Centered Service

Information, Advice, Education and support

- A patient information strategy will help ensure that patients and carers are receiving accurate and up to date information about their condition and support available
- Information needs to be given to the patient appropriate to where they are along the pathway to enable them to make informed decisions about care and treatment
- Written information should be discussed with the patient or carer to ensure that the content is fully understood
- All professionals in the team should ensure that they are all giving the same information to patients and carers to avoid confusion
- Written information about different services e.g. information about specialist nursing, will help both professionals and service users understand the support that is available
- Joint education workshops for professionals, patients and carers can raise awareness and understanding about different neurological conditions
- There should be opportunities to facilitate self management and it should always be considered whether it is appropriate when developing an individual, integrated plan of care

Integrated assessment and care planning

- A population based register of people with neurological conditions can inform professionals about the caseload and commissioners about potential service requirements
- A single point of contact enables people to have easy access to information and advice which can facilitate a more co-ordinated approach to care
- Effective multi-disciplinary and multi-agency working to ensure that people receive an integrated assessment of needs which, in turn, can inform a comprehensive plan of care

Care Planning and review

- A co-ordinated approach to assessment and care planning means that people are receiving appropriate care and support when they need it and potential problems may be anticipated and addressed
- A model care plan such as a “rehabilitation plan” provides a framework for assessment in order to record individual goals and progress against them as well as other relevant information
- Individual patient management plans e.g. for people with headache, provide a focus for the individual and GP to enable them to manage their condition themselves

Multidisciplinary Working

Timely Referrals

- People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.
- Regular monitoring and review is needed to ensure that people know how to access services through self-referral if their needs change.
- Good care planning across all agencies will ensure a rapid and flexible response to changing needs so these services can be provided promptly i.e. nutritional management, communication aids and assistive technology.

Single Point of Contact

- This describes one of a range of professionals in the neurological or rehabilitation team, or a general neurological support point.
- This person helps to access appropriate information and advice about the condition and the services available.

Review of Cases

- Enough flexibility is needed to allow for both planned and unplanned reviews when an individual’s condition suddenly deteriorates or their circumstances change.
- Regular reviews of medication are needed.

Involvement in their own management including: -

- An individual should be given the information needed to make informed decisions about their care and treatment.
- Where appropriate, this information is given to support them to manage their condition themselves.
- Successful care planning is person-centred and recognises that needs will change over time, including the nature of information required by both the individual and their carer.

- The individual and their carer should be informed about the current stage and be prepared for how rapidly their care and support needs may change.

Appendix 1: Neurological Services Development Programme Action Plan NHS Western Isles 3 Year Strategy

<i>Action Point (Summary)</i>	<i>Month</i>	<i>Measured by</i>	<i>Name Person Responsible</i>	<i>Comments on Progress</i>		<i>R</i>	<i>A</i>	<i>G</i>	*
Health Intelligence/Benchmarking		<p>Health Needs Assessment for neurological conditions across the Western Isles</p> <p>Agree definitions of which conditions are to be considered for the development of Neurological Services</p> <p>Unified systems for routine data collection to be developed on incidence and prevalence of long term neurological conditions</p>		<p>Numbers for each of the conditions (excluding headache) have been determined via Practice Managers.</p>					
Staff Education and Development		<p>Benchmarking needs to be undertaken across all AHP groups against team structures and resources to allow for gap analysis</p> <p>Exploration through the Obligate Network of opportunities for staff shadowing, peer support etc.</p> <p>Need to develop opportunities for specialist skills and knowledge development around rehabilitation programmes.</p>		<p>Staff Education has previously been delivered for a wide range of neurological conditions including Epilepsy, Multiple Sclerosis, Parkinsons Disease and Motor Neurone Disease.</p> <p>Occupational Therapy team to visit Centres of Excellence to benchmark service provision and team structures.</p> <p>Various education programmes have been discussed through the proposed LES with</p>					

				primary care for staff education and will need to be further explored as to suitability.					
Patient Education/Involvement		<p>Patients and carers must be provided with current, clear, and concise information about their condition, services and how to access them in a timely manner.</p> <p>Self management skills must be central to the development of integrated care planning.</p> <p>Routine collection of patient feedback to improve neurological services on an ongoing basis.</p>		<p>A number of focus groups took place in across the Western Isles as part of a wider consultation process.</p> <p>In tandem with this process two lay representatives have been recruited to the Neurological Services Development Group.</p>					
Neurological Managed Clinical Network Development		A managed clinical network to be developed in line with similar developments for other long term conditions.		The Neurological Development Group which has already been formed will provide the basis for this development.					

Development of Care Pathways for Neurological Conditions		<p>A need for clear, formalised care pathways for those with neurological conditions which includes clear inclusion criteria.</p> <p>Each pathway has an identified clinical lead and a management lead, and agreed specialty staff.</p> <p>Palliative Care is included in any pathway development.</p> <p>Anticipatory care models are encouraged where clinically appropriate.</p>							
Obligate Network Development				<p>Developing an obligate network for neurology would help with any issues around clinical governance, education and peer review and staff (AHP, Nursing) exchanges.</p> <p>Established link with specialist colleagues in NHS Greater Glasgow & Clyde who will provide expert opinion to the project</p>					
Telehealth		<p>The opportunities for the use of telehealth are to be further explored alongside the Obligate Network Development.</p>		<p>A tele-neuropsychology service has also been launched in association with Dr Sue Copstick, Neuropsychologist, Southern General Hospital, Glasgow. This has proved successful and has improved access</p>					

				to psychological therapies for individuals with neurological conditions.					
Review local services against HIS National Standards for Neurology									
Integration of services with Social Care Services for care planning and co-ordinated service delivery									
Development of Local Neurology MCN									

Progress Report Key

Not Started 

 Red  (at risk)

 Amber  (some slippage)

 Green  (on target)

 Completed 

Planning Lead

Phil Tilley, Deputy Head Planning & Development
Email phil.tilley@nhs.net
Tel. no. 01851 708307

Planning Officer

Elaine MacKay, Planning & Development Officer
Email elainemackay@nhs.net
Tel. no. 01851 708035

Appendix 2. Patient and Public Involvement Report



Step 1: ANALYSE Report

390 - Neurological Services Improvement Programme

Start date: 20 Dec 2010

Print date: 19 Oct 2011 12:15 p.m.

Review date: 20 Dec 2011

Lead contact details: Phil Tilley
NHS Western Isles
37 South Beach Street
Stornoway
HS1

Background

NHS Western Isles have been reviewing Neurological services in order to meet the Clinical Standards for Neurological Health Services. The engagement activity outlined in VOICE is specific to Standard 3 - Patient encounters in neurological health services.

To ensure that all neurological patients receive equitable quality of care as recommended.

Significant contribution to developing and implementing a three year plan will involve lay representatives and voluntary sector agencies and stakeholders from within communities of interest.

The remote and rural challenges are complex and communication is essential to ensure the sustainability and success of future service delivery.

Uploaded documents which relate to this engagement:

This engagement has no documents.

Previous engagements which have links to this engagement:

This engagement has no linked engagements.

STEP 1: ANALYSE

Our purpose for engaging is...

NHS western Isles is moving to an improved model of service delivery for Neurological patients. This intends to provide a consistent approach to care and deal with the challenges of delivering a service across a remote and rural area.

Fundamental is the need to ensure equity for all neurological patients in terms of access to specialist care, treatment and support

Patients views are central in reviewing current service provision-and considering future models of care

The challenges faced by a remote and rural Board are complex and communication and the use of technology will assist in the delivery of appropriate care model

We are seeking to

Engage

To take shared decisions - This means the community will influence options and choices of action.

To take shared action - This means the community will share in any action taken.

To support community led action - This means the community will lead the action.

What we know:

Some patients are accessing hospital appointments on the mainland only,

Some are accessing Appointments in the Western Isles using telehealth

Some patients only access support from their GP

Access to AHP services is an area for improvement between mainland Boards and NHS Western Isles

What do we need to know:

Feedback from patients on their experience, and based on that experience what they would regard as best proactive in terms of information, help and support, care and treatment

Patient and carer opinions on the future use of technology within a package of care

Community stakeholders

Carers

Patients

People with disabilities

Agency stakeholders

Community Health Partnership

Hospital Services

Who needs encouragement?

Patients whose illness is acute and restricts ability to travel and engage

Are there any conflicts of interest that might emerge?

Central vs local, role of specialist vs role of expert-generalists

- Paternalistic vs self management

- Location of focus groups

What is the engagement locality?

Stornoway, Uist, Barra, Uig and Borve

Who are we engaging with, are they a thematic group?

Neurological Patients and their carers

What is the overall purpose of the engagement?
Plan or rationalise services
Status of engagement
Active

STEP 2: PLAN

What outcomes are stakeholders looking for, and what will success look like?

The engagement should achieve these outcomes	Outcome indicators and sources of evidence
1 A wide variety of Patients from different geographies and backgrounds have had their say in influencing and shaping three year neurological services plan	Views of patients from a variety of areas and backgrounds engaged 2. Feedback from patients following diagnosis, and throughout their recovery and rehabilitation (information gained using participant questionnaire). 3. Focus groups held across the Western Isles to gain more in depth information from patients and carers 4. Feedback on the engagement approach demonstrating both its effectiveness and level of impact
2 Stakeholders feel that they have enough information and are receiving sufficient support to be a part of the engagement process.	support needed and given will be assessed through the results of the consultation feedback questionnaires which will be gathered through face to face, telephone, emailed or postal communication. 2. Auditable trail of how patients felt about the process e.g. Focus Group report, Neurological Steering Group.
3 A model of engagement and influence is developed which is flexible	Evaluation/ summary report template reviewing the effectiveness/success of the approach.
4 Acts on patient, (referrer and staff) feedback it collects	Input to Neurological Steering Group on Patient Participation Representation of data gathered to MCN including patient /carer representatives involvement in

The engagement should achieve these outcomes

Outcome indicators and sources of evidence

improvement network

- 5** A new model of participation and influence is developed with Patients to the fore supported by health care professionals.

Patients, carers identify themselves for involvement as lay representatives on Neurological Planning Structures

What barriers might affect anyone who should be involved?

- Physical barriers, by nature of participants being neurological patients
- possibly undergoing longer-term treatment.
- Generic emotional barrier of being in a group situation.
- Generic emotional barriers - possibly still actively receiving care, and reluctant to express views
- Physical barriers by nature of demographics of a remote and rural community

What resources might be needed to overcome these barriers?

- Physical barriers, by nature of participants being neurological patients
- possibly undergoing longer-term treatment.
- Generic emotional barrier of being in a group situation.
- Generic emotional barriers - possibly still actively receiving care, and reluctant to express views
- Physical barriers, by nature of demographics of a remote and rural community

Is there a need for independent advocacy, community development support, or specialist advice and, if so, where would it come from?

Yes - NHS colleagues available to clarify on general points/practical issues of policy and clinical standards.

What resources are available to us?

- Consider alternative ways to engage - e.g. use of questionnaire, use of semi structured telephone interviews (Rather than support to attend a group).
- Cover out of pocket expenses using our existing expenses policy

What methods will we use and what actions will be taken to meet our outcomes?

Key actions (including the lead responsibility) are:

Method and related outcome	What, who and when
1 Advertise for Lay Representatives for Neurological Group	PFPI on behalf of Neurological Services steering Group DEc 10 - March 2011
2 Lay representatives recruited	PFPI and Public Health Planning April 2011-June 2011
3 Long Term Condition Questionnaire Core Questions and localised	PFPI and Public Health Analysts and Public Health Planning May -

Questions developed	June 2011
4 Consider Patients VC with mainland Board to share experience	To be identified
5 Following facebook pilot Investigate use of public helath facebook page for neurology forum	To be identified
6 Gather information from Teleneurology/neuro psychiatry	To be identified
7 Input to Community of Practice on Patient Participation	To be identified
8 Representation of data gathered to MCN including patient /carer representatives involvement in improvement network	PFPI and Public Health Analysts and Public Health Planning invoved in questionnaires and focus groups July- september 2011

Progress 1 of 8

Method and related outcome

Advertise for Lay Representatives for Neurological Group

What, who and when

Lay Representative recruitment advertisements ran from December 2010 to March 2011

What actions have we taken so far?

Poster advertisement in GP surgeries, hospitals and outpatients. Advertisement ran from December to end March

What issues have arisen?

More interested individuals than places on Neurological Group

What remedial actions are we taking?

Refer to Neurological Voices programme

Progress 2 of 8

Method and related outcome

Lay representatives recruited

What, who and when

Recruitment process followed, references received and confidentiality agreement developed and signed

What actions have we taken so far?

Recruitment planned for June

What issues have arisen?

1. Interview process went smoothly, but finalisation of recruitment practices was delayed due to staff illness.

2. Finalisation of recruitment was delayed as confidentiality agreement was under development and included input from the information commissioner

What remedial actions are we taking?

Prospective lay representatives were informed of the delay in recruitment and kept up to date on progress

Progress 3 of 8

Method and related outcome

Long Term Condition Questionnaire Core Questions and localised

What, who and when

Questionnaire developed in conjunction with Public Health Intelligence analysts and Public Health Planning division

Questions developed

What actions have we taken so far?

Questionnaire developed in conjunction with Public health Intelligence analysts and Public Health Planning division

Questionnaire sent out to GP surgeries to identify Neurological Patients and issue questionnaire

Questionnaire available on survey monkey only two returned electronically thus meaning analysis of questionnaire was not available electronically

What issues have arisen?

Not enough postage on envelopes and GP surgeries raised that they had to cover additional costs

Circulation of the questionnaire clashed with holidays within some GP surgeries so questionnaires were not issued

What remedial actions are we taking?

Progress 4 of 8

Method and related outcome

Consider Patients VC with mainland Board to share experience

What, who and when

Will be considered as ongoing workplan of Neurological MCN once developed

What actions have we taken so far?

Email Gareth Davies re his involvement and consider whether Semis Structured interviews, Emotional Touchpoints or Digital Stories should be used

Questionnaires were agreed as main source of information supported by focus groups

What issues have arisen?

Due to remote communities and nature of condition some people who wished to attend focus groups were unable to participate in this forum

What remedial actions are we taking?

Individual telephone semi structured interviews for people who could not travel to a focus group

Progress 5 of 8

Method and related outcome

Following facebook pilot
Investigate use of public health facebook page for neurology forum

What, who and when

Will be considered as ongoing workplan of Neurological MCN once developed

What actions have we taken so far?

Action Plan with Neurological Planning Group, following development of three year plan an MCN will be established and the action plan will be shared for information-and consideration

What issues have arisen?

None

What remedial actions are we taking?

None required

Progress 6 of 8

Method and related outcome

Gather information from
Teleneurology/neuro psychiatry

What, who and when

Will be considered as ongoing workplan of Neurological MCN once developed

What actions have we taken so far?

Action Plan with Neurological Planning Group, following development of three year plan an MCN will be established and the action plan will be shared for information-and consideration

What issues have arisen?

None

What remedial actions are we taking?

None required

Progress 7 of 8

Method and related outcome

Input to Community of Practice on Patient Participation

What, who and when

Awaiting national information-and will be considered as ongoing workplan of Neurological MCN once developed

What actions have we taken so far?

Action Plan with Neurological Planning Group, following development of three year plan an MCN will be established and the action plan will be shared for information-and consideration

What issues have arisen?

None

What remedial actions are we taking?

None required

Progress 8 of 8

Method and related outcome

Representation of data gathered to MCN including patient /carer representatives involvement in improvement network

What, who and when

Feedback on Questionnaire and report on Focus groups including evaluation of the process forwarded to Neurological Services Steering Group to inform the three year plan

What actions have we taken so far?

Feedback on Questionnaire and report on Focus groups including evaluation of the process forwarded to Neurological Services Steering Group to inform the three year plan

What issues have arisen?

Timescales and competing priorities with new consultations being planned in tandem

What remedial actions are we taking?

Information shared with governance structures and priorities identified

	Type of Service Model	Organisation	Location of Service	Name of Service	Who is the service for	Brief Description of Service
1	Multidisciplinary Team	Portsmouth	Community	Community Neurology Service	Adults with a specified long term neurological condition	Community Matron for Neurology, Occupational Therapists, Physiotherapists, Podiatrist, Psychologist, Speech and Language Therapist, Parkinsons Disease Nurse Specialist. Support Individual through early Intervention Proactive Review self management.
2	Multidisciplinary Team	Nottingham City PCT	Community sites	Community Neurology Service	Anyone with a diagnosed neurological condition	Community based Multi disciplinary team Specialist Nurses MS, Parkinsons and Epilepsy supported by general neurology nurse specialists, Occupational Therapists, Physiotherapists Speech and Language therapy and psychologist. Nurses attend consultant clinics in acute trust as well.
3	Specialist Nurses	Royal Berkshire NHS Foundation Trust Berkshire West PCT	Reading West Berkshire Community Hospital Looking at Townlands hospital in Henley	Long Term Conditions Team (Clinical Specialists Neurology including Multiple Sclerosis, Parkinsons Disease, Rarer Neurological Conditions	Parkinson's disease, Multiple Sclerosis, MND, Myasthenia Gravis, Huntingdon's, Ataxia, Post polio syndrome, Parkinson's	Assessment. Nurse Led Clinics in Community settings. Domiciliary assessment of patients who cannot get to clinic. Expert Patient Programme. Specialist advice to health and social care colleagues. Each department has telephone support line for patients.
4	Specialist Nurses	Milton Keynes PCT	Bletchley Therapy Unit Bletchley	Neurological Clinical Specialist Team	Acquired, non-progressive brain injury, excluding strokes. New episodes of stroke, (inclusive of subarachnoid haemorrhage) and Transient Ischaemic Attack within the first year of onset. Parkinsons Disease and MS, Motor Neurone Disease. (Not epilepsy -nurse specialist based in acute trust)	Open referral system including self referral by patient. Must have confirmed diagnosis. Oversee symptom management. Offer guidance and support signposting to other services
5	Specialist Nurses	Southwark PCT	13 community clinics across the 3 PCT's		Adult with a confirmed diagnosis of MS, a clinically isolated syndrome and Devics Disease	4 Clinical Nurse Specialists managing case load of approx 900 patients. Covers Southwark PCT and has contracts to cover Lewtsham and Lambeth PCT's as well. Honorary contracts with acute trust to be able to see patients. Run Information days for people newly diagnosed. Newly diagnosed contacted by specialist nurse within 5 days of receipt of referral and appointment within 2 weeks of first contact. review appointment within 3 months of first appointment. All other referrals contacted within 2 weeks.
6	Physiotherapy	Corwall and Isles of Scilly PCT	3 venues in Corwall	RENEW - Really Effective Neurological Exercise Workouts	Anyone with a neurological condition	Free 20 week fitness programme. Led by qualified fitness trainers local fitness centre. Involves gentle exercise, healthy lifestyle advice and relaxation techniques. Posture and stretching exercises. 15 places per course
7	Physiotherapy	Sheffield	Based Hallamshire Hospital	Neurology Outreach Therapy Service	Neuromedical patients e.g. MS, MND, PD, neuropathies, muscular dystrophies etc. (No head injury, stroke, cerebral palsy, neurosurgery). Must be over 16 and have been seen by a consultant neurologist in past two years.	2 Physiotherapist and 1 Occupational Therapists do home visits and mainly work in community. During assessment briefly discuss mobility, equipment, pain, speech & swallow, bladder & bowels, memory & cognition, sensation etc, support for patient & relatives around issues of diagnosis, falls, functional ability, vision & hearing. Refer on to separate specialist nurse (MS AND PD etc) team and other professional as required. Assess posture, seating & wheelchairs & give appropriate advice/ refer on. Patients can self refer if known to team. Strong links with MND group locally re: funding for equipment

<u>Document</u>	Sent to	Date
<u>Management</u>	<i>Version</i>	