Action On Neurology
Improving Neurology Services – a practical guide
March 2005
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#### Description
The *Action On Neurology* Programme through engagement with clinical staff and their professional organisations, have followed a step by step process involving scoping the issues, identifying potential good practice, testing and developing good practice through pilot sites. The results are published in this guidance with evidence of local/national benefits achieved by implementation.

#### Cross Ref
10 High Impact Changes for service improvement and delivery: A guide for NHS leaders; NHS Modernisation Agency and many other related MA guides/toolkits which are referenced on the website: [www.modern.nhs.uk](http://www.modern.nhs.uk)

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#### For Recipient’s Use
FOREWORD

The NHS is currently undergoing its largest period of sustained investment and modernisation since its creation. The benefits of this period of change are being felt by patients across the NHS, including those with long term disabling conditions such as the neurological diseases. Investment in new staff and facilities is not enough, however, and to really influence the lives of people for the better, new ways of working are needed. In particular, teamwork and collaboration are vital and the skills of many different professionals need to be brought together to deliver a whole range of services.

The National Service Frameworks have set out the standard of services that should be provided to people with a number of conditions, and the NHS and social services have risen to the challenges that they have set. The most recent is the National Service Framework (NSF) for Long Term Conditions, and it sets many challenges for those delivering services to people with neurological disorders. To meet these challenges will require team working and a new look at how the services are organised.

This Practical Guide to Improving Neurology Services, developed by the Action On Neurology programme team, provides many examples of how small changes to the organisation of services can make them more effective and more responsive to the needs of people with long term neurological conditions. It shows that working in partnership and ensuring that the right person with the right skills is available to help an individual at the right time in their illness provides tangible benefits for the person with a long term condition. The projects from across the entire country have involved hospital doctors, GPs, nurses, allied health professionals, patients, carers and representatives of the voluntary sector working together.

I believe that the Practical Guide to Improving Neurology Services will be a useful tool for implementing the NSF which can be used in conjunction with the Long Term Conditions NSF Good Practice Guide. I was therefore delighted to be asked to endorse this document, and commend it warmly to you.

Dr Stephen Ladyman, MP
Parliamentary Under Secretary of State, Department of Health
Neurological problems are not uncommon. Approximately one in seven consultations in primary care are for a nervous system symptom of some kind and one in five emergency admissions to hospital are due to a neurological problem. Referrals to neurology outpatients are also increasing and, with long waits to see a specialist or to have investigations, people may not be diagnosed until several months after their first visit to the general practitioner. Once a diagnosis has been 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.

All this highlights the need to look more closely at how services are delivered to see where improvements could be made. Action On Neurology was set up in 2003 to do just that – a national steering group provided advice and guidance to ensure that the programme was in line with national priorities, and eight pilot sites were selected to find and test different ways of working that might improve the quality of and access to neurology services. This guide draws on the experience of the programme.

The guide is divided into four parts. The first part highlights the problems faced by people with neurological conditions, many of which have the potential for causing great disability. The care pathway for these conditions includes a range of services from different professionals and organisations spanning health, social care and other sectors. Part One discusses some of the barriers to providing optimal care and issues impacting on the effective delivery of neurology services. These range from difficulties accessing a specialist neurological opinion to communication between professionals and agencies and the way neurology services are currently organised.

Part Two focuses on lessons learnt by the Action On Neurology pilot sites and links the outcomes of the projects to Quality Requirements set out in the National Service Framework for Long Term Conditions. Issues identified through Action On Neurology are highlighted under the relevant Quality Requirement and examples of changes made by the pilot sites show how they have been addressed. Reference is also made to the 10 High Impact Changes developed by the NHS Modernisation Agency, which underpin service redesign.

Assessment of services against national standards and guidance and the development of a local strategy for neurology services are discussed in Part Three. Involvement of key stakeholders from statutory and voluntary organisations as well as patients and carers is identified as key to the success of any service change. Well established tools and techniques to support redesign including process mapping, assessing capacity against demand and using data to measure the impact of change are also described.

The guide ends with a list of conclusions in Part Four, drawn from the work of the pilot sites giving ideas that could be adapted by health communities to meet local needs when looking at ways to improve their own neurology services.

The projects undertaken by the pilot sites, including contact details are summarised in Appendix A with a list of members of the national steering group and other information the reader might find useful in Appendices B and C.

The CD accompanying this guide contains an electronic copy of the guide, additional information about the Action On Neurology pilot sites and other useful documents for reference.
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INTRODUCTION

This guide to improving neurology services has been written for clinicians, managers and commissioners to help them improve services for people with neurological conditions and to support the implementation of the National Service Framework for Long Term Conditions. It is based on the findings from the Action On Neurology programme, which was designed to find and test different ways of working that might both improve the quality of neurology services and access to them.

The national steering group, with representation from patient and professional groups and other stakeholders with an interest in neurology, provided advice and guidance to the programme to ensure that services were designed in line with national priorities. Their first task was to select eight health communities to become pilot sites for the Action On Neurology programme from a large number of applications. This was a difficult task as the quality was so high, but at the same time it was encouraging to see a real commitment from so many health communities to improving services where there have often been long waits to see a specialist and for investigations, and a lack of integrated care to support people with complex health and social care needs.

The selected pilot sites covered different types of services and a range of conditions and despite having less than twelve months to complete their projects, produced some encouraging results. This guide highlights examples of good practice developed by the project teams, some of which are still in the development phase at the time of writing this report. There are however, many other examples of good practice across the country and these can be found in the NSF for Long Term Conditions Good Practice Guide on the Department of Health website (www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LongTermConditions/fs/en).

There is no single model for neurology services since they all serve different communities and different patients, so what works in one organisation or health community might not work in another. What are important are the principles behind change and seeing how a change in one organisation may be translated into another. The ultimate aim of the Action On Programme is to share these principles and the learning from the pilot sites with the wider health and social care communities and this guide is the start of that process.

There are four main parts to the guide. The first part focuses on the problems faced by people with neurological conditions and how services are currently organised. The second highlights issues identified by the Action On Neurology pilot sites and some lessons they learnt whilst undertaking their projects. The third gives practical suggestions about redesigning services including how to identify problems and bottlenecks, and refers to tools and techniques for improvement, while the fourth summarises the conclusions from the Action On Neurology programme.

Finally, acknowledgement goes to everyone who has participated in the Action On Neurology programme, for their enthusiasm for trying out new ideas, for sharing their learning about what worked and what didn’t, and above all for their commitment to improving services for their patients.
PART 1: NEUROLOGY SERVICES IN THE UK – WHAT IS NEUROLOGY AND WHY IS IT A PROBLEM?

Neurological problems are common

About one in six to one in eight consultations in primary care relates to a nervous system symptom of some kind, and about one in five emergency admissions to hospital are due to a neurological problem. Many of these cases are dealt with entirely in primary care. However, approximately 330,000 new referrals were made to neurology outpatient clinics in 2003/4 compared with 195,700 in 1999/2000. Despite this increase in activity there is a widespread feeling that the services provided to people with neurological diseases are not achieving all they could, and that we could, and should, do better. In addition to access to specialist neurological opinion many of the patients referred will need special investigations. The waiting times for these are often even longer than the initial wait for outpatient appointments so that the time to a diagnosis and starting treatment is still often unacceptably long. With the targets set in the NHS Improvement Plan, including a maximum of 18 weeks wait from referral to hospital treatment including all diagnostic tests, waits for diagnostics have to improve and this will itself prove challenging to the NHS.
Figure 1 shows the process by which a patient with suspected multiple sclerosis may be diagnosed. There are various steps in the process that lead to a definite diagnosis. The circles give some of the reasons for delay or variation in practice. The waiting times explain why it may take over two years to confirm a definite diagnosis. It is less the complexity but the bottlenecks in the system that slow things down.

There are a wide variety of neurological diseases. These include common disorders such as migraine, epilepsy and strokes, less common ones such as Parkinson’s disease and multiple sclerosis and relative rarities such as myasthenia gravis. Many neurological diseases affect the young and economically active including epilepsy, multiple sclerosis, traumatic brain injury and many of the inherited disorders. The neurodegenerative conditions, such as Parkinson’s disease, Alzheimer’s disease and motor neurone disease largely affect older people. With an aging population their incidence is increasing. On the bright side our ability to treat them is improving.
The neurological conditions cause a great deal of disability and require a range of skills to care for them well.

There are many forms of disability due to neurological diseases

“What I would really like is my freedom back. I wish I could drive a car and go wherever I want, whenever I want. I wish you could make it go away without me having to take pills everyday. And I wish you could make people understand that if I have a fit I do NOT wanted to be carted off to casualty yet again. Disability is not just about being not able to walk or throw properly.”

A patient with epilepsy

What these conditions have in common is the potential for causing great disability. This may be intermittent as in migraine or epilepsy (although the interference with day to day life goes on between attacks), permanent as in stroke or head injury or progressive as in multiple sclerosis and other neurodegenerative disorders. Many of these conditions are truly “Long Term Conditions” which a patient will live with for many years. For optimal care, patients may need the help of a wide range of professionals (figure 2) who may be based in a variety of organisations spanning health, social care and other sectors. Each professional will bring their own skills to support the person. However, barriers between the different professionals, whether real or perceived, often seem to impede the delivery of person centred care.

Figure 2

Professionals likely to be involved in care of a person with multiple sclerosis

<table>
<thead>
<tr>
<th>General Practitioner</th>
<th>Benefits Agency</th>
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<tr>
<td>Neurologist</td>
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<td>Occupational Therapists</td>
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<tr>
<td>Speech and Language Therapists</td>
<td>Outpatient administrative staff</td>
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<tr>
<td>Dieticians</td>
<td>Neurologist’s secretary</td>
</tr>
<tr>
<td>General practice receptionists &amp; admin staff</td>
<td>Social Services</td>
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Why is neurology thought to be so “difficult” a subject?

Many doctors would rate their understanding of the brain and nervous system as less good than other organ systems. This comes from a combination of the genuine complexity of the brain and a tendency for teaching to focus on the detail of brain function rather than basic principles. The popular perception that the brain is amazingly complex is summed up by phrases such as “You would need to be a brain surgeon to do that”! The result is that neurology, for many doctors, may be consigned to the “too difficult” box before they have even started. This is most unfortunate, since although some neurological diseases do require special diagnostic and therapeutic skills, many are common disorders which are straightforward to diagnose and treat.
There are very few population based registers for neurological disease. Nonetheless, based on how common the diseases are, an average GP with a list of 1,500 patients should have about 10 patients with active epilepsy, 20 patients who have had a stroke or transient ischaemic attack and as many as 100-150 migraine sufferers. However, they are likely to have only one or two patients each with either multiple sclerosis or Parkinson’s disease and they may see only a single patient with myasthenia or motor neurone disease during their career. When they are in training, doctors often receive limited formal neurological teaching. That which they do get 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 lynchpin in patient care.

Patients get little respite from their conditions

“Although I don’t think of myself as a “Parky patient” and we lead an active life, it’s always there. I don’t always sleep properly and sometimes have to wake my wife Jill to help me turn over. When I wake up I take my first pill but it takes about half an hour to kick in so I stay in bed and have a cup of tea. If it’s a good day then I am OK dressing but otherwise Jill has to help. Once I’m up I have my breakfast and may then go to work in the garden. It’s good exercise but I need to be careful not to stretch too far into the flower beds in case I topple over. It doesn’t happen often but if I do it’s not always easy to get up. Sometimes as the medication wears off I get some stiffness and painful cramps but on the whole the pills work OK. I should be thankful it hasn’t got worse quicker, I suppose.”

67 year old patient with Parkinson’s Disease

Not all of the neurological diseases are necessarily straightforward to diagnose. It is well known, for example, that the diagnosis of epilepsy may be very challenging and errors in diagnosis may lead to inappropriate drug treatment with potentially serious outcomes. Clinical experience and skills are crucial, and tests such as scans and EEGs cannot substitute for this as they can in some other areas of medicine. In addition, while some neurological conditions are readily treatable with drugs, the speed with which advances in drug treatments occurs means that non specialists may not feel confident in their use. It is in these areas of diagnosis and medicine in particular that the skills of the neurological specialist are needed. Most often this will be a consultant neurologist but there are examples where others such as general practitioners with a special interest (GPwSIs) and nurse specialists have successfully taken on this role in one area of neurology such as epilepsy or headache.

Neurologists are still rare

There has been a significant increase in the numbers of consultant neurologists so that there are now approximately 352 whole time equivalent consultant neurologists in the UK. Nevertheless this is still only about 1 neurologist per 170,000 people, and compares extremely unfavourably to other European countries. Access to a neurological opinion remains difficult. There are long waiting times for outpatient appointments and only a minority of acute hospitals are able to offer a specialist neurological opinion to a patient admitted acutely within 24 hours of their admission on each weekday. Most acutely ill neurological patients are looked after by teams under the supervision of general physicians, or other non-specialists. Very few neurologists have access to beds or support staff in the District hospitals. These facilities are usually provided at a regional centre, which may be many miles from where the patient lives. This means the consultant is not always available onsite at the District hospital to provide help and advice. Not infrequently, patients and their families travel long distances to receive their care.
Services may not always be delivered as close to home as they could be

“One patient gets on the same train as me so we can then meet 30 miles away in my clinic! ”

Consultant Neurologist

As well as accurate initial diagnosis, patients also require ready access to services throughout the course of what may be lifelong illness. All too often the only way to access the correct services is through a further referral to the hospital clinic, or else to remain under regular follow-up. This itself places extra burdens on the hospital follow up clinics, and while national targets for first appointments are met in most parts of England it is often more than six months before patients can be seen for follow up. The main need at follow up may be for input from therapists or specialist nurses, with the neurologist mainly acting to orchestrate different aspects of care that they do not actually provide themselves. In a well functioning team with smooth communication and peer to peer referral, and multiple points of access (i.e. not always through the neurologist) patients may more readily get access to the services they need. Moreover, clinician time may be freed up for other tasks for which they are specifically trained.

Difficulty accessing specialist services can have devastating consequences

In the report of the National Sentinel Clinical Audit of Epilepsy-Related Death, it was noted that although 93% of the adults who died had not been recorded as free of seizures for at least a year before they died, at least 37% of them had not been seen in secondary care in the year before they died. The reasons for this were often not clear, but the implication is that warning signs of worsening seizure control could have been spotted by someone with specialist skills.

Services are organised in a way that may not always serve patients best

The planning of services can also prove problematic. The wide range of different organisations involved, each with different priorities and accountabilities, makes it a challenging task at best. When these span all levels from local authorities to supraregional neuroscience centres, the complexity is obvious (see Figure 3 for an example). Rather too often, decisions that should be made at local level are made at a regional level and those which require central planning are not made at all. Changes in services are often made with little evidence of cooperation between different organisations. Often providing services closer to the patient’s home is described as “repatriation” and undertaken for financial reasons rather than to spread high quality care across a network.
The current hub and spoke model of services has been successful in delivering reasonable services with small numbers of consultants and other specialist staff. Although the neurologists work as part of a clinician network the rest of the service shows little coordinated planning. However, as numbers of staff have increased, so has the need to evolve into more of a network of care, with more services being delivered closer to the patient's home and with less being undertaken at the regional centres. Such a model has worked well for cancer and cardiac services, but key to their success has been a levelling up of standards. Some of the models of good practice outlined in this guide would fit easily into such a network model of care, helping to develop high quality care in a setting convenient for the patient.

Overall the numbers of all kinds of neurological specialists, be they clinicians, nurses or therapists, remain too low. However, neurological services are also often not organised in a way that may be responsive to patients needs or make best use of resources. While increased resources are important, it is clear that these resources need to be used differently to the way they are at present. There is a pressing need to look at different ways of working to use the available skills most efficiently.

This Practical Guide to Improving Neurology Services contains examples of the ways in which teams at pilot sites have examined how they function and tried to change for the better. The National Service Framework for Long Term Conditions (NSF) (www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LongTermConditions/fs/en) sets out Quality Requirements and markers of good practice for health and social services for people living with long-term neurological conditions and their carers. The lessons learnt from the Action On Neurology pilot sites will inform planning to implement the NSF.
PART 2: LESSONS LEARNT FROM THE ACTION ON NEUROLOGY PROGRAMME

Introduction

Eight pilot sites, covering a range of different services were selected at the end of 2003 to participate in the Action On Neurology programme. Their remit was to redesign the patient pathway by testing different ways of working that might both improve the quality of neurology services and access to them which could then be shared more widely. A summary of the individual pilot sites can be found in Appendix A.

The National Service Framework for Long Term Conditions (NSF) describes a set of core principles in the form of Evidence Based Quality Requirements (QRs), with evidence based markers of good practice which put the person at the centre of care. The Quality Requirements are designed to address the needs of people living with long term neurological conditions and aim to improve their quality of life so that they can live as independently as possible from diagnosis to when they may require end of life care.

Whilst implementation of the NSF for Long Term Conditions will take place over a ten year period, experience from the Action On Neurology Programme shows that small changes can have a significant and immediate impact on the experience for the patient and the way services are delivered.

Issues within neurology services have already been discussed in Part 1. This section illustrates some of the lessons learnt by the Action On Neurology pilot sites and gives examples of some of the changes that have been made to try and address some of these issues. There are also many other examples of good practice across the UK and details of these can be found in the NSF Good Practice Guide on the Department of Health website (www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LongTermConditions/BestPractice/fs/en)

The information arising from the Action On Neurology Programme relates mainly to the following Quality Requirements although many are inter-related. We will go through these in turn to illustrate the links with the work undertaken by the pilot sites.

QR1 A Person Centred Service (which underpins all other ten QRs)
QR2 Early recognition followed by prompt diagnosis and initial treatment
QR3 Emergency and acute management
QR5 Community rehabilitation and support
QR10 Support for family and carers

The 10 High Impact Changes for Service Improvement and Delivery (www.modern.nhs.uk/highimpactchanges) developed by the NHS Modernisation Agency also provide an invaluable source of ideas to support service redesign and underpin many of the changes made by the Action On Neurology pilot sites.
National Service Framework for Long Term Conditions Quality Requirements

QR1: A Person Centred Service

All people with long-term neurological conditions are to have the opportunity of integrated assessment and planning of their health and social care needs. They are to have the appropriate information to help them make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

1. What does “person centred” really mean?

People with neurological conditions may have complex needs that affect their ability to function not only physically but also emotionally and mentally. The condition may impact on different aspects of their lives including family and carers, education, housing, finance and employment. A person centred service therefore requires that all aspects of an individual’s life are taken into account when assessing needs, often involving a number of different professionals and agencies across health and social care.

An effective person centred service needs:

- good co-ordination
- services planned and delivered in an integrated way around the needs of the patient
- an understanding of the skills of different professionals and the role of different agencies
- an integrated assessment of health and social care needs
- up to date information given at the appropriate time along the patient pathway
- involvement of the patient and carers in the decision making process
- access to general and specialist advice as necessary
- support to help patients manage their condition themselves
- encouragement to the patient to join any of the support groups relating to their condition

In other words, seeing the right person at the right time in the right setting with the right information to help make informed decisions.

2. Issues identified through Action On Neurology

People with neurological conditions and their carers were asked about current service provision through surveys and focus groups and their responses indicated that services are not always delivered in a person centred way. They highlighted the following issues:

- Some did not feel involved in decisions about their care and treatment and were left feeling isolated and confused
- Either too much information or too little was given to help them understand their condition well and the options available to them
- Inconsistent information was given by different professionals within the same team
- Services were found to be poorly co-ordinated, with patients waiting several weeks for an appointment for investigations or to see a specialist
- Patients had to give the same information to several different professionals
- Long waits to see a neurologist, access to investigations, and lack of co-ordination between professionals and agencies were also identified.
3. Experience from pilot sites

a) Improving access to Information, Advice, Education and Support

Information and guidance on neurological conditions and the type of help and support that people might expect is now widely available through:

- the Internet and the world wide web
- leaflets produced by pharmaceutical companies and national voluntary organisations
- books found in shops and libraries
- magazines and journals

However, too much information can sometimes be overwhelming and cause unnecessary anxiety, as it may be misunderstood or misinterpreted. It may not always be accurate and can also raise expectations that can’t always be met. The importance of providing consistent, accurate, up to date information at the right time along the pathway, relating it to an individual’s specific needs cannot therefore be overestimated.

Figure 4 illustrates a typical patient pathway, which shows where information might be given at different points along the pathway. Every neurological condition manifests itself in a different way and patients will move in and out of the system at different times according to their own specific needs. Information needs will also change with developments in a person’s circumstances and in treatments and services available. The complexity of the pathway and the need for information and support to be delivered in a planned way is common to most conditions, however.

![Figure 4](image.png)

North Staffordshire University Hospitals NHS Trust and Lancashire Teaching Hospitals NHS Trust both identified the need to improve the quality and consistency of information for people with epilepsy. Figure 5 shows how they each addressed this issue to ensure that patients received the right information at the right time, enabling them to make informed decisions about their care.
PART 2

Figure 5

Patient Information Pack

North Staffordshire University Hospitals NHS Trust worked with a group of clinicians, patients and carers to develop an epilepsy patient information pack.

All information leaflets:
■ follow the same design and layout
■ cover a range of generic and specific issues relating to epilepsy
■ are written in plain English so that they are easy to understand
■ contain accurate and up to date information which is objective and unbiased
■ are given to the patient by either the consultant, GP or Epilepsy Clinical Nurse Specialist at the most appropriate time along the pathway and the contents discussed to ensure they are fully understood and patients have the opportunity to ask questions.
■ are kept in an A5 file so that they are easily accessible

The information was gathered from a variety of sources so it is not new but it is clear, concise and up to date and is tailored to address specific needs along the patient pathway.

The information pack is to be used as the standard for which patient information should be produced throughout the organisation.

A4 posters of the patient information have also been produced for ward notice boards to ensure consistency. All staff are now using the new information and have been asked to ensure that verbal information given to patients is backed up with the appropriate leaflet.

The team at Lancashire Teaching Hospitals NHS Trust are in the process of developing an information strategy which aims to improve access to patient information:
■ a leaflet has been produced outlining the services offered by the Epilepsy Specialist Nurse which will be available at the District General Hospital clinics to be an initial first point of contact for a newly diagnosed patient
■ information that is already provided by the specialist nurse is to be consistent across the population area at the District General Hospitals ensuring that information is provided at the appropriate time in the patient pathway
■ discussions are ongoing to investigate the feasibility of extending the Hospitals Information Network to the District General Hospitals.
■ the possibility of the Epilepsy Specialist Nurse attending more of the clinics at the District General Hospitals is being investigated.
■ patient specific information written by the consultant specialising in epilepsy has been reviewed and updated in accordance with Trust patient information production.

In North Hampshire, the main issues for carers of people with acquired brain injury were found to be communication and access to information. Carers found that the quality of information varied greatly and there were issues in relation to the transfer of information between departments, organisations and agencies.

The team set about improving access to information as part of a wider strategy for supporting carers. By involving key stakeholders including carers and the local voluntary organisation, they were able to improve the quality of information and address a number of other issues to streamline the care pathway (Figure 6).
A focus group involving carers, professionals and representatives from Headway, discussed what forms of support they needed. This included access to an information resource pack. These are some of the ways they are addressing issues in relation to information: -

- a video is being produced for carers and professionals, showing what support is available in North Hampshire for clients who have experienced a brain injury.
- a new carer support manual, providing information on all aspects of living with a brain injured person, covering emotional, physical, and financial issues, etc. is being developed.
- notice boards in A & E departments and wards of the local trusts, to raise the profile of Headway and the support they offer to clients and carers.
- leaflets detailing the role of the Specialist Head Injury Nurse, to raise the profile of the role and to improve the links between the Acute Trust, the Community Rehabilitation Team and Headway.
- head Injury cards given out by the Accident & Emergency department are being revised to provide more details of the support available.
- an ‘educational’ day for professionals and carers to provide an opportunity for people to meet those involved in the services has been held.

The Expert Patient Programme (also supports NSF QR5)

People with neurological disorders often become experts in their own condition, as they have to face the challenges arising from the effect it has on their daily lives over a very long period. The Expert Patient Programme provides an opportunity for people to manage their conditions more effectively with an improved quality of life and reduced need for professional intervention.

Services developed by some of the Action On Neurology pilot sites found that the Expert Patient Programme complemented the work they were doing and provided additional support for patients (e.g. East Elmbridge and Mid Surrey (EEMS) PCT and Epsom and St Helier Hospitals NHS Trust and Scarborough Health Community).

More information about the Expert Patient Programme can be found at www.expertpatients.nhs.uk and by referring to High Impact Change No. 7.

Figure 7 shows that over 200 patients in one of the pilot sites have been given a leaflet describing the Expert Patient Programme and have been informed how to make contact with the organiser. A detailed analysis of uptake and impact of the programme has not yet been undertaken.
Figure 7  Number of patients who have been given a leaflet about the Expert Patient Programme

“We are aware that some patients have taken the course. The Pro-Active Care Team (PACT) clinic provided an ideal opportunity for the multi disciplinary/multi agency team to be fully informed about the course, and to alert patients who it was felt could really benefit.”

b) Integrated assessment and care planning

People with complex needs resulting from a neurological condition need a 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 value of this has been demonstrated by the Pro-Active Care Team (PACT) approach developed by a team in Surrey (Figure 8).

The PACT service found that the benefits of this approach for both staff and individuals with neurological conditions included:

■ 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 others roles
Figure 8
Pro-Active Care Team (PACT) Approach, East Elmbridge and Mid Surrey PCT and Epsom and St Helier University Hospitals NHS Trust

The PACT approach was designed to facilitate the implementation of integrated assessment and care planning, including regular reviews. The team comprises a range of disciplines and agencies, including the voluntary sector. The key elements of this approach are:

- Development of a register of patients with neurological conditions so that the team understands the profile of the caseload
- A single point of contact to enable users and carers to access the service more easily
- Multiple referral routes to the PACT service (from GPs, consultants, multidisciplinary, multi-agency providers, self referrals, and proactive referral from registration forms)
- A lead GP or specialist nurse who assesses the situation and initiates any appropriate actions within their competence – they may also confer with other providers, refer to other services and or book the patient to be seen or discussed at the bi-monthly multi disciplinary clinic which is attended also by the consultant neurologist.
- Bi-monthly multidisciplinary PACT clinics
- All referrals responded to within the bi-monthly PACT cycle
- A means to confer as well as refer across disciplines (informal as well as formal activity) to ensure a co-ordinated approach to care eliminating duplication and gaps in service provision
- Registered patients can re-access the service for non urgent assistance by using the contact number.
- Bi-monthly multidisciplinary clinics are particularly useful for the management of patients with complex needs, and the knowledge and expertise shared by the clinic team is invaluable.
- Appropriate review intervals of at least once a year, which may be a discussion at the PACT meeting, a visit to the patient’s home or a clinic appointment.
- Sharing and spreading knowledge and expertise across disciplines.

c) Improving the Care Planning and Review process

The care planning process for people with complex neurological conditions needs to be well co-ordinated to ensure that the individual is receiving the right care at the right time to enable them to live as independently as possible.

This involves a multi-disciplinary approach, ideally co-ordinated by one person at each stage of the patient pathway. Evidence from the Action On Neurology Programme shows that care is not always well co-ordinated, particularly for people living in the community or those transferring between organisations or agencies.
Rehabilitation Action Plan

The PACT approach previously described shows a model that can improve the process of care planning and review. Another model based on individualised rehabilitation plans (Figure 9) has been developed by the team in North Hampshire who found that one of the difficulties for people with acquired brain injury in the current system is inconsistent transfer of care between agencies, often caused by poor communication and lack of knowledge. Clients have to find their way around health, social services and Headway whilst each agency has their own way of working.

Figure 9

Rehabilitation Action Plan for people with Acquired Brain Injury, North Hampshire

(model also applies to NSF QR5)

To improve the care planning process in North Hampshire, a group of representatives from all agencies including individuals from the Community Neuro Rehab Team, Headway, Social Services, the acute Trust, and carers, designed a Rehabilitation Action Plan.

The Rehabilitation Plan:

- is an assessment record that focuses on goals for the brain injured person
- is accessible by all agencies involved in that person’s care.
- uses 13 functions of daily living and assesses how the client is currently able to perform in these areas. In conjunction with the key-worker, the client and carer can together agree future goals for development. This is reviewed on a regular basis.
- is kept in a folder and held by the patient, in a similar way to the ‘Red Book’ used in Child Health.
- enables anyone involved in the care of the client to have immediate access to the assessment, see what progress has been made, and can contribute to future goals/reviews.
- enables evidence of progress for the client, who is often unable (or unwilling) to accept that progress has been made to be tracked.
- can be combined with a client ‘diary’ or ‘journal’.
- includes a sheet for the client/carer to keep a record of all professional contacts and contact details – this was requested by carers

The rehabilitation plans are part of a hand held record kept by the client so that it is accessible to everyone involved. In addition to the rehabilitation needs the plan also identifies the need for equipment and adaptations (NSF QR7) as well as personal care and support (NSF QR8)

Although the Rehabilitation Action Plan had not been formally evaluated at the time of writing this report, all agencies recognise its potential benefits not only for people with acquired brain injury but also for a wider range of services.

Integrated Patient Held Records

The integrated care record being developed as part of the National Programme for Information Technology (NPfIT) should in the longer term enable all professionals involved in a person’s care to have instant access to relevant information to help them deliver a high quality person centred service. In a similar way, hand held patient records contain comprehensive information about the patient’s condition, their medication and any other information relevant to professionals.

One of the aims of the Lancashire Teaching Hospitals NHS Trust project was to improve access to information for patients and staff which resulted in the development of patient hand held records (Figure 10). These can be used by any member of the multidisciplinary team to ensure a co-ordinated approach to care planning.
Lessons learnt include:

- Involving all those who will be using the record at the initial development stage ensures ownership – e.g. GPs, patients, carers, nurses, therapists, consultants and social workers.
- Piloting the record ensures that it is user friendly and fit for purpose.
- A patient held record may contain sensitive information so design needs to be scrutinised by the appropriate committee within the organisations or health community.
- The record is a useful tool when several professionals are involved in the care of a patient as it facilitates an integrated approach to care planning and monitoring progress.
- The patient is able to use the record to write down any relevant information about their condition in between consultations with the nurse of doctor.

Some patients do not necessarily require the services of a large multidisciplinary team but do need a plan of care to help them manage their own condition. Individual management plans and lifestyle advice developed as part of the headache service in Scarborough enabled people to manage their condition as appropriate without needing to see a consultant (Figure 11).

**Figure 10**
Patient Hand Held Records, Lancashire Teaching Hospitals NHS Trust

Lessons learnt include:

The record was still being piloted at the time of writing but early feedback indicated that it is welcomed by patients as well as professionals, including GPs, specialist nurses and consultants.

**Figure 11**
Individual Patient Management Plans, Scarborough Health Community

Headache and migraine currently make up a large percentage of referrals to a neurologist in an acute hospital. Many of these referrals would not be classed as urgent so individuals have to wait long periods of time to see the consultant. In the meanwhile the personal burden of headache to the sufferer and the economic burden on society is high.

The British Association for the Study of Headache (BASH) identified that headache affects at least 75% of the population at some time. BASH believes that only a minority of cases of primary headaches are best managed in secondary care and the role of primary care in the management of headache disorders should be expanded.

Within the Scarborough Health Community, a one-stop clinic led by the GP with special interest in headache (GPwSI) has reduced the number of referrals to the neurology department. All patients are assessed by the GPwSI and given a personalised management plan based on their history and lifestyle to help them manage their own condition. They are also referred to the Expert Patient Programme as necessary.

Contact with a nurse specialist also allows for a more in depth discussion on lifestyle factors and encourages patients to take a more active approach in their management.

Feedback from both GPs and patients has shown:

- An increase in patient understanding and an increase in their ability to manage their own condition.
- An increase in GP confidence and an improvement of the management of headache in primary care.
- Increased GPs satisfaction with the communication about their patients.
- Increased patient satisfaction in feeling listened to and taken seriously and feeling involved.
QR2 Early recognition followed by prompt diagnosis and treatment

People suspected of having a neurological condition are to have prompt access to specialist neurological expertise, accurate diagnosis and treatment as close to home as possible.

The first point in the patient pathway for someone presenting with neurological symptoms is usually a visit to their GP. Neurological conditions are however relatively rare and often present a challenge as symptoms can be mistaken for other more common conditions leading to misdiagnosis before finally making a referral to a specialist. Basic education for GPs and other members of the Primary Care Team will improve their knowledge and awareness of neurological conditions thus preventing possible delays in referrals through:

- Education sessions and presentations to the primary care team
- Resource packs
- Electronic access to advice from specialists
- General Practitioners with a Special Interest

Once a referral has been made, waiting times to see a neurologist are in many areas unacceptably long resulting in delayed diagnosis and increased anxiety for the individual and their family.

Waits can often be reduced by addressing problems within the service using some of the tools and techniques described in Part 3. However, delays can be also caused by other factors such as insufficient workforce with the necessary skills to provide specialist advice and support as well as issues relating to capacity e.g. to diagnostic tests (High Impact Changes Nos. 2, 8, 9 and 10).

It has already been suggested that there is a shortfall of consultant neurologists in the UK, which compounds the problem of long waits to see a specialist. The Association of British Neurologists estimates that 600 more consultants are required – to achieve a ratio of 1:100,000 population. There is also a shortfall in other specialties such as Neurophysiology and Neuroradiology, and specialist therapists for Neurorehabilitation.

By December 2008, the government expect all patients to be seen within 18 weeks from GP referral to first treatment. This presents a real challenge for neurology as access to a neurologist and diagnostic services have been found to be major bottlenecks in the patient pathway.

1. Issues identified through Action On Neurology

An assessment of services in the Action On Neurology pilot sites highlighted the following examples of issues in some of their services:

- Referrals from some GPs for people with suspected epilepsy contained insufficient information to enable an informed decision about how to proceed
- People were therefore generally put on the list to see a consultant often resulting in long waits before they were seen
- Major bottlenecks caused by long waiting times to see a neurologist and long waits for radiology investigations – MRI and CT Scans – in some cases over 18 months
- Workforce issues in neuro-physiology departments resulting in long waits for EEGs

(High Impact Changes Nos.2, 5, 9)
2. Experience from pilot sites

Improving the referral process

In order to improve the referral process, North Staffordshire developed a proforma and protocol based referral system for people with suspected epilepsy for use by the Accident and Emergency Department, Medical Assessment Unit, General Practitioners and Consultants, ensuring appropriate and efficient use of the service. Lancashire Teaching Hospitals NHS Trust and Scarborough Health Community have also developed similar referral proformas for people with epilepsy and headache for use by GPs. The introduction of the proforma has made a significant difference to the quality of the referrals in all three pilot sites.

It is important to remember however that introducing new processes cannot be done without engaging all key stakeholders right from the development stage. The success of a referral proforma for instance relies on the understanding and compliance of GPs and other departments to use it so engagement at an early stage is essential. In North Staffordshire after 6 months, there were some GPs who were still not using it so further work was necessary to raise the awareness and the benefits of the proforma to improve the uptake. It is also important to remember that GPs are covering many different specialties so any new process must be easy to follow.

The North Staffordshire pilot was able to reduce waiting time from referral to treatment from a maximum of 42 weeks to a maximum of 13 weeks. Figure 12 describes the impact of the redesigned service in North Staffordshire in more detail including other changes that were also made.

**Figure 12**

Redesigning the referral process, North Staffordshire University Hospital NHS Trust

A GP referral proforma and guidelines have been introduced which ensures that:

- Patients are referred with appropriate information, ensuring that they are on the right pathway for their diagnosis
- Proformas are received in one portal of entry (the Department of Neurology) which has reduced the pathway by up to 2 weeks
- The referral form has ensured that the relevant information is available i.e. For some patients it is necessary for them to stop taking their medication for a few days prior to having an EEG and technical staff need to be advised if it is safe for them to do so. This information was often not available on the referral, resulting in technical staff having to write to the referring doctor and placing the referral on hold until an answer was received. A small change to the referral form has meant that the relevant information is missing less frequently and, when it is still necessary for technical staff to seek further advice from the referring doctor, they no longer place the referral on hold, but continue to process it whilst waiting for a reply.

A triage system for the referral proforma has been put into place which means that:

- Proformas can be triaged by the Epilepsy Clinical Nurse Specialist, thereby reducing the pathway by a further 2 weeks
- Patients suitable for an EEG prior to seeing the consultant can be more easily identified meaning that some patients can receive initial treatment at their first out-patient appointment
- Waiting times for this group of patients has reduced from a maximum of 90 days to a maximum of 48 days

A portable EEG machine (brain-spy) has been purchased which has increased capacity and provided the facility for an ambulatory EEG service.

- Due to shortage of appropriately skilled staff within the Neurophysiology department it has not yet however been possible to offer an ambulatory service

From August to November 2004, 63 patients were seen on the new patient pathway, 39% of which had their EEG before first outpatient appointment with the Consultant. As a result 21% patients received initial treatment at their first consultation.

Waiting time for referral to treatment has reduced from a maximum of 42 weeks to a maximum of 13 weeks.
Neurological symptoms are very common in general practice and it is not easy for general practitioners to know which patients need to be seen or how soon. Some of these patients could be managed on the basis of advice alone but in most areas there is no system for reliable, easy communication with Consultant Neurologists and vice versa. Redesigning the referral process by making a few simple changes can improve communication and avoid unnecessary referrals to outpatients (figure 13).

**Figure 13**

*Improving the referral process, North Cumbria*

The neurologist in North Cumbria wanted to see whether some outpatient referral letters could be dealt with on the basis of advice back to the general practitioner or by advice with investigation, rather than an outpatient appointment.

In North Cumbria, the project involves all general practitioner and consultant neurological referrals being read by the neurologist and dealt with in one of three ways, i.e.

(a) letter back to GP plus advice,
(b) letter back to GP plus appropriate investigation arranged
(c) see the patient for an out-patient appointment

**Method**

An initial neurological diagnosis is made on the basis of the referral letter. To assess the accuracy, this is compared with the final diagnosis, made when the patient is seen in the outpatient clinic. Follow up letters are sent to GPs three months later for those patients who have not been seen, to establish whether the advice and/or investigation was helpful and whether the patient has been referred elsewhere.

During December 2004, there were 105 referrals. Of these 69% resulted in an appointment being offered; 1% resulted in further tests; 9% resulted in a letter back to the referrer with a suggested care plan and, finally, 18% resulted in a letter to the patient direct, the patient being seen on the ward or no information being recorded against the referral.

There were 34 patients identified where a letter was sent to the referrer with a suggested care plan. The GPs for the patients were contacted and asked if the care plan response had been useful, as opposed to just offering an appointment. Out of 21 initial replies, 81% of respondents said the response enabled management of the patients condition; 86% did not have to re-refer the patient for a consultation; 24% indicated the patient was referred elsewhere and 81% of respondents felt this was an acceptable method of dealing with the concern.

Comments received back are mixed. GPs are happy with the service although some patients still wanted a referral due to anxiety.

It is anticipated that further analysis of the data in North Cumbria over a longer period will highlight the benefits of managing referrals in this way.

**Improving access to specialist advice**

It has already been mentioned that there are insufficient neurologists in the UK to cope with the growing number of people presenting with neurological symptoms. Different models of care have therefore been developed in an attempt to improve access to specialist neurological expertise. GPs and other practitioners such as nurses or Allied Health Professionals can help by developing skills and knowledge in a specific neurological condition or a range of conditions and working closely with consultant colleagues in secondary care (also refer to High Impact Change No.10).

Guidance has been published by the Department of Health and Royal College of General Practitioners on the development of GPwSI services and can be found at [http://www.dh.gov.uk/Policyandguidance/organisation/policy/primarycare/GPswithspecialinterests](http://www.dh.gov.uk/Policyandguidance/organisation/policy/primarycare/GPswithspecialinterests). Information and guidance about Practitioners and GPs with a Special Interest can also be found on the NatPaCT web site ([www.natpact.nhs.uk/special_interests](http://www.natpact.nhs.uk/special_interests)).
Nurse Specialists

Nurses with specialist knowledge in specific neurological conditions can enhance a service by supporting patients from when they are first diagnosed.

Specialist nurses working in the Action On Neurology pilot sites undertook a number of different roles, some of which are outlined in figure 14. Feedback from patients indicates that they have made a significant difference to the quality of the service as they are more accessible than the consultants and can spend time with the patients explaining to them about their condition, medication and other support that might be available.

Specialist nurses working across organisational boundaries in both the acute and community settings can also support people with long-term neurological conditions while they are receiving care for other reasons in any health or social care setting (NSF QR11).

Figure 14

Nurse Specialists

Scarborough – Headache Nurse Specialist
Support with the headache management plan
Follow up telephone calls to the patient and GP
Life style advice

North Staffordshire – Epilepsy Nurse Specialist
Triaging patient referrals resulting in faster access to EEG tests and appointment with consultant

North Hampshire – Brain Injury Nurse Specialist
All admissions to the acute Trust should be referred to the nurse to facilitate better co-ordination of services

Surrey – Parkinson’s Disease Nurse Specialist
Initial assessment
Advice and support preventing crises resulting in hospital admission
Medicines management and monitoring

General Practitioners with a Special Interest (GPwSIs)

There needs to be a “whole system” approach in developing GPwSIs, to ensure that everyone is aware of the role of the GPwSI and how it supports the overall strategy for delivering care. Primary Care Trusts need to be fully involved, as they will need to agree funding and participate in the recruitment process. They also have a crucial role to play in encouraging and supporting GPs to develop a special interest in a specific condition.
Figure 15

GPwSI Service for people with Headache and Migraine, Scarborough Health Community

For GPs in the Scarborough area, options for referring patients with symptoms of headache were affected by the lack of a local consultant neurologist. Patients with headache could therefore be seen by a visiting Neurologist or a Consultant General Physician.

The development of the GPwSI led headache service has made it possible to redirect patients to a specialist clinic where patients are seen by a GP who has developed specialist expertise in the assessment and management of headache, freeing up secondary care consultants to see the more complex cases.

Changes to the patient pathway include:
- Direct referral to the headache clinic by GPs using a referral proforma and referral guidelines
- Reduction in waiting times to see a specialist
- Patient informed of follow up appointment immediately
- Individualised patient management plans developed
- Support from a specialist nurse as necessary
- Diagnostic tests provided within a specific timeframe

The target from referral to 1st appointment was 2 weeks and from 1st appointment to follow up was 4 weeks (in which time investigations, if needed, would be done). However it was identified that most patients with symptoms of headache can be diagnosed without the need for further investigation and so can be diagnosed during the 1st appointment.

Patients are recommended to revisit their GP 2 weeks after their GPwSI consultation so that their management plan can be put into action. The whole patient pathway should therefore take no longer than 8 weeks.

Salford Primary Care Trust and Salford Royal Hospitals NHS Trust – GPwSI services for people with headache and epilepsy

Salford has a strong track record of integrated primary and secondary care, which has shown proven benefits across the city in terms of reduction in waiting times, better access, greater convenience and choice for the patient whilst freeing capacity in the hospital. An analysis of Salford GP referrals suggested that the implementation of a GPwSI led primary care based headache and epilepsy services should reduce the number of secondary care neurology referrals by around 15% for each of the two conditions. This would free capacity for more urgent conditions, whilst reducing waiting times and providing an enhanced service provision for those patients suffering from headache and migraine or epilepsy.

The main aims of the Salford project were to:
- Develop a primary care triage service, staffed by a multidisciplinary team (GPwSIs, Nurse Practitioners), ensuring that patients are referred to the most appropriate service, either within primary or secondary care.
- Develop GPwSI Services in Headache and Epilepsy, supported by a robust CME training programme along with appraisal and processes for re-accreditation, which would be replicable across Greater Manchester.
- To develop and agree integrated referral pathways and improve the interface between primary/secondary/tertiary care, including a rapid access service.

The Salford pilot site has concentrated on developing the two service models for epilepsy and headache, the recruitment of the two GPwSIs to deliver the service and a comprehensive training programme to ensure that the GPwSIs have the necessary skills to provide high quality care.
Different models can be developed to meet local needs but experience from the Action On Neurology programme suggest that there are a number of key issues to address before starting to set up a GPwSI service (figure 16).

**Figure 16**

**Issues to consider before implementing a GPwSI service**

- Is there a need for the service?
- What will the service model look like?
- How does it fit into the overall strategy?
- Who needs to be involved in the service?
- What skills and knowledge are required?
- What training will be necessary and how will it be provided?
- Will the training be accredited?
- What ongoing professional support will be available for the GPwSI?
- How do you go about recruiting a GPwSI?
- What are the contractual arrangements including salary?
- What are the accountability arrangements?
- What are the clinical governance arrangements?
- What impact will the GPwSI service have on other services e.g. partners in GP practice, outpatient neurology clinics, other GP services?
- What are the implications for the waiting time targets?
- How will the service be evaluated?
- What facilities will be needed including space and equipment?
- Has succession planning been considered?
- What are the alternative options if you are unable to recruit to the role?

Within the Action On Neurology Programme GPwSI services have been developed for people with epilepsy and headache. Figure 15 describes the experience of two pilot sites within the Programme. Two other project sites planned to develop GPwSI services for people with epilepsy but were unable to recruit to the posts and had not considered some of the issues listed in Figure 16.

**Improving Access through Technology**

Advancements in technology such as the Internet, email, telemedicine and teleconferencing have had a major impact on the NHS, improving access to information and enabling services to be managed more effectively.

**Telemedicine**

In Cornwall, the introduction of telemedicine has reduced the need for clinicians and managers to travel long distances to clinics or meetings (figure 17). This has not only increased capacity but has also meant that people can be seen at relatively short notice for emergencies. Telemedicine has also been well received by clients and carers. Some of the issues faced by the team in setting up the service include:

- Location and accessibility of telemedicine sites to maximise the use of the equipment
- Training of staff
- Acceptability for specific client groups – e.g. clients with learning disability responded best to a life size image of the consultant projected onto a wall
- Confidentiality issues
- Set up and ongoing operational costs
- Contingency plans if the system stops functioning
- The need to involve the multi-disciplinary team
Figure 17

Specialist Epilepsy Telemedicine Service
– Cornwall Partnership NHS Trust

Cornwall is spread over 1,370 square miles, including the Isles of Scilly and has a population of over 50,000. Cornwall Partnership NHS Trust has a specialist epilepsy service that currently sees and treats approximately half of the 1000 people known to have epilepsy and learning disabilities. The service is community based with clinics previously held in 3 locations across the county, each run by a specialist nurse and covers the life span of the individuals from childhood to old age. A memory service for people with learning disabilities is run along similar lines.

Barriers to maintaining and improving the quality of these two services include poor roads and public transport and long travelling distances. The consultant was travelling approximately 800 miles per month attending clinics and special schools, spending a disproportionate amount of time on the road moving from base to base.

Prior to the introduction of the telemedicine service, the nurse would assess all new referrals in their home, and then arrange for them to be seen by the consultant in the clinic. The whole process could take up to 4 months.

4 telemedicine clinics have now been set up which means that the consultant can see patients from his base in Bodmin without having to travel long distances.

A simple information booklet has also been designed in conjunction with the speech and language therapist, which has helped clients understand about the new telemedicine service

The new telemedicine service has resulted in

■ Reduced average waiting time between referral and first consultation.
■ An increase in number of clinic slots available, by reduction in wasted travel time
■ An emergency service is now available
■ Better use of resources, by reduction in consultant hours spent travelling and travel expenditure
■ Better communication links between members of this dispersed team, allowing more frequent meetings with less travel
■ Extension of facilities to other services, giving them access to the same benefits.

Email discussion system

Advice provided via email by the neurologist in North Cumbria has also improved the patient pathway by increasing the number of people whose conditions can be managed without needing to see a specialist (figure 18).
Neuromail, Cumberland Infirmary, North Cumbria

The single handed neurologist in North Cumbria has piloted a system to provide fast and accessible advice for GPs about new clinical problems, treatment and referral queries.

All GPs within the catchment area have been given the Neuromail address and the neurologist aims to respond to requests for advice within 48 hours. The reply to the general practitioner also contains a short questionnaire to assess usefulness of the reply.

Neuromail queries are filed under three categories:
- requests for further advice
- requests for treatment advice
- requests for diagnosis advice

Patient details are not included on Neuromail so there are no concerns regarding patient confidentiality.

Initial data indicates that the majority of GPs who have used the service find it useful. The responses to the questionnaire received in December found that 100% found the reply extremely helpful, 70% thought it avoided the need for a referral, 100% said the communication did not result in a referral that would not have been made and 70% thought the response was educational.

A small minority of GPs indicated that they did not like technology so would continue to use the old system.

Improving Access to Investigations

Waiting times for investigations cause a major bottleneck in the pathway for people with a suspected neurological condition. In many areas they are so long that people could be waiting months or even years, resulting in a delayed diagnosis and deterioration in their condition. Across the country, service improvement work has been undertaken in many diagnostic departments in an attempt to reduce waiting times and real improvements have been made (refer to High Impact Change No. 2 and www.modern.nhs.uk/radiology). However, to improve the service even more so that people receive a prompt diagnosis, alternative ways of delivering these services should be considered.

For people with suspected epilepsy, EEGs, CT Scans and MRI Scans are some of the tests that may be needed. CT and MRI Scans are also used to rule out underlying pathological causes of headaches.

In North Staffordshire and Lancashire, the waiting times for EEGs were many weeks long, resulting in potential delays in both diagnosis and the start of treatment. Both sites have redesigned their services so that selected people are now having their EEGs prior to seeing a consultant, which has reduced the waiting times significantly (figure 12). The referral proforma previously discussed has also helped the specialist decide who needs an EEG resulting in a reduced number of people being sent for investigations.

One stop diagnostic clinics can facilitate a prompt diagnosis, and it was the aim of two of the pilot sites to develop these. The reality was that it was not possible to access CT and MRI scans on the same day as this would have meant reserving slots which may not have been used, making the situation worse (refer to High Impact Change Nos. 8 & 9).

In Scarborough the project aimed to improve response times for specialist investigations, with a 4 week target from referral to appointment and reporting for patients needing a CT scan. 81% (13/16) of patients referred for a CT scan were under the 4 week target. However there were 2 patients that waited 5 weeks for CT scan and 1 patient that waited 10 weeks for a CT scan.

The impact of changes within one service do need to be looked at in the context of others as improving access for one specialty may mean that other people are waiting longer.
QR3 Emergency and acute treatment

People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.

Trauma is the most common cause of death in people under 40, and 50% of deaths in this group are due to head injury. The pathway for people with head injuries in many cases is extremely complex as there are often so many organisations and agencies involved. This means that good communication between agencies and organisations is essential as patients are often transferred out of their local area for specialist care and treatment and then return to their local community for rehabilitation.

1. Issues identified through Action On Neurology

The team in North Hampshire found that there was no agreed pathway for people with acquired brain injury within their service. There is also no dedicated neuro rehab unit in the PCT area and, as a result, patients have to be transferred to Southampton if they require surgery. From there, they are either returned to the acute trust, or placed in specialist rehabilitation units, most of which are not based locally. Much is dependent on a member of staff having specialist knowledge, resulting in some clients being referred to appropriate rehabilitation resources whilst others are not.

Patients who did not require surgery were sometimes discharged from Accident & Emergency with no follow up and were then “lost” to the system. There was little co-ordination between the different services or departments which meant that some people were unable to access appropriate care and support.

2. Experience from pilot sites

Figure 19 shows how the North Hampshire team have improved the service for people being admitted to Accident and Emergency by making small changes to the pathway and improving communication between the different parts of the service.

The team found that early and appropriate intervention by the specialist Head Injury Nurse following admission to hospital ensures that the care is well co-ordinated and facilitates patients to receive the right care in the most appropriate setting.

This illustrates that with just minor administrative changes and improved communication leading to a better understanding of the issues faced by the different organisations, the experience for the users and carers can be greatly enhanced.
Figure 19
Improving communication, North Hampshire Service for People with Acquired Brain Injury

The project team set out to complete a patient care pathway and started with a process mapping workshop. This showed how complex the pathway is, and as such they were only able to complete the patient journey within A & E.

Following the process mapping, the team visited all the specialist units used by the service to open communication channels and resolve any outstanding issues around referrals to, and discharge from the units. These visits were very successful and have contributed to making the pathway more efficient. For example patients admitted to specialists units are now identified to the community neuro team immediately, in order that the team can plan, ready for discharge. This means that patients can be discharged as soon as they are able, as there will be appropriate support in place from the community team.

As a result of the visits, a decision was made to review the commissioning strategy of specialist rehab placements, as the decision to use some of the units has been historical, and not reviewed for some time. One of the major units used is at a long distance from Basingstoke, whereas there are now alternative local units that patients can be referred to. This would also enable carers to be offered choice around where their relatives are treated.

The project team have also worked on the pathway within the acute Trust – visiting various departments to present the project and discuss ways of improving the patient experience. They are also looking at the role of the Specialist Head Injury Nurse, and how her role links in the pathway.

Another outcome of this work has been that A & E have now agreed to change their practice, so in future all moderate/severe head injury patients are automatically referred to the Head Injury Nurse. The head injury card given out by A & E, which advises patients about access to the specialist Head Injury nurse, the Community Neuro rehab team, and Headway is also being rewritten to ensure they are receiving comprehensive, up to date information.

QR5 Community rehabilitation and support

People with long-term neurological conditions living in the community are to have ongoing access to a comprehensive range of rehabilitation, advice and support to increase their independence and autonomy and help them to live as they wish.

People with neurological conditions often need a wide range of services to enable them to live independently in the community. Services therefore need to be well co-ordinated to avoid duplication or gaps in provision and to ensure that individual agencies and professionals know who else is involved. No matter what type of support is needed the way it is delivered can have a major impact on the individual's life.

1. Issues identified through Action On Neurology

Pilot sites involved in the Action On Neurology Programme highlighted the following issues in some of their services:

1. No comprehensive care pathway for a patient with a specific condition once they had been diagnosed
2. Single pathways existed for individual services such as physiotherapy but there were no links to other services on discharge
3. Services were poorly co-ordinated
4. Poor communication between different professionals, organisations and agencies
5. Patients having to navigate a complex health and social care system if they needed help
6. Lack of knowledge about the role of different professionals and agencies amongst the staff themselves resulting in delayed discharge to community services, gaps in service provision and poor co-ordination
2. Experience from the pilot sites

Effective multidisciplinary team working and good communication between different professionals and agencies are the most essential prerequisites to supporting people to live in the community, as health and social care needs are inextricably linked.

**Multi-disciplinary Team Working**

A multi-disciplinary, multi-agency team can make a significant difference to the experience of people with long term neurological conditions by ensuring that the right person is seeing the patient at the right time and in the most appropriate setting.

This does not mean a group of people sitting in the same office or building, treating the same patients, sending emails or discussing their care on an informal basis. It means that professionals meet or communicate on a regular basis and develop systems whereby all people with neurological conditions are known to the service and are assessed and reviewed as necessary on a regular basis so that their immediate needs can be met and future needs anticipated.

The Pro-Active Care Team (PACT) approach developed by Epsom & St Helier NHS Trust and East Elmbridge and Mid Surrey PCT has already been discussed. The PACT service consists of a core team of professionals from health and social services who are most likely to be involved in the care of people with neurodegenerative conditions. Others, including the voluntary sector are invited to join the discussions as necessary.

Feedback from those involved in the service highlight the benefits of this way of working from their own perspective:

“PACT clinic is a good opportunity for us all to meet face to face, which does improve working relationships and you always have a couple of conversations which are useful from the management of particular patients or highlighting a particular problem or need within services. It also stops unnecessary referrals if I can clearly say NO rather than “let’s just see if a physiotherapist has anything to offer”, especially if a patient has been seen recently”

“I met another patient through our review system the next week who was a very good example of a patient with multi agency involvement where the co-ordination is poor. They have a case manager or reviewer but it’s obvious that no one really knows who is doing what and no one oversees if things don’t happen. I think this is the aspect of care that patients want addressed”. – senior neuro physiotherapist

“...In particular I feel that PACT enables a more holistic approach to patient care, enables discussion of complex patients including management concerns and provides support to decide on appropriate management plan. I also feel supported and therefore more confident in decision making”. – speech and language therapist

“I see the benefits in reducing professional isolation, learning, working as a team, knowing how other services interrelate and having contact with others who care for the same people. I had wondered if the service would generate an avalanche of new referrals, but probably the opposite is happening as inappropriate referrals are avoided”. – physiotherapist

“The benefits of a project like this are around overcoming crisis management, maintaining people at home, preventing admissions to residential care, and increasingly supporting self management, with carers going in to enable, rather than going in to take over care for someone. It will be interesting to see if the number of carers’ assessments goes up as a result”. – social services representative

A new member of staff from the general hospital OT dept attended the PACT clinic having been invited by another to meet “the drivers of what is going on” – occupational therapist

A patient’s GP took the opportunity to attend when his patient was seen at the clinic. He commented that ‘from a GP’s point of view it is very useful having a collective opinion to fall back on, encompassing all aspects of a patient’s care, particularly in this patient’s case where the problems are less clinical and more rehabilitative and social. Just knowing where to refer is helpful.’ – General Practitioner
As a result of PACT, a speech and language therapist has attended a course to enable her to provide a specific therapy programme for Parkinson’s Disease patients. A continence clinic has also been established to run alongside the PACT clinic.

Following the first joint continence clinic the continence nurse expressed great pleasure in being involved in the project and the sense that change and improvement are possible.

Figure 20 illustrates the impact of the PACT approach on one individual reinforcing the benefits of this type of approach for both staff and patients.

Figure 20
Experience of the PACT Approach

Patient X was referred to PACT and was found to already be known by several members of the team. Over the years they had been referred to different therapists, social services and had seen most of the neurologists within a large radius. However every one of them had had a difficult experience and admitted to feeling inadequate in dealing with the patient’s apparent anger towards the “system”. As a result of the referral, discussion took place about how to deal with the situation which led to a feeling of mutual understanding and support amongst the professionals. As a result, an agreed action plan was drawn up, the Expert Patient Programme Co-ordinator became involved, the PALS manager made a home visit to the patient to discuss benefits and other forms of support, different members of the team were able to offer physical intervention and a referral was made to local MS Society’s physiotherapy gym. Feedback from both Patient X and his GP the following day was extremely positive as there was now a clear plan of action to deal with Patient X’s problems.

This highlights the bleak experience for patients in their endless search for help. Once the team understood what was happening, they could see the potential for supporting Patient X. Staff display a tendency to avoid patients like this, or withdraw because it is not possible for individuals alone to support and manage someone who puts so much energy into looking for help, but failing to find what they need. There was hope after the meeting that the cycle could be broken.

On reflection too, the team realised that this patient may be suffering from depression, which was something the PACT approach could address.

Improving Community Rehabilitation Services

The complex needs associated with neurological conditions, require access to a range of rehabilitation services to enable individuals to live independently in the community. Models and providers of rehabilitation services vary across the country and include community based rehabilitation teams, outreach services, day care and outpatient provision with many patients needing a combination of services. Good communication between all providers from health, social services and the voluntary sector is essential to facilitate a comprehensive “package” of care.

The Community Neuro Rehabilitation Team (CNRT) in North Hampshire believed that an increased level of intensive rehabilitation in the client’s own home in the immediate period following discharge would significantly improve the client’s ability to manage their condition themselves, and help reduce re-admission rates to acute care.

A review of the CNRT has resulted in an increase in therapy input and revised criteria for referral, which has enabled increase support to be provided. The team now electronically record their contacts with CNRT clients, allowing the team, and the PCT to understand the impact of their work. The membership has expanded from 5-6 members to 12 members (from within the existing therapy services) which has allowed the number of cases they can take on to expand from approximately 15 to around 50 cases at any one time.

In addition, due to a shortage of qualified practitioners in rehabilitation, the team took the opportunity to explore the role of a Community Rehabilitation Assistant (figure 21), which has also enhanced the service (also refer to High Impact Change No. 10).
The aim of the post was to explore the benefits to clients with acquired brain injury of providing home-based cognitive rehabilitation programmes. Extensive training was provided by the therapists within the CNRT and the psychologists. The assistant is responsible for assisting in the delivery of the programmes, including working on a one-to-one basis with clients, and with groups. The rehab assistant works under the guidance and with the support of the community neuro rehab team.

Early indications show that this role has proved valuable in supporting therapists in delivering individual rehabilitation programmes.

One aspect of the role, which has proved to be a real benefit, has been the ability to have the Community Rehabilitation Assistant carrying out observation. This part of the role had not previously been considered and has provided insight into the client's behaviour and needs, which was something the CNRT team did not have the capacity to carry out. The observation work means that assessments are now far more accurate which is beneficial to all involved.

Improving Day Care Provision

The voluntary sector has an important role to play in the provision of rehabilitation services. Voluntary organisations such as the Multiple Sclerosis Society, The Motor Neurone Disease Association and Headway, to name but a few, have developed a wide range of services in partnership with health and social care organisations to improve access to rehabilitation and other forms of support.

Headway has a number of branches across the UK providing day services for people with acquired brain injury. In Basingstoke, the local branch extended the hours of the day service as part of the Action On Neurology project. This has had a positive impact on the service, benefiting both staff and clients (figure 22).

Prior to the project, Headway staff worked for 5 hours a day, 3 days per week. These hours coincided with client attendance time and left no time for staff to debrief, discuss plans for the day, carry out administration, training etc. In addition, it was recognised that the programme of activities needed to be updated in line with best practice.

Funding was allocated to extend the staff hours at Headway to allow activities above to be carried out prior to, and after client attendance hours. This also allowed staff to take a half hour lunch-break (to comply with employment law).

Research into best practice is continuing for the programme of activities, and changes are being made to the structure of the days’ programmes.

This piece of work has seen a very positive outcome, both for staff and for the clients. The staff have been interviewed and report feeling less stressed as they now have time to plan the day, and to debrief at the end of each session. For the clients this has meant that the programme of activities can be delivered in a more structured way, from which they will directly benefit.
QR 10 Support for family and carers

Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.

“There is a real need to flag up more the role carers play and the support they need. At the end of the day, carers have to make things work even when all else in the system fails – being a carer puts a strain on you that you wouldn’t believe, so when things go wrong, support is essential” – carer of a person with acquired brain injury

These few words sum up the situation carers find themselves in day after day, highlighting the need for structured support to enable them to cope with this important and often demanding role.

1. Issues identified through Action On Neurology

There are a number of different ways of supporting carers but they need to be tailored to the needs of the client or patient group, as well as to the individuals themselves.

Carers highlighted the following changes they felt would help them in their role:

■ Access to up to date, comprehensive information at the time of diagnosis
■ A single point of contact to ensure the smooth transfer of care between agencies and professionals, and to make sure people were receiving the right care at the right time
■ Better communication between organisations and professionals
■ Carer support network
■ Respite care to enable them to have periodic breaks

2. Experience from the pilot sites

The North Hampshire team set about addressing some of the issues listed above, recognising that every individual has different needs requiring different levels and styles of support (Figure 23)

Figure 23
Support for Carers, North Hampshire Services for people with Acquired Brain Injury

To find out the real issues faced by carers a focus group was set up to discuss the types of support they needed, and a questionnaire devised by carers themselves was sent to all known carers of people with acquired brain injury in the area.

The questionnaire was very successful in finding out how many clients were in the community needing support. It also confirmed what support clients wanted, and more importantly, the type of support they did not want (for example, they said they did not want home visits by other carers – something the team were originally looking at setting up!)

In addition to the initiatives highlighted in figure 9, the following changes have been made:

■ Promotion of carer support meetings held via Headway which had previously been poorly attended. Work has taken place to promote the meetings more widely using various methods, and to find out what carers would like to use the meetings for. The first meeting held since this work was very successful and had the highest attendance in a long time.
■ Possibility of a carer support telephone line, manned by carers. Various support lines are available (for example through Social Services). However, carers feel very strongly that they want to talk to people who have been through the same experience – the team are therefore looking at the possibility of having a telephone line manned by other carers.
■ Potential recruitment of an acquired brain injury co-ordinator to act as a single point of contact. This is a role that is becoming more popular across the country. The team were undertaking work to review just what is needed and how the needs can be met, e.g. another means of providing this may be through the use of Headway, or the PCT Community Neuro Rehab Team.
Summary

This section has identified a number of issues highlighted by the Action On Neurology pilot sites which many health and social care communities might recognise within their own neurology services. The examples illustrate some of the lessons learnt by the project teams, which could be translated to other organisations to help improve quality and access to their services. All health communities are different however and what works in one area may not work in another. The next part of the guide talks about the principles underpinning change and by adapting some of the lessons learnt in this section and combining them with these principles, health communities can make a significant improvement to the way services are delivered.
PART 3: MAKING CHANGES

Improving services for people with long term neurological conditions has been identified as a priority by the publication of the National Service Framework for Long Term Conditions. In addition, guidance on providing high quality services for people with neurological conditions has been published by agencies including the National Institute for Clinical Excellence (NICE), Professional Bodies and Voluntary Organisations. A list of useful documents can be found in Appendix C.

With all this information available, how does an organisation know what the issues are within their neurology services and then go about making changes to ensure that they provide high quality services?

1. Assessment against national guidance

An essential first step in planning and developing neurology services is an assessment of the current local situation in relation to standards such as the NSF for Long Term Conditions and condition specific NICE Guidelines. Auditing existing services will establish a baseline for developing a strategy. The long-term conditions self-assessment tool developed by the NHS Modernisation Agency could be used to identify areas of good practice as well as gaps in service provision (http://www.natpact.nhs.uk). Other initiatives such as the competency frameworks developed by Skills for Health are useful in assessing the skills profile of the workforce and identifying training and development needs (http://www.skillsforhealth.org.uk).

The complexity of the care pathway for people with neurological conditions has already been highlighted in Parts 1 and 2. Key stakeholders should be therefore be identified at the start of the assessment, to ensure that all aspects of service provision are included. The voluntary sector has a valuable role to play in supporting people with neurological conditions and should be included in the process.

As the pathway for people with neurological conditions transcends primary secondary and tertiary care, a clinical network with identified leadership and accountability arrangements comprising stakeholders from both provider and commissioning organisations, would facilitate an integrated approach to assessment of current services and service delivery.

Stakeholders might include clinicians and managers from:
- Primary and community care service providers
- Secondary care providers
- Tertiary care providers
- Commissioners
- Social services and care providers
- Voluntary Organisations
- Strategic Health Authorities
- Others involved in the care pathway

Patients and carers are also key stakeholders who bring a valuable perspective to discussions around service planning.

The pilot sites participating in the Action On Neurology Programme found that the involvement of key stakeholders, particularly clinicians and service users, gave a comprehensive range of views and perspectives to inform decisions about the development of integrated services.

2. Developing a Strategy

Implementation of the NSF for Long Term Conditions is to be completed over a period of ten years. The development of a local strategy for neurology services across a health economy or network could be used to facilitate the delivery of the NSF in a planned and co-ordinated way. Issues identified from an initial assessment can be used to inform the strategy, developed in the context of other services provided within the health economy. If individual services or departments are looked at in isolation, changes made to one part of the pathway may have a negative impact on another.
The Salford Health Community developed a clear strategy for the delivery of neurology services (Figure 24) which enabled them to identify specific areas for service development and redesign taking into account the whole patient pathway.

Figure 24
Salford Health Economy – extract from the bid to participate in the Action On Neurology Programme

“The health economy of Salford has a common vision to develop a first class Neurology service, spanning primary, secondary and tertiary care services. We have a shared history of innovation, partnership working and providing high quality clinical services. The Action On initiative is an important way to continue and advance this. The health economy is relatively unique, insofar as the neurology services are provided through a hub-and-spoke system between Salford Royal Hospitals NHS Trust (the hub) and 14 PCT districts and DGH units (the spokes) with Salford PCT providing Specialist Commissioning for Neurosciences across the city.

With the integration of neurosciences in Greater Manchester since May 2001 we have extensive experience of developing governance structures across more than one organisation, with the support and active participation of users and carers. We are therefore uniquely placed to deliver significant improvements in the accessibility and efficiency of neurology services in Salford and then roll out the model across Greater Manchester”.

A strategy or vision will set out clearly the direction for neurology services. Experience from the Action On Neurology Programme has shown that it is more likely to be implemented if it is mutually agreed by all those involved and drawn up in sufficient detail to show:

- Priorities for the local health community to deliver the strategy and meet the quality requirements in the NSF and national guidance
- What services are to be provided
- How they fit into the local planning
- Where they will be provided
- Who will provide them
- What resources are needed
- What the relationships and communications systems between the various service components are
- Expected outcomes

3. Redesigning a service

A range of service improvement tools and techniques has been developed to help health communities identify and articulate changes that need to be made in a structured and logical way. These tools have been extensively tested in many different care settings and are fundamental in identifying improvements needed to support the implementation of the Quality Requirements of the National Service Framework for People with Long Term Conditions. They are also a good means of providing robust information to support the need for additional resources identified in business cases.

The tools and techniques have been incorporated into a series of Modernisation Agency Service Improvement Leader’s guides (www.modern.nhs.uk/improvementguides)

Having identified the priorities within the local organisation or health economy, the next step is to review how the current systems and processes work within a specific service or department. Simple diagnostic tools such as measuring capacity against demand can help determine if best use is being made of scarce resources, and mapping processes along the patient pathway can help identify bottlenecks and issues impacting on the patient’s overall experience.

Some of the tools and techniques are described briefly below, with examples of how they have been used as part of the work of the Action On Neurology programme.
Process Mapping
The first step before any changes are made is to understand what is currently happening within the service.

Process Mapping is a tool that can be used to help a team identify issues along the patient pathway and identify opportunities for improvement that will have the biggest impact for patients and staff.

A process can be described as a series of connected steps or actions to achieve an outcome and has the following characteristics:

- A starting point and an end point
- A purpose or aim for the outcome
- Rules governing the standard or quality of inputs throughout the process
- It is usually linked to other processes
- It can be simple and short, or complex and long.

Figure 25 gives some examples of the different types of processes mapped by the Action On Neurology Pilot Sites.

![Figure 25 Examples of different processes](image)

The Action On Neurology pilot sites undertook to map either a small part of their service or the entire patient pathway depending on the aims of their projects as shown below:

- **Scarborough Health Community**
  Mapped from first visit to the GP with headache or migraine to the development of a personalised management plan

- **North Staffordshire University Hospitals NHS Trust Salford Health Community**
  Mapped from GP referral for patient with suspected epilepsy to attendance for consultant outpatient appointment

- **North Hampshire Service for People with Acquired Brain Injury**
  The team aimed to map from emergency admission at A&E to provision of community rehabilitation services – they found the process so complex however, it had to be broken down into smaller parts of the pathway – each to be mapped separately

Who should be involved?
Process Mapping can be done in different ways but the most effective is a workshop with all those involved in the service, including service providers, commissioners, patients and carers and representatives from the voluntary sector where either the whole or part of the patient pathway can be mapped from beginning to end. This results in collective ownership of the issues identified and the resulting action plan and supports the need for more integrated working.

Some of the Action On Neurology project teams found the process challenging due to the resistance of some of the key stakeholders, in particular some of the clinicians who did not feel they needed to attend a workshop to find out what the issues were within their service. This is a common reaction but those who did attend found it extremely valuable and were often surprised by the issues being highlighted.

Where services were mapped by interviewing individual members of staff instead of holding a dedicated workshop, the project manager had a good understanding of what the issues were in the individual parts of the patient pathway but did not have a feel for how they impacted on each other. Those delivering the service also did not have an opportunity to see the whole "picture". As a result these projects appeared to find it more challenging to implement change and services can remain fragmented.
Which services should be “mapped”?

It is essential to define and agree the part of the service and / or group of patients to be mapped as well as the first and last step in the process. Neurology services are complex since they cover such a wide range of conditions, each of which will have a different pathway. Once a strategy has been developed and priorities identified, the part of the service to be mapped can then be selected.

Figure 26 describes how two of the pilot sites set about mapping their services.

Figure 26

The North Hampshire project team decided to map the entire patient pathway for people with acquired brain injury. They invited representatives from local health and social care providers, tertiary centres, patients and carers, as well as the voluntary sector to a process mapping workshop. There was a lot of commitment to see how services could be improved and to develop more integrated working.

The team found that the pathway was so complex they didn’t get beyond admission to the acute trust in the first workshop and had to repeat it on another occasion to complete the pathway. It was however an extremely valuable experience and identified several issues that needed to be addressed to improve the patient pathway.

In Scarborough the project manager mapped the previous service for people with headache by talking to the relevant staff and finding out what happened to a referral once it was received in the acute hospital. She found that there were three routes for referral, each one being dealt with differently, and it could take up to 11 weeks before the patient was seen and if investigations were required up to 23 weeks before a treatment plan was put in place. It was not possible to hold a process mapping workshop but a comparison of the service before and after the introduction of the GPwSI rapid access headache clinic highlights the improvements that have been made, particularly in relation to access where the whole process now takes no longer than 8 weeks.

It is important when doing the process map, that accurate records are kept of what is actually happening in the service and not what people assume or have heard or what they think should be happening as a lot of time can be wasted trying to solve the wrong problem.

Solutions can only be sought once all the issues have been identified.

Benefits of Process Mapping

There are clear benefits to using Process Mapping to review services. Experience from those pilot sites that held dedicated process mapping workshops found that it:

- Provided an accurate starting point for service redesign
- Gave an overview of the complete patient process which helped everyone involved understand how complicated systems can be for patients
- Highlighted those parts of the system that would benefit most effectively from change,
- Helped identify priorities for service redesign
- Provided a unique opportunity to involve people who really knew how the service worked, many of whom had never met each other before
- It generated several ideas for change and provided an opportunity to challenge the way things are currently done

The end result of Process Mapping will be a “map” showing every step in the patient pathway, who is involved in each step, how long each step takes and how long the patient waits between each step. This can be used to identify gaps in meeting the Quality Requirements for the NSF and condition specific NICE Guidelines.

Full details and instructions of how to map a process can be found at www.modern.nhs.uk/improvementguides

Below is an example of a process map developed by North Staffordshire University Hospitals NHS Trust at the beginning of their project, before any service changes were made:
By comparing the process map above with the one below which shows the new patient pathway, it can be seen that a number of steps have been removed and new ways of working have been introduced. This has resulted in a much more simple process and a reduction in the amount of time patients wait to see the consultant. Many of the steps that have been removed were found not to add any value to the patient experience.

**Epilepsy Patient Pathway – April 2004**

**Referral to Treatment:**
- **Min** 72 days (10 weeks)
- **Max** 297 days (42 weeks)

**Epilepsy Patient Pathway – August 2004**

**Referral to Treatment:**
- **Min** 42 days (6 weeks)
- **Max** 91 days (13 weeks)
As a result of the process mapping a referral proforma was introduced which ensures that:

■ Patients are referred to a single portal of entry within the Department of Neurology, which reduces the patient pathway by up to two weeks.
■ Patients are referred with appropriate information, ensuring that they are on the right pathway for their diagnosis.
■ Referrals are able to be triaged by a specialist in epilepsy, which reduces the patient pathway by up to a further two weeks.
■ Patients suitable for electroencephalogram tests (EEG) prior to first consultant outpatient appointment can be identified.

The example given in figure 27 shows how process mapping can be used to identify bottlenecks, resulting in a change in the way the service is delivered which has:

■ optimised patient flow (High Impact Change No.9)
■ improved access to key diagnostic tests (High Impact Change No.2)
■ avoided unnecessary follow ups (High Impact Change No.5)

It has also started a process for implementing the NSF Quality Requirements.

4. Measuring The Impact Of Change

Once the process map has been completed, and issues identified, it's very tempting just to get on with making the changes. It is essential, however, to ensure that the results of any change can be assessed by collecting information to measure progress, and evidence to demonstrate the impact of the change. Some ideas will work, others won’t, so it is important to be able to show that the changes in the service have resulted in an improvement.
**Figure 28**

**Model for improvement**

- What are we trying to accomplish?
- How will we know that a change is an improvement?
- What changes can we make that will result in the improvements that we seek?

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**Remember – All improvements involve a change, but not all changes are improvements**

The basis for these measurements comes from the Model for Improvement (figure 28), developed by the Institute for Healthcare Improvement. This is an extremely useful framework for setting objectives and targets for service redesign.

Baseline measurements will need to be determined before any changes are implemented so that comparisons can be made before and after.

Always find out what information is available about the services currently provided. For example, “standard” activity and waiting list returns are available for all NHS Trusts via the Department of Health website (www.doh.gov.uk/waitingtimes/index.htm).

Figure 29 gives examples of the types of quantitative measures used by the Action On Neurology Pilot Sites.

**Figure 29**

**Examples of quantitative measures**

- Time taken in days from initial referral to first out patient appointment
- Total number of patients referred to PACT Clinic for assessment
- % of total number of patients referred for further investigation by consultant
- Number of referrals received on the referral proforma
- Number of patients having an EEG prior to first appointment with consultant
- Time taken in days from GP referral to investigation
Although information can be obtained from local clinical and non clinical information systems, the lack of robust quantitative data for neurology services was found to be a significant challenge for many of the pilot sites. Many were testing changes in particular sub specialty areas of neurology, i.e. headaches and epilepsy, and did not have information systems that could provide such detailed data. Project managers often found that the only means of collecting complete and meaningful data was therefore by manually trawling through clinical records.

The lessons learnt by the Action On Neurology pilot sites in relation to data collection are summarised below:

- Measurement should be used to speed improvement up, not slow things down.
- Discuss data requirements with the Trust information department
- See if the information already exists somewhere in the system
- If information needs to be collected manually, make sure that this can be maintained
- However data is collected it needs to be accurate, complete and consistent
- It may be necessary to collect prospective rather than retrospective data which may not exist
- Ensure that measures link to the overall aim of the service development / change

The value and importance of collecting qualitative data (figure 30) must not be overlooked, especially where quantitative data is not readily available. Whatever you measure, its relevance should be that any change will improve things for the patient and their carers.

There are many ways of doing this, including focus groups, staff and patient satisfaction questionnaires, patient diaries and discovery interviews.

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**Figure 30**

**Examples of qualitative data**

- experience of and confidence in the service
- confidence and knowledge to support self management
- experience of the responsiveness of the service
- experience of access to information/signposting

Once measures have been agreed and baseline data collected:

- Targets need to be set that may be challenging but achievable – these need to be agreed by key stakeholders
- Progress must be monitored. Different software packages including readily available ones such as Excel can be used to record and track data to demonstrate the impact of the change.

The examples below are from the Action On Neurology pilot sites. Figure 31 shows the different actions taken by the lead GP between the bi-monthly PACT Clinics. Figure 32 analyses the ratio of new to follow up appointments in the rapid access headache clinic.
Figure 31

PACT Approach – Easing Pressure on Outpatients

The bar chart below indicates the kinds of actions undertaken by the lead GP in her role in between the bi monthly PACT clinics. Discussions with the Consultant meant that a proportion of patients were dealt with without the need for an outpatient appointment. Further work is needed to clarify the extent to which the service has potential to ease pressure on the outpatient waiting list (mdma means multidisciplinary multiagency services).

Figure 32

Scarborough Health Community

In order to see if the clinic appointments were being utilised effectively the ratio of new referrals and follow ups was measured. Annual leave was taken in the months of August, September and January which reduced the capacity of new appointments. Additional new patient appointment slots were generated in September when it was recognised that less follow ups were being seen than allocated slots.
Matching Capacity And Demand

“Demand” is all the requests and referrals coming in from all sources
“Capacity” is the resources available to do the work.

It is the variation and mismatch between capacity and demand in a service that creates queues and bottlenecks in the system (refer also to High Impact Changes Nos. 8 & 9).

From the process mapping exercise, the parts of the system where patient flow is obstructed (the constraint) will have been identified. These constraints may be caused by a lack of equipment or skill (people) or inefficiencies in the way the system is operating.

Detailed instructions of how to analyse a process map are available in the Improvement Leaders’ Guide to Matching Capacity and Demand, but the main questions that should be asked are:

■ Is the patient getting the most appropriate care?
■ Is the most appropriate person giving the care?
■ Is the care being given at the most appropriate time?
■ Is the care being given in the best place?
■ How many people are waiting?
■ How many different queues are there?
■ Is it someone with “expert” skills who is causing the delay? Experts include all staff with expertise, including medical, nursing, administration and technical staff.

At the steps where the longest delays occur, keep asking ‘why?’ By exploring the real reasons for delays in more detail, ideas for new ways of working can be generated. Examples of measuring capacity and demand are shown in figure 33.
Figure 33

Measuring Capacity and Demand – examples from the Action On Neurology Pilot Sites

■ Reducing delays in the whole patient pathway for patients referred with suspected epilepsy in North Staffordshire

In North Staffordshire, as a result of undertaking capacity and demand, the time from GP referral to clinic attendance was reduced from a maximum of 188 days in April 2004 to a maximum of 65 days in August 2004. The time from the appointment being made to the patient attending the clinic was reduced from a maximum of 119 days in April 2004 to a maximum of 91 days in August 2004. This was as a result of changes made in the referral process and the introduction of a referral proforma and guidelines.

■ Reducing delays from GP referral to outpatient appointment in Scarborough

In Scarborough patients with headache were waiting several months for an outpatient appointment due to lack of capacity. The aim of the new GPwSI led service was that patients would be seen, assessed and diagnosed by a General Practitioner with a special interest in headache, and followed up where necessary by a Clinical Nurse Specialist within 2 weeks of referral. By measuring the capacity in relation to demand this was found to be an unrealistic target as shown in the chart below. Analysis showed that annual leave, referral patterns and ratio of new to follow up clinic slots all had an impact on waiting times.

■ Reducing delays in referral to outpatient appointment in Cornwall

In Cornwall, clinics were not used to maximum capacity due to the long distances having to travel from the consultant’s base to the clinic location. The introduction of telemedicine has increased the capacity in the clinics and reduced waiting times for patients.

All these initiatives are supported by agreed criteria and protocols that have been developed locally with key stakeholders.
4. Involving Patients and Carers

The importance of involving key stakeholders in redesigning a service has already been discussed but it is also worth mentioning separately the impact of involving those who actually use the services – patients and carers.

The Action On Neurology pilot sites all involved patients and carers in different ways, depending on the services they were redesigning. Some used questionnaires to gain feedback both before and after changes were made. Others set up focus groups so that patients were involved right from the beginning. This was particularly valuable where the changes were having a direct impact, such as the development of patient held records or setting up a carer support system, as the people using the service often wanted different things to what the professionals thought were needed. Some of the pilot sites invited service users to become members of the project boards, where they brought a completely different perspective to the discussions and were able to influence the way services were being developed. This is summed up by two carers who made an invaluable contribution to developing services in one of the pilot sites:

“It has been interesting to explore and highlight how decisions and actions within and between departments – both Health and Social Services, as well as outside agencies, affect the quality of life of clients and carers. We have found it useful to be able to explain to health and care professionals, the reality of caring for someone 24 hours a day, 7 days a week. Being involved in one of the Action On Neurology pilot project boards, we are now in a position to help the decision makers make a real difference to the brain-injured as well as their families and carers. It has been refreshing to find that Health and Social Services and others are successfully clarifying and trying to achieve the same goals. It is crucial to lay the correct foundations for the future and we are relieved and pleased to be part of the process.” – Carers

There is always room for improvement – involving those who use the services and acting on what they say will ensure:

- that services are designed around patient needs
- they feel valued and are being listened to
- they are involved in the decision making process
- they are better informed about the health and social care system

Further information about how to involve patients and carers can be found in the Improvement Leader’s Guide to Involving Patients and Carers (www.modern.nhs.uk)

Summary

This section has provided a brief overview of some of the ways organisations can go about redesigning their services to support the implementation of the Quality Requirements in the NSF for Long Term Conditions. The methods described have been used successfully in organisations across the UK over the past few years, and have made a huge impact on both the quality of and access to services. Applying the learning from the NHS Modernisation Agencies' High Impact Changes will also help organisations look at ways that might improve their services.
PART 4: CONCLUSIONS

This section draws on the lessons learnt by the Action On Neurology pilot sites and gives ideas for implementing the National Service Framework for Long Term Conditions Quality Requirements and suggestions as to how to go about making changes to improve neurology services.

National Service Framework for Long Term Conditions Quality Requirements

QR1. A Person Centred Service (this underpins all other ten QRs)

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
- The Expert Patient Programme facilitates 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
- A Pro-Active Care Team approach facilitates 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

The characteristics of a PACT approach are:

- a multi-disciplinary, multi-agency team of professionals and managers
- the development of a population-based register
- a single point of contact to access the service
- a lead practitioner (e.g. GP or specialist nurse) to undertake an initial assessment and initiate immediate actions
- multiple referral routes
- regular meetings and PACT clinics
- regular patient reviews, at least annually
- a means to confer as well as refer across disciplines
- a key worker can facilitate a co-ordinated approach to care, ensuring the patient is receiving the right service by the right person at the right time.
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.
- Hand held patient records facilitate an integrated approach to care planning and enable anyone involved in the care of the person to have immediate access both to record and to read information relating to the condition, progress and any problems that may arise.
- A model care plan such as a “rehabilitation care 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.

QR2 Early recognition followed by prompt diagnosis and initial treatment

Referral process

- Referral pro formas with associated guidelines can improve the quality of information to enable the specialist to make an informed decision about what action to be taken e.g. investigations, out patient appointment etc.
- A single point of entry for referrals and a triage system can reduce the time taken for a referral to be processed.
- The number of outpatient appointments can be reduced by the neurologist making an initial diagnosis based on the referral letter and then providing advice to the referring GP on a course of action but still inviting those who cannot be dealt with in this way to an outpatient appointment.

Access to specialists in neurology

- Nurses, Allied Health Professionals and General Practitioners play an important role in improving the patient pathway by developing skills and knowledge in a specific neurological condition or a range of conditions, and working closely with consultant neurologists.
- If an organisation is considering developing a GPwSI service, a number of issues are important such as involving all stakeholders, the model of service, impact on existing services, recruitment, training and contractual arrangements etc.
- Telemedicine can improve access to specialist services, in certain settings by reducing travel time and increasing available time for patient contact.
- An email discussion system between the specialist and the GP can reduce the number of inappropriate referrals by providing easily accessible advice about clinical problems, treatment and referral queries.

Access to investigations

- Access to investigations can be improved by triaging referrals, and having investigations done prior to seeing the consultant. This may however have a negative impact on waiting times for other specialties so should be considered in the context of other services.

QR3 Emergency and acute management

- For people requiring acute and emergency management, the pathway can be improved by making small administrative changes such as referral to the specialist nurse on admission to the Accident and Emergency Department so that services can be co-ordinated.
- Regular communication with specialist units enables patients to be identified to the community neuro team immediately after admission, to allow planning for discharge to be started early.

QR5 Community rehabilitation and support

- Multidisciplinary team working such as the Pro-Active Care Team approach ensures that the right person is seeing the patient at the right time in the right setting.
Support workers such as a Community Rehabilitation Assistant can enhance a team by supporting the delivery of rehabilitation programmes. The role has been found to be particularly beneficial in observing patients with acquired brain injury.

Flexible working hours in a day care unit can have a significant impact on the structure of the day for both staff and patients by allowing more time for planning and structuring the day's programme and debriefing at the end of the day.

**QR10 Support for family and carers**

- Carers and families need support that is tailored to the needs of the client group as well as to the individuals themselves.
- Involvement of carers in developing a strategy for support is beneficial as they are able to identify the issues that are most important to them which may be different to those anticipated by the professionals.

**Making changes**

**Assessing Neurology Services**

Mapping the different services across a health community and identifying what each provides and then assessing them against national standards such as the NSF for Long Term Conditions and against NICE Guidance for specific conditions will highlight both areas of good practice and possible gaps in service provision. The long-term conditions self-assessment tool developed by the Modernisation Agency could be used to support the process.

**Involving key Stakeholders**

Involving key stakeholders right from the beginning of any service development or service redesign enables them to gain ownership and commitment. Involving them when changes have been made may result in a lack of understanding and compliance.

**Developing a strategy**

A mutually agreed strategy for neurology informed by the findings of the assessment will set out a clear direction for service development and service redesign and should be developed in the context of other services.

**Redesigning a service**

A range of service improvement “tools and techniques” such as process mapping, measuring capacity and demand and using measures to demonstrate the impact of change are available to help organisations redesign their services. These methods are tried and tested and form the basis of the “10 High Impact Changes for Service Improvement and Delivery” (www.modern.nhs.uk/highimpactchanges). They can also be found in the Service Improvement Leader Guides on www.modern.nhs.uk/improvementguides.

**User and Carer involvement**

Involving the people who actually use the service can have a positive impact on service redesign and development as they bring a different perspective to the planning process and can influence the way services are developed to meet their needs.
APPENDIX A

Summary of the *Action On Neurology* Pilot Sites

Eight pilot sites were selected to participate in the *Action On Neurology* Programme to find and test new ways of working to improve neurology services over a period of approximately 12 months. One of the original projects (the development of an online referral and discussion system by Royal Berkshire and Battle Hospitals NHS Trust) unfortunately had to withdraw part way through the programme. A smaller project led by a neurologist in North Cumbria, based on similar principles but using emails instead of an online system, joined the programme in its place to run for just six months.

An overview of each of the pilot sites is provided over the following pages. Some were still in the development phase at the time of publication. However, despite the challenging time frame, the projects have produced some encouraging results.

Further information about the projects can be obtained from the Project Clinical Lead from each of the sites. A comprehensive report from 7 of the original pilot sites selected are also included on the CD accompanying this guide and can be accessed via the NHS Modernisation Agency website (www.modern.nhs.uk).
Rapid Access Headache Clinic

### Background
For GPs in the Scarborough area, options for referring patients with symptoms of headache were affected by the lack of a local consultant neurologist. Patients with headache could therefore be seen by a visiting Neurologist or a Consultant General Physician. Of the 900 referrals per year to the Consultant Physician or visiting neurologist at Scarborough, it was estimated that at least 15-20% of those were for headache. Many of these referrals were not classed as urgent, so patients were waiting long periods of time to see a consultant. The rapid access headache service has been piloted to develop the role of the GPwSI and a specialist team to enable patients to be rapidly seen, assessed and diagnosed, and to then help them to better manage their own condition.

### Aims and Objectives
To improve local headache services by:
- Improving access for patients presenting with headache by reducing response times for first appointments and investigations
- Developing the role of the GPwSI so that patients are seen by a professional with specific training in headache
- Developing the role of a specialist nurse
- Developing standardised referral guidelines and patient pathways for use across the two PCTs and the acute Trust
- Developing the role of a specialist nurse in headache
- Developing a triage service to enable patients to be seen and assessed more quickly, treatment instigated, and timely onward referral to secondary care where appropriate.
- Developing patient information

### How changes were made
- The current service was mapped by talking to key stakeholders, and proposals for the new service were agreed by the project board
- Referral guidelines were agreed, and a proforma developed which allowed GPs to refer directly into the GPwSI service
- Triage and radiology referral criteria were agreed
- Changes made to the investigation request form enabled the date of follow up and patients contact number to be included. The radiology department was therefore able to easily inform the patient when a space was available and helped to ensure that any patient who needed investigations would have these carried out prior to being followed up. However, it was identified that most patients with the symptoms of headache can be diagnosed without the need for further investigation, and could therefore be discharged at the first visit.
- Management plans were sent to the patients GP, and patients recommended to visit 2 weeks after their consultation with the GPwSI so that this can be actioned.

### Outcomes
- A reduction in the overall patient pathway, including a reduction in time taken from referral to 1st appointment, referral to diagnostic tests and referral to follow up appointment
- A decline in the number of secondary care referrals for headache to the Consultant Physicians.
- Consultant time has been freed up which has been utilised for more complex cases.
- An increase in the confidence of local GPs to manage headache in primary care.
- An increase in patient and GP satisfaction with the service provided.
- An increase in patient understanding and ability to self manage their condition.
- Recognition locally of the potential to shift some services from primary to secondary care.

### Conclusions / Lessons learnt
- The service has been well received locally, and patient feedback has been positive.
- The pilot has demonstrated a model for other services, and the potential for shifting services from secondary to primary care.
- There is potential to further develop the role of the specialist nurse.
- Ongoing training and support for the GP community in the management of patients with headache is integral to developing this type of service.

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## Salford Royal Hospitals NHS Trust and Salford Primary Care Trust

### Intermediate Services for patients with Headache and Epilepsy

#### Background

Within the health economy of Salford in Greater Manchester, neurology services are provided through a hub and spoke model, between the Salford Royal Hospitals NHS Trust (the hub) and 14 PCT districts (the spokes). There were different routes of referral for urgent and routine patients, and significant variation in the referral patterns of individual practices, matched by variations in waiting times.

#### Aims and Objectives

To improve local neurology services by:
- Providing a high quality intermediate tier service within primary care, directly accessible by Salford GP practices enabling easy and timely access for patients.
- Managing referrals via one single point of entry at the Referral Booking Management Centre.
- Developing common standards and referral protocols to ensure that patients are referred to the most appropriate point of care.
- Developing GPwSIs roles in Epilepsy and Headache.
- Reducing referral rates into the acute trust by ensuring that appropriate patients are managed within primary care, thereby supporting a reduction in waiting times and a release of consultant Neurologist time for more appropriate/complex cases.
- Providing information, support and training to GP practices and other primary care practitioners in order to develop services at a practice level.
- Integrating the new services with the Access, Booking and Choice initiatives.

#### How changes were made

- The current service was mapped in consultation with key stakeholders and proposals for the new service were agreed by the project board.
- Retrospective audits were carried out to test assumptions about referral rates.
- The patient pathway was redesigned, and will be implemented once training of the GPwSIs has finished.
- A comprehensive communication plan to educate local G.Ps about the change to the service has been carried out.

#### Outcomes

- GPwSIs have been appointed to both the Epilepsy and Headache services and training is in progress.
- Training packages and competency framework agreed and in progress.
- Electronic triage protocols and exclusion criteria agreed.
- The GPwSI will have direct access to diagnostic services through a proforma based referral system.
- Managed transfer of services from secondary to primary care is planned to coincide with the completion of the training package.

#### Conclusions / Lessons learnt

- The services for epilepsy and headache have been developed as part of an ongoing strategy within the local health economy to develop primary care based service models.
- Whilst there has been insufficient time within the lifetime of the project to demonstrate changes in waiting times, the project has built on local expertise in both partnership working and the implementation of GPwSI roles.

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APPENDIX A

Lancashire Teaching Hospitals NHS Trust

Redesigning the Epilepsy Service

Background
Lancashire Teaching Hospitals NHS Trust serves a population of approximately 1.6 million. Royal Preston Hospital, at the hub of the neurology service with 6 District General Hospitals forming the spokes has 6.5 w.t.e neurologists, two of whom hold epilepsy clinics at Royal Preston Hospital. All the neurologists see patients with epilepsy at the District General Hospitals in general neurology clinics. The geographical area has 12 PCTs. The patient pathway for people with epilepsy from GP referral to treatment can be several months, involving several visits to the hospital. Routine waits for an EEG or MRI Scan is up to 9 months.

Aims and Objectives
To improve local access to epilepsy services by
- Reducing the number of visits for a newly diagnosed patient to hospital based outpatient clinics by appointing a GPwSI first seizure clinic and establishing local epilepsy clinics
- Reviewing referral and treatment criteria.
- Diagnosing and treating newly diagnosed epilepsy patients within 28 days of referral.
- Providing high quality patient information
- Improving shared care between patient, primary and secondary care by developing patient hand held records
- Communicating diagnosis to the patient within 10 days of undergoing investigations.

How changes were made
- The epilepsy patient pathway was mapped by the project manager by interviewing a range of staff and collecting retrospective data to provide a baseline for future comparisons – the aims of the project were changed as a result from establishing a GPwSI first seizure clinic to a diagnostic clinic
- Diagnostic clinic set up so that investigations performed on same day as outpatient appointment
- Research into GPwSI services in other parts of the country was researched and a job description to meet local needs written – this was not progressed due to internal processes
- Information about existing patient held records was researched to inform the newly designed hand held epilepsy records which were passed through governance processes within the trust and then piloted with a group of newly diagnosed patients with epilepsy
- Clinics at the DGHs were reorganised by changing a general neurology clinic to a specialist epilepsy clinic
- Specialist nurse researched existing information to inform the new patient information pack
- Referral proforma and guidelines developed for use by primary and secondary care

Outcomes
- Referral proforma enabled consultant to effectively triage patients to determine who needed an EEG prior to appointment
- Investigations on the same day as the consultant appointment have enable patients to receive a diagnosis within 10 days
- It was not possible for MRI and CT Scans to be performed on same day due to capacity issues in radiology
- Patient hand held records received positive feedback from patients and staff and provide comprehensive information accessible to all those involved in the patient’s care
- Patient information packs, given to patients by the specialist epilepsy nurse ensure consistency across the neurology service
- Insufficient data had been collected at the time of writing this report to assess improvements in the service but early indications show a reduction in waiting times, improved patient information and improved access to the specialist nurse

Conclusions / Lessons learnt
- Engagement of key stakeholders and commitment at a senior level is essential to the success of any change in a service
- A clear action plan with timeframes and named personnel provides focus and direction
- An assessment of current services through a process mapping workshop would have highlighted the issues along the whole patient pathway such as capacity in radiology more clearly
- Reserving appointments for investigations for an individual clinic impacts on waiting times for other patients
- Collecting data for a specific condition within the speciality is challenging as it is not readily available through existing IT systems
- Any new service development such as a GPwSI service needs to start with a clear service model before the recruitment process starts. A longer time frame for a development such as a GPwSI is essential in order for discussions to take place, recruitment of candidates, training and audit of the effectiveness of the initiative to occur.

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University Hospital of North Staffordshire NHS Trust

Improving Services for Patients with Epilepsy

**Background:**
Patients referred to the University Hospitals of North Staffordshire with symptoms that may lead to a diagnosis of epilepsy are seen within the Neurology Out-Patient clinic by a consultant neurologist. Prior to the Action On Neurology project, patients waited on average 5-8 weeks for an urgent appointment and between 9-17 weeks for a routine appointment. There were also lengthy waits for neurophysiological investigations, and the total time from GP referral to diagnosis/treatment could take between 12-18 months. Some patients with seizures were also being monitored by Health Care Professionals other than neurologists.

**Aims and Objectives**
To improve services by
- Developing a proforma and protocol based referral system for use by the Accident and Emergency Department, Medical Assessment Unit, General Practitioners and Consultants, ensuring appropriate and efficient use of the service.
- Developing a network of other Health Care Professionals, initiated by the Trusts lead consultant in epilepsy, to deliver a cohesive and co-ordinated service that best meets the needs of the patient.
- Reducing the need for all first outpatient appointments to be conducted by the consultant, thereby creating additional capacity for more urgent/complex cases.
- Improving access to the Neurophysiology department for EEGs, to facilitate an earlier diagnosis.
- Improving patient information prior to their first visit/investigation.

**How changes were made**
- The current service was mapped in consultation with key stakeholders and proposals for the new service were agreed by the project board.
- Patient and staff satisfaction surveys were carried out, and the results used to inform changes to the service.
- The Epilepsy Clinical Nurse Specialist undertook a Health Assessment module, which will enhance the level of nurse led services available. On completion, the ECNS will be able to undertake follow up clinics.
- A referral proforma was introduced, creating a single point of entry for all referrals, which are then triaged by the Epilepsy clinical Nurse Specialist.
- A designated epilepsy clinic was created in order to test the proforma and triage process.
- Where appropriate, patients who require an EEG have this done prior to their first outpatient appointment.
- Small administrative changes were made within the neurophysiology department to prevent delays in patients receiving appointments.
- Additional capacity was created by the purchase of an EEG machine.
- A comprehensive patient information pack was produced, with information being given to patients incrementally as appropriate.
- An Epilepsy Resource pack for GPs was also produced, which includes the referral proforma, new patient information, and guidelines on the diagnosis and management of patients with epilepsy.

**Outcomes**
- Patients are referred to a single point of entry within the Department of Neurology, which reduces the patient pathway by up to two weeks.
- Patients are referred with the appropriate information, ensuring that they are on the correct pathway for their diagnosis.
- Referrals can be triaged by the ECNS, which reduces the patient pathway by up to a further two weeks.
- Plans to recruit a GPwSI to this project were unsuccessful due to lack of applicants. There are plans to consider advertising again, or to consider the appointment of a Nurse consultant.
- Patients suitable for EEG prior to consultant outpatient appointment can be identified.
- Between August 2004 and November 2004, 39% of patients had their EEG prior to seeing the consultant, resulting in 21% of patients receiving initial treatment for epilepsy at their first outpatient appointment, and 27% of patients being discharged.
- Patients having their EEG prior to seeing the consultant reduced the wait time from referral to treatment from a maximum of 42 weeks to a maximum of 13 weeks.
- The University Hospital of North Staffordshire NHS Trust has adopted the epilepsy patient information package as the gold standard for which patient information should be produced throughout the organisation.

**Conclusions / Lessons learnt**
- Time needs to be taken to encourage GPs to use proformas consistently.
- Small changes to administrative processes can make significant difference to the length of the patient pathway.
- There are difficulties both locally and nationally in maintaining reasonable waiting times for neurophysiological tests due to a national shortage of qualified clinical technologists.
- Recruitment of GPwSIs can depend greatly on local circumstances.

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North Cumbria Health Community

Managing Out-Patient Referrals, Neuromail & Advice on Receipt of Out-Patient Referral Letter

Background:
The neurologist in North Cumbria is single handed, covering a large rural area. Waiting times for outpatient appointments and investigations can be up to several months and patients may have to travel long distances to see the neurologist. GPs have difficulty making appropriate neurological referrals because they have poor training and experience in Neurology. Neurological symptoms are very common in general practice and it is not easy for general practitioners to know which patients need to be seen by a Neurologist and which could be managed on the basis of advice. GPs often telephone for advice in these circumstances, which is time consuming, owing to the lack of immediate availability of the Neurologist. An E-mail system (Neuromail) with rapid response, giving appropriate advice, is much more efficient and could be extended to manage routine referrals with advice as well, instead of necessarily seeing all referrals in the outpatient clinic. The neurologist has already been providing email advice to some GPs about patients with neurological symptoms, and wanted to extend this to all referring GPs within the area, at the same time redesigning the referral process.

Aims and Objectives
- To see whether some out-patient referral letters can be dealt with on the basis of advice back to the general practitioner or by advice with investigation, rather than an out-patient appointment.
- To provide fast and accessible advice for GPs about new clinical problems, treatment and referral queries (Neuromail). Requests for advice sent to Neuromail to be replied to within 48 hours.

How changes were made
Neuromail
- All GPs were advised of the email system and given the address of the Neuromail box.
- The usefulness of this method of communication was assessed by means of a short questionnaire attached to the response.
- Neuromail queries were filed under three categories, i.e. requests for further advice, requests for treatment advice, and requests for diagnosis advice. The time taken for the Consultant to reply was recorded.

Referral process
- All general practitioner and Consultant neurological referrals to North Cumbria were read by the neurologist and dealt with in one of three ways:
  - (a) Letter back to GP, plus advice,
  - (b) Letter back to GP, plus appropriate investigation arranged, and
  - (c) See the patient for an out-patient appointment
- For patients needing to be seen in the outpatient clinic, an initial neurological diagnosis is made on the basis of the referral letter and compared with the final diagnosis, to assess accuracy.
- Follow up letters are sent to GPs three months later on for those patients who have not been seen to establish whether the advice and/or investigation was helpful and whether the patient has been referred elsewhere.

Outcomes
Initial analysis of data over a two month period shows:
- an improvement in communication between the consultant and the General Practitioner
- acceptability by General Practitioners
Further data and analysis is needed to show whether the new referral system has had an impact on waiting times for outpatient appointment and investigations. Early indications are that a number of referrals can be managed with advice from the consultant neurologist without the need for an outpatient appointment.

Conclusions / Lessons learnt
- Analysis of Neuromail was more difficult than first envisaged due to the service being provided through email as opposed to having a “Web” based system set in place.
- Systems need to be kept in place to deal with the small number of patients for whom this type of service is not appropriate.

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### Cornwall Partnership Hospitals NHS Trust

#### Providing a Specialist Epilepsy Service in a rural area by Telemedicine

**Background**
Cornwall covers a large rural area with a poor transport network and has a dispersed population of just over 500,000 (2001 census). Approximately 500 people with epilepsy and learning disabilities are treated by the community based specialist epilepsy service of Cornwall Partnership Trust. New patients are usually seen at home by a specialist nurse and then by the consultant neuro-psychiatrist in a special school or clinic held in one of three bases across the county. The whole process can take up to 4 months. The same consultant runs a similar service for people with memory problems and learning disabilities. The poor roads and public transport network meant that the consultant was spending a disproportionate amount of time travelling which equated at times to two sessions a week. The telemedicine service has been piloted to try and reduce travelling time and increase capacity in the service.

**Objectives**
- To improve and enhance the community-based epilepsy service for people with learning disabilities
- To develop a telemedicine service.
- To maximise the skills of the staff in the service
- To improve access by reducing the waiting time for consultant appointments and increasing capacity
- To provide better seizure control for those with epilepsy and improved quality of life for people with epilepsy and for people with dementia by providing a more flexible and immediately responsive service
- To make better use of available resources by reducing consultant travel time and expense

**How changes were made**
- Current service was mapped by talking to staff and clients, and proposals for the new service were agreed by the project board
- The project team visited a Tele-neurology service in Belfast to see how it was run and to discuss lessons they had learnt
- A technical trial was undertaken and equipment specification agreed and ordered at the earliest opportunity
- Potential sites for the installation of the telemedicine equipment were surveyed and the kit installed in 4 of the identified sites over a phased period. The 5th identified site was found not to be viable and there were difficulties finding another suitable location
- Staff were trained in the use of the equipment
- A booklet specifically designed for people with learning disabilities was developed in conjunction with the speech and language therapist to explain about the clinic
- The first clinics were held for both epilepsy and dementia, which highlighted a number of issues that needed to be addressed before further clinics were held. As a result a protocol for running the clinics and the set up of the room was developed.
- An “Easy to read and Understand” Questionnaire was sent out to clients and a standard questionnaire was issued to carers.

**Outcomes**
- A reduction in average waiting time between initial referral and first consultation
- Increase in capacity in the clinics as they can start earlier and finish later
- Clients can be seen at short notice as an “emergency”
- Better use of resources in terms of time and money as there has been marked reduction in travelling for the consultant
- Improved communications links between dispersed members of the team allowing for more frequent interaction and less travel
- Extension of facilities to other services giving them access to the same benefits
- Positive feedback from both staff and service users

**Conclusion and Lessons learnt**
- The telemedicine has been well received and has opened a number of different opportunities for developing the service
- A technical trial enabled the team to find out which equipment will give the best results
- Training not only in the use of the equipment but also how to conduct the clinic and end a consultation using telemedicine ensures the smooth running of the clinic
- Contingency plans enable the service to continue in case of technical failure
- Clinics should be adapted for different client groups

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## Improving Services for people with Acquired Brain Injury

### Background:
The North Hampshire Primary Care Trust and North Hampshire Hospitals NHS Trust have a well-developed Community Neurological Rehabilitation Team, working across a range of organisations. However, they identified a number of areas in which they wished to make improvements as part of the Action On Neurology programme.

These included:
- Inconsistent transfer of care between agencies.
- The need to develop an effective carer support programme.
- Difficulty in providing consistent and regular therapeutic input into the home environment.
- Inequity in the provision of day services.
- Limited day rehabilitation and respite care.
- The need to update the day rehabilitation service program in line with the latest evidence and best practice.

### Aims and Objectives
To ensure that all clients with an acquired brain injury, and their carers, have access to a service that is seamless and without boundaries, using quality information to help inform decisions, encouraging open communication between all. To be achieved by:
- Achieving a clear understanding of the patient pathway
- Improving support to clients and carers
- Designing a model rehabilitation plan
- Creating a new role of community rehabilitation assistant
- Improving the service of the local Headway by increasing funding for staff working hours.

### How changes were made
- A questionnaire was sent to all known carers of acute brain injury clients in the area, asking for their views on what support they needed. As a result of this, a large part of the project has concentrated on improving information and communication
- A process-mapping event was held to show the pathway that patients with acute brain injury follow.
- The rehabilitation plan was designed by a group who included members of the Community Neuro Rehabilitation Team, Headway, Social Services, the acute trust and carers. This is an assessment record that focuses on goals for the brain injured person, and is accessible by all agencies involved in that persons care.
- A rehabilitation assistant was appointed to deliver care in the home environment.
- Funding was allocated to extend the staff hours at Headway, to allow essential activities such as training and debriefing to be carried out prior to, and after client attendance hours. Research into best practice is ongoing and changes to the structure of the day’s programmes are being made.

### Outcomes
- The rehabilitation plan uses the 13 functions of day-to-day living and assesses how the client is currently able to function in each of these areas. The plan is kept in a folder and held by the patient so that it is available to anyone involved in the care of the client.
- A video has been produced for carers and professionals, showing what support is available locally. A carer support manual has also been produced, giving information on all aspects of living with a brain injured person. Carer support meetings have been promoted and the content updated. The possibility of a carer support telephone line is also being considered, as well as the appointment of an acute brain injury coordinator. Information for professionals caring for these patients has been revised and updated, and made more widely available.
- The key responsibility of the community neuro rehabilitation assistant is to assist in the delivery of cognitive rehabilitation programmes, including working on a one-to-one basis with clients. Initial review of this post is positive.
- Increased funding to extend the working hours of the Headway team has allowed essential activities such as training and debriefing to be carried out prior to, and after client attendance hours. Research into best practice is ongoing and changes to the structure of the day’s programmes are being made. Initial feedback from both staff and clients is very positive.

### Conclusions / Lessons learnt
- Qualitative data has shown that this project demonstrates the value of ensuring that carers are fully consulted and involved in any changes. As a result of the carer questionnaire the team were clear about what carers didn’t want, as well as what they did want.
- In order for patients to have access to a seamless service, it is essential for communication between professional group and across organisational boundaries to be continuously improved. As a result of the work of the project, other services within the patient pathway are changing their practice.
- The project has demonstrated that this model of care is successful, and could potentially be used for other patient groups.

Clinical leads: Liz Grice Consultant Clinical Psychologist Email: Liz.grice@nhpct.nhs.uk / Margaret Topping, Specialist Nurse, margaret.topping@nhht.nhs.uk
Project Manager: Vanessa Harding, vanessa.harding@nhpct.nhs.uk
East Elmbridge and Mid Surrey PCT and Epsom and St Helier NHS Trust

Neurology Pro-Active Care Team (PACT) approach

Background
Patients with neurological conditions are largely dealt with on an outpatient basis, and because disease-specific data is not recorded for neurology outpatients, it is impossible to collect accurate information to understand the caseload. The neurologist works from the District General Hospital generally in isolation from community services. Referrals can take up to 12 weeks for a first consultation after which some patients are followed up – others are referred back to their GP without any further appointment. If these patients are not then seen within a year, they are then termed as new patients again. There is no single map for the current patient journey. There are maps for single services, such as physiotherapy, or for short term access to a neurologist, but most journeys are not co-ordinated with other services, and discharge the patient after an episode of care or activity. This means in practice that patients are often bewildered about who to turn to for help in navigating the system.

Aims and Objectives
The aim of the Pro-Active Care Team approach is to improve services for people affected by neurodegenerative conditions such as Multiple Sclerosis and Parkinson’s Disease by:

- Reducing waiting times for reaccess to specialist opinion
- Co-ordinating timely, concurrent, multiple access to a wide range of multi-disciplinary, multi-agency services including the neurologist
- Setting up a register and profile of the caseload
- Supporting patient self-management
- Introducing regular review
- Providing a single point of contact for the service
- Providing or signposting timely and targeted information
- Preventing avoidable deterioration, hospital admissions, or prolonged in-patient episode.

How changes were made

- A Pro-Active Care Team Service has been established with core membership – neurologist, GP, Speech and Language therapist, physiotherapist, occupational therapist, social care manager, psychologist and secretary.
- All referrals to PACT are assessed initially by the lead GP, but Parkinson’s Disease and Multiple Sclerosis Nurse Specialists have now also been appointed. Many issues are dealt with at this point. Patients needing multidisciplinary input can be discussed or seen at the bi-monthly PACT clinic.
- A review date, no more than one year, is identified.
- Registration forms help build up a picture of individual and caseload needs, for better-informed commissioning
- A single point of contact for the service has been set up so that patients and carers have access to information and advice
- Relationships have been developed with the local voluntary organisations to ensure a comprehensive approach to care
- Links with the Expert Patient Programme co-ordinator have been established with a view to helping people manage life with their conditions.
- Patient and staff questionnaires have provided feedback about the new service

Outcomes

- Effective multidisciplinary/multi-agency working has resulted in a more efficient and integrated service
- The PACT approach enables referrals to be better managed, ensuring that people receive the right level of support
- The service is able to offer co-ordinated specialist assessment for those with complex needs
- Professionals have a much better understanding about what each service can offer and an increased awareness of initiatives for carers and ability to signpost resources
- The contact number facilitates easy reaccess to the PACT service and enabled patients to access information more easily
- As the caseload patients become known, there is potential for prevention and early treatment, e.g. urinary tract infections, pressure sores, avoiding unplanned admissions
- Extremely enthusiastic staff feedback on the benefits of the PACT clinics and their teaching potential, and reduction of professional isolation. This has increased confidence and has the potential to avoid some patients just being referred back to the OPD waiting list, when a little more knowledge and support enables other professionals to deal appropriately. Effects are subtle and difficult to measure, especially in the short term on a small scale.
- Feedback from patients who have had direct contact with elements of the service, such as the helpline, or the clinic has been very positive.

Conclusions / Lessons learnt

- Although the lack of availability of quantitative data has made it difficult to assess the impact of the service on waiting times, qualitative measures demonstrate the benefits of this way of working for both staff and patients
- The PACT approach has provided a real focus for building relationships across organisational boundaries and providing integrated care to people with multiple needs
- The project was limited to people with Multiple Sclerosis and Parkinson’s Disease but referrals for people with other conditions such as Motor Neurone Disease showed that there was an unmet need that the PACT approach could address.

Project Clinical Leads: Dr Stephen Wilson Consultant Neurologist, Stephen.Wilson@doctors.org.uk or Susan.huxtable@epsom-sthelier.nhs.uk
Dr Susan Mitchell General Practitioner, Susan_Mitchell@dial.pipex.com
Project Manager: Lesley Rice, Lesley.rice@eeandms-pct.nhs.uk
## APPENDIX B

### Membership of the *Action On* Neurology National Steering Group

<table>
<thead>
<tr>
<th>Action On Team</th>
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<tr>
<td>Nick Evans</td>
<td><em>Action On</em> Programme Director</td>
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<tr>
<td>Dr Phillip Barnes</td>
<td><em>Action On</em> Neurology Clinical Lead</td>
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<tr>
<td>Sue Barrow</td>
<td><em>Action On</em> Neurology Associate Director</td>
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<tr>
<td>Debbie Ingleby</td>
<td><em>Action On</em> Neurology Programme Manager</td>
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<tr>
<td>Julia Johnson</td>
<td>Allied Health Professionals Federation / Royal College Speech and Language Therapy</td>
</tr>
<tr>
<td>Rosamund Wade</td>
<td>Allied Health Professionals Federation / Association for Chartered Physiotherapists interested in Neurology</td>
</tr>
<tr>
<td>Dr David Bateman</td>
<td>Association of British Neurologists</td>
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<tr>
<td>Dr Stephen Pollock</td>
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<td>Dr Graham Venables</td>
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<td>Dr Stephen Wroe</td>
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<tr>
<td>Carole Kirrane</td>
<td>British Association of Neuroscience Nurses</td>
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<tr>
<td>Alison Stewart / Fiona Mackinnon</td>
<td>British Association of Neuroscience Nurses</td>
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<tr>
<td>Dr Richard Newton</td>
<td>British Paediatric Neurology Association</td>
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<tr>
<td>Judith Sergeant</td>
<td>Department of Health – Older People and Disability Division</td>
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<tr>
<td>Chris Morley</td>
<td>Epilepsy Nurse Specialist Association</td>
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<td>Caroline Dunn</td>
<td>Electrophysiological Technicians Association</td>
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<td>Jo Garside</td>
<td>Joint Epilepsy Council</td>
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<tr>
<td>Barbara Howe</td>
<td>London Specialist Commissioning Group / NSF for Long Term Conditions Implementation Group</td>
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<tr>
<td>Judith Kidd</td>
<td>The Neurological Alliance</td>
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<td>Mike O’Donovan</td>
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<tr>
<td>Dr Leone Ridsdale</td>
<td>Royal College of General Practitioners</td>
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<td>Dr Henry Smithson</td>
<td>Royal College of General Practitioners</td>
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<tr>
<td>Dr Phil Anslow</td>
<td>Royal College of Radiologists and British Society or Neuroradiologists</td>
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<tr>
<td>Jeff Jerome</td>
<td>Social Services</td>
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### Useful information

These lists are not intended to be exhaustive, and inclusion here does not necessarily imply support or approval by the Action On Neurology Steering Board.

**Organisations and Professional Bodies**

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<td>Association of British Neurologists</td>
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<td>Joint Neuroscience Committee</td>
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<td>Primary Care Neurology Society</td>
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<td>National Patient Access Team</td>
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**Website addresses for professional bodies that currently comprise the Allied Health Professions Federation (AHPF):**

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<td>British Association/College of Occupational Therapists (COT)</td>
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<td>Society and College of Radiographers (SCoR)</td>
<td><a href="http://www.sor.org">www.sor.org</a></td>
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<td>The Society of Chiropodists and Podiatrists (SCP)</td>
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## Voluntary Organisations and patient support groups

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<td><a href="http://www.healthcareforcarers.co.uk">www.healthcareforcarers.co.uk</a></td>
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SOME USEFUL DOCUMENTS FOR REFERENCE

(this list is not exhaustive and additional information can be found in the NSF for long Term conditions and its associated Good Practice Guide).

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<td>UK Neurology – the next ten years</td>
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<td>Department of Health</td>
<td>Improvement, expansion and reform – the next 3 years: priorities and planning framework 2003-2006</td>
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<td>Practitioners with Special Interests: A step by step guide to setting up a General Practitioner with a special interest (GPwSI) Service</td>
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APPENDIX D

References

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8 MacDonald BK, Cockerell OC, Sander JNAS, Shorvon SD. The incidence and lifetime prevalence of neurological disorders in a prospective community-based study in the UK. Brain 2000, 123: 665-676.