



The National Service Framework for Long-term Neurological Conditions

National Support for Local Implementation 2008

DH INFORMATION READER BOX

Policy	Estates
HR / Workforce Management	Commissioning
Planning / Clinical	IM & T
	Finance
	Social Care / Partnership Working

Document Purpose For Information

ROCR Ref: **Gateway Ref:** 9758

Title LTC NSF - National Support for Local Implementation 2008

Author Beverley Hopcutt, DH

Publication Date April 2008

Target Audience PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs ,

Circulation List Directors of Adult SSs

Description The document is intended as a resume for Health and Social Care practitioners updating them on tools, guidance, resources and DH initiatives that have been produced since the NSF was launched 3 years ago.

Cross Ref Long-term Conditions NSF
LTC Compendium of Good Practice

Superseded Docs N/A

Action Required N/A

Timing N/A

Contact Details Helen Wiggins
Social Care, Local Government & Care Partnerships
Room 8E25, Quarry House
Quarry Hill, Leeds
LS2 7UE
0113 2546486
www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Long-termNeurologicalConditionsNSF

For Recipient's Use

© Crown copyright 2008

First published 6 May 2008

Published to DH website, in electronic PDF format only.

<http://www.dh.gov.uk/publications>

The National Service Framework for Long-term Neurological Conditions

National Support for Local Implementation 2008

Prepared by Beverley Hopcutt, Clinical Adviser, Long-term (Neurological) Conditions

NSF

Contents

Contents.....	5
Executive summary.....	7
1. NSF Specific Resources & Initiatives	8
a. Care Planning Guidance	8
b. Vocational Rehabilitation (QR6)	8
i. Multi-agency guidance on vocational rehabilitation for Long-term Neurological Conditions.....	8
ii. Survey to map vocational rehabilitation services.....	8
c. Liverpool Care Pathway for LTNCs (QR9)	8
d. Good Practice Guide	9
i. Examples of good practice	9
ii. Costings paper	9
iii. Guidance papers – tackling key issues	9
e. Development of neurological minimum dataset.....	9
f. Workforce	9
i. Development of a LTNC workforce.....	9
ii. Skills for Health NSF competences	9
g. NSF Research Programme	10
2. National Underpinning Programmes.....	10
a. 8 week wait from referral to treatment pathways for neurology	10
b. New framework for commissioning and outcomes	10
c. The Operating Framework for 2008/09.....	11
d. Local Area Agreements (LAAs)	11
e. Payment by results and tariff development.....	11
f. Review of specialised commissioning definitions for neurosciences	11
3. Other Initiatives	11
a. Choice	11
i. Generic choice model for long term conditions (QR1).....	11
ii. NHS choices (QR1).....	12
b. Information Prescriptions (QR1)	12
4. Supporting People with Long Term Conditions Programme.....	13
a. Supporting People with Long Term Conditions to Self Care: a Guide to Developing Local Strategies and Good Practice (QR1).....	13
i. Care Planning Guidance for Commissioners (QRs 1 & 5).....	13
ii. Raising the Profile of Long Term Conditions Care: A compendium of Information.....	13
b. Stroke Strategy (All QRs)	13
c. Institute of Knowledge	13
i. Map of Medicine (QR2)	14
ii. National Electronic Library for Health specialist neurology branch.....	14
iii. Electronic-learning for healthcare	14
d. Individual budgets (QR8).....	14
e. NHS Continuing Healthcare Framework (QR8).....	14
f. End of Life Care (QR9).....	15
i. End of Life Care	15
ii. Prognostic Indicator Guidance (2006)	15
iii. Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care services (2008)	15

g.	Healthcare Commission	15
i.	Better Metrics	15
ii.	National Patient Survey on LTNCs.....	16
h.	NHS Next Stage Review (Lord Darzi’s review of the NHS)	16
i.	Transitions from children’s to adult services.....	16
j.	LINKs	17
k.	Equality Impact Assessment	17
5.	Care Services Improvement Partnership (CSIP) Resources and Initiatives	17
a.	NSF Website and Community of Interest	17
b.	Commissioning Services for People with Long-Term Neurological Conditions	17
c.	10 Quick Wins to Support Long-Term Neurological NSF Implementation	18
d.	National Events	18
e.	Regional Development Centres (RDCs).....	18
6.	Third Sector.....	19
a.	The Neurological Alliance NSF Action Plan.....	19
b.	Resources and Tools.....	20
i.	Information Access Toolkit (QR1).....	20
c.	Getting the Best from Neurological Services (QR1)	20
d.	Personalised information about the LTNC (QR11)	20
e.	MS Society Audit Tool Quality Neurology.....	20
f.	Commissioning a Year of Care.....	21
g.	Taking Control	21

Executive summary

This document is the product of collaboration between the Department of Health, Care Service Improvement Partnership (CSIP) and the Third sector, and gives an overview of resources, tools and initiatives that are/will be available to support local implementation of the National Service Framework for Long-term (neurological) Conditions (NSF). There is a brief description of each item, with web addresses where relevant.

The NSF was published in March 2005 with a 10-year implementation period. It sets 11 quality requirements to improve treatment, care and support from diagnosis to the end of life for people with neurological conditions. It underlines the need for appropriate, integrated services planned and delivered around individual needs, and to support people to live independently with good quality of life.

Since publication of the NSF, the Department has provided service planners, commissioners and providers with guidance, expert advice and support to help them to deliver the NSF's quality requirements. However, in line with devolving responsibility to local organisations, we are moving to new phase with much greater emphasis on local health and social care communities and the third sector taking responsibility for driving forward service change and improvement. This also recognises that the NSF is not a stand-alone priority but that it needs to be closely aligned and integrated into mainstream NHS and Social Services local activity. The Third sector, including the Neurological Alliance, are looking at ways of aligning their work with local health and social care communities' priorities so that they can fully support local implementation.

This is a summary of resources, tools and guidance that are available to local commissioners and service providers to support local delivery of the NSF. It includes

- an outline of DH's NSF programme including work still in progress, and other relevant resources from key broader programmes
- tools and awareness raising activities developed by the Care Services Improvement Partnership,
- resources developed by the Third sector and a programme of future actions

1. NSF Specific Resources & Initiatives

a. Care Planning Guidance

Good care planning for people with long-term conditions: updated version. September 2005. This resource contains user-friendly guidance on good care planning for people with long-term conditions, and tools to support health and social services to deliver effective person-centred care planning. While the pack has generic application, experts in neurological conditions were heavily involved in its development, and there is a neurorehabilitation case study.

http://www.networks.nhs.uk/uploads/2005_Oct/CarePlanningReportSep05.pdf

b. Vocational Rehabilitation (QR6)

i. Multi-agency guidance on vocational rehabilitation for Long-term Neurological Conditions

DH has commissioned the British Society of Rehabilitation Medicine (BSRM) to develop multi-agency guidelines for LTNCs to complement the Vocational assessment and rehabilitation after acquired brain injury interagency guidelines produced in 2004. This will be a good practice resource to help local providers across the NHS, local authorities and JobCentre Plus develop the capacity and capability to deliver high-quality local vocational rehabilitation. The guidelines are due to be published in Summer 2008 on the BSRM website: www.bsrn.org.uk

ii. Survey to map vocational rehabilitation services

The findings of a survey conducted by the BSRM in 2007 is reported on the CSIP LTC community website www.longtermconditions.csip.org.uk

c. Liverpool Care Pathway for LTNCs (QR9)

The End of Life Care national programme has commissioned the development of a neurological Liverpool Care Pathway. This will enable practitioners to meet the specific palliative care needs of people with LTNCs as they near the end of life. This project will start in 2008 and take about 18 months to develop and pilot. See www.mcpcil.org.uk

d. Good Practice Guide

i. Examples of good practice

This was originally produced in 2005, and has been updated in 2006 and 2008. The examples in the guide are listed under each Quality Requirement (QR) and identify services and developments, which are judged to be good practice (as measured against a defined set of criteria). These examples could be used by other services looking to develop similar initiatives, and staff are willing to share their experiences, expertise and resources to support colleagues.

ii. Costings paper

This is a synopsis of research papers and reports which contain information about the cost benefits of implementing aspects of the QRs, and is particularly helpful when writing business cases.

iii. Guidance papers – tackling key issues

- Care coordination
- Service models
- Local information provision

www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Longtermconditions/Bestpractice/index.htm

e. Development of neurological minimum dataset

The project, sponsored by DH, is managed by the Information Centre, and is aiming to produce a set of data items that can be easily extracted from the NHS record system. This dataset will be useful for identifying epidemiological information about people with LTNCs and their needs as service users, and for identifying whether services are meeting key clinical indicators and markers of good practice defined in the NSF. Commissioners will use this information to inform Joint Strategic Needs Assessments, and to help them to monitor the quality of service provision. The project is due to complete its work at the end of 2010.

f. Workforce

i. Development of a LTNC workforce

The DH workforce team has commissioned NHS National Workforce Projects to produce a resource pack to help local commissioners and providers develop the multi-professional workforce involved in the delivery of services to people with neurological LTCs. This will be launched by the Minister at a LTC Conference on 1 May 2008.

ii. Skills for Health NSF competences

Skills for Health has produced a set of competences which define the skills required to deliver services for people with LTNCs described in the NSF.

There are a number of tools which enable the competences to be used when generating job descriptions and producing job profiles.

www.skillsforhealth.org.uk/tools/view_framework.php?id=95

g. NSF Research Programme

Initially the NSF was allocated £2 million funding and six research projects were commissioned. A further £1 million funding was made available in 2007 and it is anticipated that four more projects will be commissioned in spring 2008. The projects look at different aspects of implementing the NSF, and will provide useful tools and information for commissioners and service providers.

The original 6 research topics are:

- i. Integrated services: impact of the NSF
- ii. Needs & experiences of people with progressive neurological conditions
- iii. Carer support needs
- iv. Palliative care needs in late stage LTNCs
- v. Transition into adulthood in Duchenne MD
- vi. Fitness enablement programme for LTNCs

The overall programme is due to end in 2010. For further information and regular newsletter see www.ltncc.org.uk

2. National Underpinning Programmes

a. 8 week wait from referral to treatment pathways for neurology

Care pathways for five important neurological conditions have now been rolled out to commissioners and are available on the website. Work proceeds on workforce planning to achieve the workforce needed. A national event is planned in April 2008 to help support neurology clinical directors and general managers deliver the 18 week referral to treatment Public Service Agreement target. See www.18weeks.nhs.uk

b. New framework for commissioning and outcomes

World-class commissioning is about creating world-class clinical services and a world-class NHS that improve health outcomes and reduce health inequalities. By improving their commissioning and by working closely with local authorities, Primary Care Trusts (PCTs) will be better able to invest in order to achieve high-quality and personalised services that improve health and wellbeing for their local population.

The Department is collaborating with partners to develop four key elements of the work- outcomes, vision and competencies, an assurance system, and a support and development framework. The assurance system, managed by Strategic Health Authorities, will drive performance and development and reward commissioners as they move towards world-class status. There will be local emphasis on “vital signs” that PCTs are focusing on in relation to health improvement, reducing inequalities and building public confidence and patient satisfaction. The organisational competencies that a world-class commissioner will need have been published. A support and development framework is also

being developed that will offer resources for sharing, for internal building capacity, and for buying in external expertise.

c. The Operating Framework for 2008/09

This clarifies the health and service priorities for the year ahead. These include:

- Improving access through achievement of the 18-week referral to treatment pledge
- Keeping adults and children well, improving their health and reducing health inequalities. PCTs will need to make particular progress driving up standards of care to reduce mortality and morbidity through implementation of the stroke strategy
- Improving patient experience, staff satisfaction, and engagement

In addition to these national priorities, PCTs will need to set local improvement plans for areas of concern identified through consultation with patients, public and staff, Joint Strategic Needs Assessment, and in agreement with partners.

d. Local Area Agreements (LAAs)

By June 2008, new LAAs should have been agreed for each English locality. PCTs and NHS trusts now have the opportunity to work with their partners in their Local Strategic Partnership (LSP) to agree LAA priorities for local people that improve health outcomes.

e. Payment by results and tariff development

Work is underway led by expert clinicians to develop a currency i.e. groupings or bundles of care services which are similar in terms of care delivered and resources used, that are sensitive to the different requirements of people with complex long-term care needs at different stages of the patient journey. These currencies are developmental and a tariff based on them will not come into use until 2011 at the earliest.

f. Review of specialised commissioning definitions for neurosciences

There is a phased review by the National Specialised Services Commissioning Group (NSSCG) of which services / aspects of services should be viewed as specialised for the purposes of commissioning. Neurosciences, spinal surgery and neurorehabilitation are currently under review in the first phase.

3. Other Initiatives

a. Choice

i. Generic choice model for long term conditions (QR1)

This guidance published in December 2007 demonstrates how people with long-term conditions can be offered more choices around treating their

condition. It illustrates how a collaborative approach to care planning between the health professional and the patient can identify a range of specific options tailored to suit the individual.

The model is intended to be generic, flexible and for local adaptation. It is flexible in that it can be applied to either one person or a group of people, to people with one condition or a number of conditions, and to all age groups.

Although the model is generic, its application to long-term neurological conditions is demonstrated in one of the illustrative case studies about a person living with multiple sclerosis. See: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081105

ii. NHS choices (QR1)

This website gives the individual information so they can make informed choices about their health and healthcare. This information includes comparison data on waiting times and treatment outcomes intended to allow people to choose between hospitals, lifestyle information on subjects such as smoking cessation, and information about local primary and community care services. See: www.nhs.uk

b. Information Prescriptions (QR1)

Information prescriptions, to be available from 2008, ensure that people with long-term health conditions or social care needs, and their carers, receive timely information they need to help them manage their condition. They include helpful and relevant information, for example about conditions and treatments, care services, benefits, and support groups. They contain links or signposts to sources of information about local health, social care, and other services, usually phone numbers, websites etc. Information prescriptions are given to people by their health and social care professionals, and will help individuals to access information when they need it and in the ways that they prefer.

To ensure the successful design and delivery of information prescriptions, the DH recruited 20 pilot sites to test and provide evidence of their effectiveness and their impact on the individuals, professionals and organisations. The piloting phase came to a close in January 2008. The information and momentum built through this piloting phase is being used to help shape what support is needed nationally to help organisations consider how to implement Information Prescriptions locally to meet the needs of their local populations.

A dedicated website has been set up to provide instant access to all the latest developments. <http://www.informationprescription.info/>

The interim report has already been published with initial findings from the pilots. A report summary will be available from 19 March and the full report from 30 April. To help organisations introduce information prescriptions locally, an online

resource pack is also being developed that provides practical examples of the approaches taken to implementation gathered from twenty pilot sites.

4. Supporting People with Long Term Conditions Programme

a. Supporting People with Long Term Conditions to Self Care: a Guide to Developing Local Strategies and Good Practice (QR1)

This was published in February 2006 and it aims to help health and social care staff to promote and support self-care for people with long-term conditions. The guide describes how people with long-term conditions can be supported in the main components of self-care, which are information, self-monitoring devices, self-care skills and self-care support networks. Examples of good practice refer to neurological conditions including Parkinson's disease, acquired brain injury, and stroke.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4130725

i. Care Planning Guidance for Commissioners (QRs 1 & 5)

This is due to be published in early 2008 and outlines the benefits of effective care planning for people with long term conditions. It shows how the process can be supported through the commissioning of health and social care services that place the individual at the centre of their care and engage them in individualised care planning. Multidisciplinary teams which offer integrated assessment and joined up services support this approach. This will be followed by a companion guide which is aimed at staff who provide services.

ii. Raising the Profile of Long Term Conditions Care: A compendium of Information

Published in January 2008, the compendium provides compelling evidence for the commissioning and provision of a variety of health and social services to provide care and support for the growing numbers of people with long-term conditions. It includes a number of case studies highlighting the benefits of implementation of aspects of the long-term conditions model published in 2005.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082069

b. Stroke Strategy (All QRs)

Published in 2007, this cites the NSF as an important framework for improving stroke services. Stroke services need to be considered as part of the overall plan for developing high quality community rehabilitation and support services for people with LTNCs. This is particularly relevant for stroke survivors with long-term needs related to residual disabilities. www.dh.gov.uk/stroke.

c. Institute of Knowledge

i. **Map of Medicine (QR2)**

This is a clinical decision-making tool. It helps doctors to make clinical decisions about assessment and treatment options. The information is presented in the form of care pathways which are based on the best available evidence. See www.mapofmedicine.com

ii. **National Electronic Library for Health specialist neurology branch**

This is organised under different disease headings, and enables access to clinical guidance and pathways, recent research publications to inform the evidence base for practice, conference proceedings and other useful information including links to websites to promote continuing professional development. See: www.library.nhs.uk/specialistlibraries/.

iii. **Electronic-learning for healthcare**

A successful bid for funding will lead to the development of a multi professional learning tool to help develop the knowledge and skills of the workforce

d. **Individual budgets (QR8)**

Individual Budgets have been piloted in 13 local authorities for people eligible for services from the local authority's social services department. In addition to social care, a number of other income streams have been tested; Independent Living Funds, Supporting People, Access to Work, Disabled Facilities Grant, Integrated Community Equipment Services. The central idea behind the individual budget concept is to provide individuals who need support with greater choice and control over this and to place the person at the centre of the process. People have been enabled to design their own support in a way that best suits their own particular requirements with the knowledge early in the process of the level of finance that is available to them, and to manage the funding to provide that support (with help from a broker or advocate, family or friends if needed). People have been able to take this as a cash payment, a notional sum and a service or a mixture of both. The pilot ended in December 2007, and the evaluation report is due later in 2008.

e. **NHS Continuing Healthcare Framework (QR8)**

Implemented from 1 October 2007, the Framework sets out a single, national system for determining eligibility for adult NHS Continuing Healthcare in England so that people with equal needs should have an equal chance of getting all their care provided by the NHS. Subject to clinical safety, and the obligations of the NHS to provide a comprehensive health service to other service users (i.e. the way the service is provided should not use resources to a disproportionate extent), this care can be provided in any setting – including an individual's own home. When an individual is assessed for fully funded NHS continuing healthcare, this is based on the totality of an individual's physical and mental healthcare needs arising from one or more disability, accident or illness.

Care domains considered as part of the Decision Support tool include behaviour, cognition, communication, psychological/emotional wellbeing in addition to physical abilities such as mobility. See:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_076288

f. End of Life Care (QR9)

i. End of Life Care

During 2007 a number of working groups were set up to inform the development of a national End of Life Care Strategy for adults. The Strategy will deliver increased choice to all adult patients, regardless of their condition, about where they live and die. Part of the work has included the development of a care pathway for all life-limiting conditions. End of life care is also one of the eight Pathways the SHAs will examine as they produce the reports that will help shape the NHS Next Stage Review. The emerging findings from the Strategy have been shared with SHAs to inform the Review and we will then take account of this important local work in the development of the national Strategy. The Review and the Strategy will be published at the same time, in summer 2008.

ii. Prognostic Indicator Guidance (2006)

In LTNCs it is often difficult to make an accurate prognosis as to how close the end of life actually is. This guidance identifies trigger points in different illnesses which may be useful prompts for a healthcare professional to initiate discussions about end of life. LTNCs covered in this tool include motor neurone disease, Parkinson's disease, multiple sclerosis, dementia and stroke. See:

www.goldstandardsframework.nhs.uk/content/gp_contract/Prognostic%20Indicators%20Guidance%20Paper%20v%2025.pdf

iii. Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care services (2008)

These guidelines were developed through collaboration between the National Council for Palliative Care, the BSRM and the Royal College of Physicians, and are published as part of the latter's concise guidance series. They contain some useful tools including a checklist for use with people with LTNCs on admission to hospital, and key areas of symptom management with evidence-based care pathways

See: <http://www.rcplondon.ac.uk/standards.asp>

g. Healthcare Commission

i. Better Metrics

'Better Metrics' are more clinically relevant sets of clinical indicators that have been developed for various NSFs and other national policies. The LTNC NSF's 14 indicators closely reflect the content of the 11 QRs, and

many are based on performance indicators suggested by the NSF External Reference Group during development of the NSF. In the absence of national milestones and the range of needs and conditions that the NSF covers along the care pathway, it is difficult to devise specific clinical indicators which will apply to all individuals at all times. For many metrics the care plan will be a key tool for identifying whether the indicators are a) appropriate to the individual and b) have been delivered for that individual. http://www.healthcarecommission.org.uk/db/documents/Chapter_7_Long-term_neurological_conditions-The_Better_Metrics_project_v8-Nov07.pdf

ii. National Patient Survey on LTNCs

In 2007 the Healthcare Commission funded a feasibility study into a neurological national patient survey, and is planning to include a scoping survey of people with LTNCs in its work programme for 2008-09. It is a sample survey, so it is not designed to assess the performance of individual organisations. A report of the findings will be published and will be a useful indicator of progress in implementing the NSF based on patient experience of using local services across England.

h. NHS Next Stage Review (Lord Darzi's review of the NHS)

Long-term conditions is one of the eight health topics addressed by the review. Working groups have been set up in all Strategic Health Authorities to identify how to develop and modernise their local health services to promote good practice. The findings of the review will be reported in Summer 2008 and are likely to have wide-reaching implications for commissioners and providers of healthcare.

i. Transitions from children's to adult services

Moving on Well: A good practice guide for health professionals on transition planning for young people with complex health needs or a disability.

More children are now surviving into adulthood with conditions, which once would have been fatal in childhood. However, this often means the young person will have on-going health problems for which they will need to continue receiving care.

As the young person, approaches the time when they will leave children's services they and their families can become worried about the future, particularly as in many instances they are well known to staff within the children's health services. The manner in which their transfer to the adult healthcare system is handled is therefore crucial to their continued health and well-being and their willingness to continue and comply with treatment. It is important that this transition is seen as process and not a single event with preparation starting early ensuring that GP's and adult services are closely engaged with children's services colleagues in preparing the young person for the eventual transfer of care.

This good practice guide provides a tool for all health professionals and their partners in children's, adults and primary care services to work with the young

person and their family for greater independence and transfer to the adult healthcare environment.

j. LINKs

Local Involvement Networks (LINKs) are due to be established from April 2008. They provide a way for people and communities to engage with health and social care organisations to make sure that they are more accountable to the public. As the new LINKs will now cover a whole area rather than being tied to a specific organisation it will ensure that planning of services will be properly joined up even when they are provided by a range of organisations. It is hoped that a greater range of people will become involved in health and social care planning through LINKs.

k. Equality Impact Assessment

The [Equality Standard for Local Government](#) (2001) requires the Local Authority to impact assess for gender, disability, sexual orientation, age, and religion and belief. An Equality Impact Assessment - also known as an Impact, Needs and Requirement Assessment (INRA) - systematically assesses and records the actual, potential or likely impact of a significant change in or development of a service, policy or project on different groups of people, so that any negative consequences can be eliminated or minimised, and opportunities for ensuring equality can be maximised.

5. Care Services Improvement Partnership (CSIP) Resources and Initiatives

a. NSF Website and Community of Interest

In 2006 CSIP created a website dedicated to the Long Term Conditions NSF in partnership with the Department of Health. The website is designed to provide a virtual network for people interested in neurological conditions.

Three interlinked parts of this website work together:

- To bring information about the NSF together in one place.
- To provide a web based self assessment tool on achievement towards the Quality Requirements, provide pointers towards information and expertise to help local services with implementation and to track progress.
- To allow a community of people with a common interest in long-term neurological conditions to work together, share ideas and knowledge and achieve more than may be possible when working in isolation.

Use of the website has increased over time, and monthly hits reached over 48,000 in January 2008 with over 800 registered members.

See: www.longtermconditions.csip.org.uk

b. Commissioning Services for People with Long-Term Neurological Conditions

This web-based guidance on commissioning services for people with Long-term Neurological conditions is designed to provide practical information and assistance to those involved in commissioning, arranging and providing services. It is a product of regional workshops in which the roles of commissioners, practitioners and clinicians were examined with a view to improving commissioning practice and improving outcomes for end users. It provides a checklist, which commissioners may use to help assess their current practice. See: <http://www.longtermconditions.csip.org.uk>

c. 10 Quick Wins to Support Long-Term Neurological NSF Implementation

The 10 Quick Wins poster and leaflet was developed with input from professional and third sector stakeholders. It focuses on high priority and high impact areas where organisations and professionals can make a big difference in local service provision without the need for additional funding and resources including:

- designating a lead for the long-term neurological conditions NSF in PCTs, SHAs and Social Care
- establishing a local implementation group
- providing information and advice to service users
- developing local self-care and self-management provision
- using integrated assessment processes to identify a person's holistic needs
- appointing practitioners with specialist skills, knowledge and expertise in neurological conditions
- implementing 18 week referral to treatment pathways for neurological conditions
- establishing multi-agency health and social services' community rehabilitation and support services
- improving the quality of specialised home care and community services

The 10 Quick Wins also support the Department of Health's plan to encourage local health and social care communities and the third sector to work together to implement the NSF for Long-term Conditions by embedding it in mainstream local activity. The poster and leaflet have been widely distributed including Commissioners in Health and Social Care Organisations.

See: <http://www.longtermconditions.csip.org.uk>

d. National Events

In March 2006, CSIP hosted a series of events around the country on behalf of the Department of Health. The events enabled organisations to develop their understanding of the NSF requirements and provided opportunities for local partners to identify the next steps for implementation. For presentations see CSIP NSF website.

e. Regional Development Centres (RDCs)

CSIP provides support for both policy development and implementation support to local organisations. Its programmes are delivered principally through its eight regional development centres (RDCs). The PSI team has lead the work on the

NSF, and the main focus of work has been to identify key personnel within SHAs, PCTs, specialist commissioners, local authorities and the voluntary sector. The scoping of NSF progress across the eight RDCs has indicated that initial progress and partnership working was hampered due to the restructuring of PCTs and implications for commissioners. Competing priorities with other long-term conditions and a perception that the neurology numbers are relatively low has also impeded progress. However more recently CSIP found that partnership working is starting to develop and in a number of RDCs there are excellent examples of both strong partnership boards and third sector engagement. Work to date has identified nine SHA long term condition leads and discussions have taken place on the impact of neurological conditions and links with other long-term conditions initiatives. Networks of contacts have been developed in each RDC including specialist commissioners and third sector organisations.

The initial scoping work has resulted in further bespoke activity some of which is illustrated below:

North East and Yorkshire and Humber: two events in March 2008; the first on strategic and specialist commissioning, the second on clinical and workforce issues.

South West: work with the South West Alliance of Neurological Organisations to plan a regional event for health and social care commissioners to promote the NSF and launch a directory of services.

London: conference planned for April 2008 to progress QRs 5 and 6 (community and vocational rehabilitation). The aim is to establish five sector networks involving PCTs, local authorities and the voluntary sector.

East Midlands: support for development of partnership working with a particular emphasis on voluntary sector engagement.

South East: joint CSIP and SHA initiative to establish a South Central network. A Share and Celebrate event held in February 2008, and support to a significant number of partnership boards.

6. Third Sector

a. The Neurological Alliance NSF Action Plan

The third sector is committed to continue working to advance implementation of the LTNC NSF both independently as individual organisations for people with specific neurological conditions and collectively, through the Neurological Alliance, the umbrella group that unites over 50 third sector organisations. They are committed to building capacity to working *locally* to make it easier for commissioners, managers and clinicians to make implementation happen. The Neurological Alliance has produced an NSF Action Plan which contains a number of commitments for actions over the next 3 years to support local implementation including:

- support for effective commissioning;

- empowering of service users to get the best from services through improved information provision;
- strengthening of service user involvement in service planning and delivery;
- developing the role of regional neurological alliances, and monitoring of progress on implementation of the NSF.

See:

b. Resources and Tools

The Third sector has produced a number of tools and resources to support delivery of the NSF.

i. Information Access Toolkit (QR1)

This web-based toolkit, developed with DH Section 64 funding, helps provide good quality reputable information relevant to people living with LTNCs. The toolkit does not add new information to the wealth that already exists, but signposts and links to reliable sources. It also provides some examples of good practice, model policies and guidelines. There is a particular focus on the type of information that people with neurological conditions have said that they want more of, and the issues that health and social care professionals said they have problems accessing. There is also guidance about producing local information resources as this is an area highlighted by all as particularly important. This is also relevant to local work on developing information prescriptions.

See: www.brainandspine.org.uk

c. Getting the Best from Neurological Services (QR1)

This guide, developed and updated in 2006 by the Neurological Alliance with DH funding, provides a useful overview of services for people with neurological conditions. It acts as a signpost to the various sources of help that are available including patient support groups. See:

http://www.neural.org.uk/pages/online_ordering/GettingtheBestfromNeurologicalServices.asp

d. Personalised information about the LTNC (QR11)

A number of the voluntary sector organisations eg the MS Society, the Motor Neurone Disease Association have produced condition specific forms and leaflets for people with a LTNC to complete in anticipation of care by unfamiliar providers eg prior to admission to hospital or respite care. The Neurological Alliance has also produced a generic leaflet “what you need to know about my condition”.

e. MS Society Audit Tool Quality Neurology

DH has awarded £110K to the MS Society to lead this project with partners from the Motor Neurone Disease Association, Parkinson’s Disease Society, Ataxia UK and York University to develop an audit tool for use by local commissioners to

measure NSF implementation, incorporating service user, commissioner, provider and third sector views. It is due to complete its work in 2009

f. Commissioning a Year of Care

The Motor Neurone Disease Association has led a project on applying this concept, originally developed for diabetes, to MND. Indicative information is available about the likely costs of a year of health and social care for person living with MND. The work is now being piloted in London and Leeds.

g. Taking Control

The member organisations of the Neurological Alliance are currently collaborating with Ask About Medicines and the Association of the British Pharmaceutical Industry on the Taking Control campaign, addressing the information needs of people with a neurological condition.