



Quality Neurology

Contents Page:

	Page
Executive Summary	3
1. Introduction	5
2. Taking forward the proposal	6
3. Outline of project	7
4. Methodology and process	9
Selecting the information to be audited	9
Basis for selection of the Quality Neurology audit tool	10
Format and outline of the audit tool	10
How the audit tool works and what it can do	11
5. Focus groups	15
Purpose of the focus groups	15
Assumptions	15
Piloting the focus group approach	16
Planning the pilot site focus groups	16
Process for running the focus groups	17
6. Peer Review	18
7. Action Plans	18
8. Results: Audit Tool	19
Evaluation of the tool and learning from its use	22
Themes arising from feedback from the pilot sites	22
9. Results: Focus groups	25
Service user and carer participation	25
Outcome of arrangements	25
Reports	26
Issues arising: the focus groups, telephone interviews and questionnaire	26
Learning: process and outcomes of engaging service users and carers	28
10. Results: Action Plans	28
11. Conclusions	29
12. Recommendations	30
Acknowledgements	32
Appendices (as separate document)	33

Executive Summary

Introduction

This report describes the aims, process and outcomes of a project to measure whole systems progress against the National Service Framework (NSF) for Long Term Neurological Conditions (LTNCs). Although the National Service Framework (NSF) was published in March 2005, evidence suggests that implementation is extremely patchy.

Against this background a number of charities representing people affected by these conditions worked together, with support from the Department of Health research initiative for Long Term Conditions, to fund and develop 'Quality Neurology': an audit tool for NSF implementation.

The tool was designed to enable self assessment against NSF Quality Requirements by local health and social care organisations, with validation by local service users and carers.

Overview of the project

The project comprised:

1. Design of an audit tool to enable self assessment against the NSF for Long Term Neurological Conditions.
2. Local service user and carer focus groups to validate self-assessment findings and indicate priorities for service development and improvement against the outcome of the self-assessment.
3. Action-planning meetings to review the audit findings, assess strengths and weaknesses, identify priorities and develop action plans to address these.

The Social Policy Research Unit at the University of York was engaged as a research partner to evaluate the project.

As the project progressed, changes to the original project brief (which is set out in the report) were made to reflect what was happening 'on the ground'. The outline above therefore describes the final composition of the project.

Process and outcomes

The tool was developed using evidence based markers from the NSF, with supplementary questions generated from consultations with users of neurological services. An Excel spreadsheet format was selected on the basis of evaluation of an earlier condition-specific tool developed by the MS Society.

The tool was piloted in eight sites across England with support from the Social Policy Research Unit at the University of York. The sites used a range of approaches to completing the tool. Observation and user feedback suggested that the most successful methods involved bringing together the full range of practitioners, managers and commissioners involved with neurological conditions from right across the local area.

Providing sufficient preparation and time to help participants identify gaps and good practice, reach consensus, determine priorities and agree ways forward was also important.

The pilots pointed to a number of adjustments that could be made to improve the tool. These included building instructions and explanations into the body of the tool and providing links to evidence of standards being met.

In addition, the pilots flagged up the challenges of involving users of neurological services in validating local audits. They highlighted the need to allow sufficient time and use a wide range of methods to recruit and engage a diverse group of people who have a mix of conditions and are at different stages along the patient pathway.

Piloting indicated that with appropriate adjustments and guidance the tool would offer a robust mechanism, with engagement from service users, to measure implementation of the NSF and to drive progress.

Recommendation

It is recommended that investment is made in a web enabled version to allow for further service user involvement, benchmarking, and sharing of best practice by commissioners and providers, enhancing the tool as a vehicle for service improvement.

Quality Neurology

Introduction

1. Background

The National Service Framework for Long-term Neurological Conditions

The National Service Framework (NSF) for Long Term Neurological Conditions (LTNCs) was published by the Department of Health in March 2005. It set out 11 Quality Requirements (QRs) to transform the way health and social care services support people with long-term neurological conditions to live as independently as possible. The QRs were to be achieved by 2015.

There was, however, concern from service users and other stakeholders that there were no milestones attached to the Quality Requirements as a means of tracking progress. Subsequently evidence from neurological charities and the University of York Benchmarking Project with which the Quality Neurology (QN) project was aligned indicated that implementation of the NSF was extremely patchy.

Measuring progress

The regulatory bodies for health and social care services in 2005 (the Healthcare Commission and Commission for Social Care Inspection) expressed their desire to encourage new approaches to measuring whole systems progress against the NSF LTNCs.

The Multiple Sclerosis Society (MSS) has operated an award winning audit scheme (Measuring Success) since 1997, based on the Society's own standards of care. The underlying principles of this scheme aim to ensure that service users are at the centre of the audit process.

In 2004 the scheme was further developed, in the form of a toolkit, to assist local health economies in auditing their services against the NICE Clinical Guideline 8: 'Management of multiple sclerosis in primary & secondary care' (November 2003). The MS Society worked with stakeholders and the Chartered Society of Physiotherapy (CSP) and The Association of Chartered Physiotherapists in Neurology (ACPIN) to produce a toolkit of resources to inform and educate health professionals about the NICE guideline. Included in the toolkit was a comprehensive guide to the audit cycle and an audit tool based on the six Key Priorities that addressed the audit criteria within the NICE guideline and local implementation issues.

To date, more than 1000 toolkits have been distributed on request to NHS Trusts. In 2007 a further version of the audit tool was developed, referenced to the National Service Framework (NSF) for Long Term Conditions (LTCs), and reflecting the changes in organisation of the NHS.

With the publication of the NSF LTNCs, support was sought from the Neurological Alliance charities in September 2005 for a proposal to

broaden and re-focus Measuring Success to cover the NSF LTNCs and therefore to extend it to all neurological conditions.

The aim was to provide a consistent framework for health and social care services to audit themselves against the 11 QRs of the NSF LTNCs, which would, in turn, form the basis for instigating a dynamic improvement programme over the longer term.

Therefore, the question was, could the successful Measuring Success programme be translated into an audit tool and patient consultation methodology that would deliver a consistent framework for audit of the NSF LNTCs, in turn delivering dynamic improvement in services which take into consideration the lived experience of those people at the receiving end of the services? Additionally, could the tool enable comparison between service providers/commissioners at a national level?

2. Taking forward the proposal

Four neurological charities (the MS Society, Parkinson's Disease Society¹, Motor Neurone Disease Association and Ataxia UK) agreed to commit funds to the project, with commitment in kind from several other charities (see Appendix 19).

A successful bid (Appendix 1) was made to the Research Initiative for Long Term Conditions fund in April 2007, with a caveat that the project looked for academic support from one of the other six research projects that were also being funded. The York project involved in-depth case study research in order to inform the development of a benchmarking tool which was used to conduct a national audit of the NSF LTNCs implementation across England.

The Department of Health agreed to match fund the project and supported the extra costs of taking on the input from the University of York.

The MS Society, which was mandated to take the project forward as lead, appointed a project manager and set up a steering group comprising representatives from the funding partners, service users from the funding charities and representatives from the Healthcare Commission and Social Policy Research Unit of University of York.

The project was not intended to be a pure research project; research being concerned with discovering the right thing to do, and audit with ensuring that the right thing is done correctly. Its objective was not to test a hypothesis, nor did it require ethical and R&D approval, and only limited statistical analysis was needed.

The project, being angled more towards audit, aimed to design a tool that would enable local health and social care partners (together with other key stakeholders), to measure their progress on the implementation of the NSF's Quality Requirements. It also aimed to ensure that the results were relevant within both the local setting, in order to influence local practice, and also in comparing practice across the wider health / social care economy.

¹ As previously was; now trading under 'Parkinson's UK' as of 8th April 2010

Outline of the project

It was planned that the project would comprise:

- Design of an audit tool to enable self assessment against the NSF LTNCs (informed by the concurrent University of York research);
- Peer review to validate self-assessment findings;
- Local service user and carer focus groups to validate self-assessment findings and indicate priorities for service development and improvement against the outcome of the self-assessment;
- Whole systems workshops to review the audit findings, assess strengths and weaknesses, identify priorities and develop action plans to address these;
- Testing in ten pilot sites across England.

York University would work with the QN project in the process of the audit tools' development by undertaking the role of 'critical friend' and:

- Interviewing and meeting with the Quality Neurology team to inform the initial audit tool design;
- Viewing drafts of the audit tool in construction and feeding comments back to the Quality Neurology team;
- Discussing the audit process and completion of the tool with key contact sites and feeding comments back to the Quality Neurology team;
- Working with six of the ten pilot sites and feeding back to the Quality Neurology team about:
 - The ease of comprehension and completion of the tool
 - Usefulness of different aspects of the tool
 - Effectiveness of different approaches to completion
 - Any other major issues that arose during the audit process.
- Observing six of the ten action-planning meetings and feeding back observations to the Quality Neurology team about:
 - Effectiveness of facilitation and how this could be improved
 - Usefulness of the tool in this action planning stage
- Gathering participants views on the usefulness of the entire audit process.

It was envisaged that completion of the audit tool would be undertaken by health and social care professionals that were representative of all the services on the ground, including voluntary and private sector agencies; relevant service managers; commissioners; and service users and carers. Local Implementation Teams (LITs) often have this sort of representation and, where they existed, they completed the audit.

Service user stakeholders for focus groups would be recruited from current or recent users of the services.

Recruitment of pilot sites

As the SPRU at York had already established links with neurological leads in several PCTs across England, they were able to introduce the QN project manager to some of the PCTs that subsequently agreed to take part in the QN project. Due to the SPRU's contact with these PCTs also continuing throughout the timeframe of the QN project, they were able to observe how the tool was used and how useful the PCTs found it.

The Care Services Improvement Programme (CSIP) was approached for assistance in identifying other potential sites, and the project manager and regional workers from CSIP approached these together. Additional sites were recruited by this means, making a total of nine sites out of the anticipated ten within the bid.

Of the sites selected, there was a range of integrated and non integrated sites between health and social care (Table 1).

Table 1 Profile of sites:

Pilot Site	Profile of PCT
1	With a budget of £496 million and a population of 224,000 this is a high density population with a large ethnic mix.
2	With a budget of over £1 billion and commissioning health services for 750,000 this is one of the largest PCTs in the country.
3	With a budget of £728 million serving a population of 523,000
4	Serves a population of approximately 604,000 people with an annual budget of £681million.
5	With a budget of £330 million and a population of 216,000
6	It has a population of 170,000 people and is an integrated health and social care service employing 1500 staff and a budget of £250 million of which £32 million is ring fenced for adult social care services.
7	With a budget of £300 million and a population of 190,000 people, employing 2000 staff.
8	Employing over 1800 staff and with a budget of £426 million covering a population of 300,000 people
9	With a population of 515,000 and a budget of £675 million employing over 2500 staff.

Pilot site 5 withdrew from the project early on by mutual agreement due to a change of lead personnel and some re-organisation. Continuity of management and clinical support could not, therefore, be guaranteed. No part of their work is included in the results.

Site 9 completed the audit tool but, due to challenges with the service user element of the project, has been unable to complete the service user engagement and action planning in the timeframe of the project. Only their work with the audit tool is included in the results.

All remaining seven pilot sites completed the audit and service user engagement and delivered actions as a result of the process.

4. Methodology and process

Selecting the information to be audited.

The 11 Quality Requirements in the NSF LTNCs were based on the available evidence at that time, including what people with long-term neurological conditions said about their experiences and needs. Each Quality Requirement is underpinned by a number of evidence-based markers (EBM) of good practice, for example:

Quality requirement 1: A person-centred service

EBM1

There is timely integrated assessment involving all relevant agencies leading to individual care plans which:

- *cover current and anticipated needs (including health, social, emotional and cultural needs);*
- *are held by the person and regularly evaluated and reviewed with them by the clinical team. Review is based on clinical need, including self-assessment (see QR2); and*
- *ensure that staff have access to all relevant records and background information about the person's condition, test results and previous consultations.*

As some statements were fairly broad, the EBMs were broken into smaller questions. It became clear that these statements were process driven and could be easily deemed as met purely through process without any evidence demonstrating implementation. Therefore the views of service users were canvassed at a workshop, asking them what questions they would ask of service providers. Other views were sought from groups such as the Spinal Injuries Association's virtual reference group and Headway. The resulting comments and questions were distilled into associated themes and turned into composite questions to be asked as part of the process in addition to the EBMs. They were identified in the tool as being generated by service users.

In some instances where the EBMs had less strong evidence, such as QRs 7 and 9, then the service user generated questions were used in the main body of questioning.

Basis for selection of the Quality Neurology audit tool

The MS Society first offered the Measuring Success toolkit at a modest

cost and subsequently gave it free to all NHS service providers requesting it. The audit comprised:

- Completion of the tool;
- Gathering the views of service users through focus groups; and
- Action planning with the service provider, based on a synthesis of the audit and focus group findings.

Following piloting of the toolkit and service user focus groups within six NHS providers in England and Wales, the MS Society then offered to support as many NHS health service providers as they could to undertake the audit.

In mid 2005 a survey of over 800 sites that had requested a copy of the toolkit was undertaken with a 24% return rate. The main finding was that of all the resources, the audit tool itself was most valued but that in its printed format was not user friendly. This resulted in the production of an interactive Excel spreadsheet version of the tool in 2006 which subsequently came second in the NICE Shared Learning Awards in 2007, and is a lead example used by NICE of how service users support the implementation of NICE guidance.

Format and outline of the audit tool

In light of the experience of the 'Measuring Success' project, an Excel spreadsheet was deemed to be the best vehicle to pilot the Quality Neurology audit tool.

A company called 'Practical Participation'² was asked to develop the first EBM into a spreadsheet format and educate the project lead in further development. Subsequently, all 11 Quality Requirements were added to the spreadsheet.

The Excel Spreadsheet is a workbook with separate tabs for each element of the tool. All (19) of the tabs have colour coded titles as follows:

- Introduction – how to use the audit tool;
- A headline tab giving the details of the PCT and contact person;
- A team sheet to list all the names and designation of people involved / consulted to complete the audit;
- A list of neurological conditions*;
- The 11 Quality Requirements;
- Overview – a summary of whether each Quality Requirement and evidence-based markers had been 'met', 'part met' or 'not met';
- Action Plan - the tool includes a sample action plan (Fig 5) that encourages NHS and social care commissioners and providers to think about what they wanted to achieve post audit, the expected outcome, the actions needed to achieve the outcome, who would be responsible for the topic and an expected date of achievement;
- Mapping links** - The penultimate tab gives a list of the key headings and criteria for the four mapped-to documents and these

² <http://www.practicalparticipation.co.uk/>

in turn are hyperlinked to the web sites for the original documents where possible. (Fig 6);

- Acknowledgements - acknowledging the input from contributors from the funding partners, Headway, Spinal Injuries Association and specific service users and carers.

*Following the first evaluation of the tool, and requests from the pilot sites, an additional tab listing 35 neurological conditions (as per the list within the NSF LTNCs documents) was added. This list, using the known prevalence figures for the various conditions could calculate the expected number of cases within a PCT area given the population covered by the PCT. The tab also allowed the PCT to 'opt in' or 'opt out' the conditions they were including in the audit and to enter the known numbers of cases for comparison. (Fig 1).

**In view of the increasing number of initiatives that were emerging, for which evidence was required of compliance, it was considered appropriate to map the QRs of the NSF LTNCs to some of these to make it more attractive in terms of gathering evidence for more than one situation. The QRs were mapped against World Class Commissioning criteria, The Better Metrics Project, Seven Key Challenges for Health and the Standards for Residential Care for 18 -65 Year Old Persons. (Fig 6).

How the audit tool works and what it can do.

In the 11 QR tabs, the overarching statement concerning the QR is given and then each EBM stated as a separate section with sub-set questions below it. Each QR has an overall 'Met', 'Part Met', 'Not Met' score that is driven by completion of the individual EBM, which in turn is driven by the answers to the sub-element questions

The sub element questions of each EBM allows auditors to pick from a drop down menu of 'Met', 'Part Met', 'Not Met' options or not to answer. In selecting any of these options the box will change colour to green, amber or red respectively. (Fig 2)

The EBM overall score and the sub element score automatically update the overview sheet at tab 16 that allows for an overarching view of all the QRs and their EBM elements. (Fig 3)

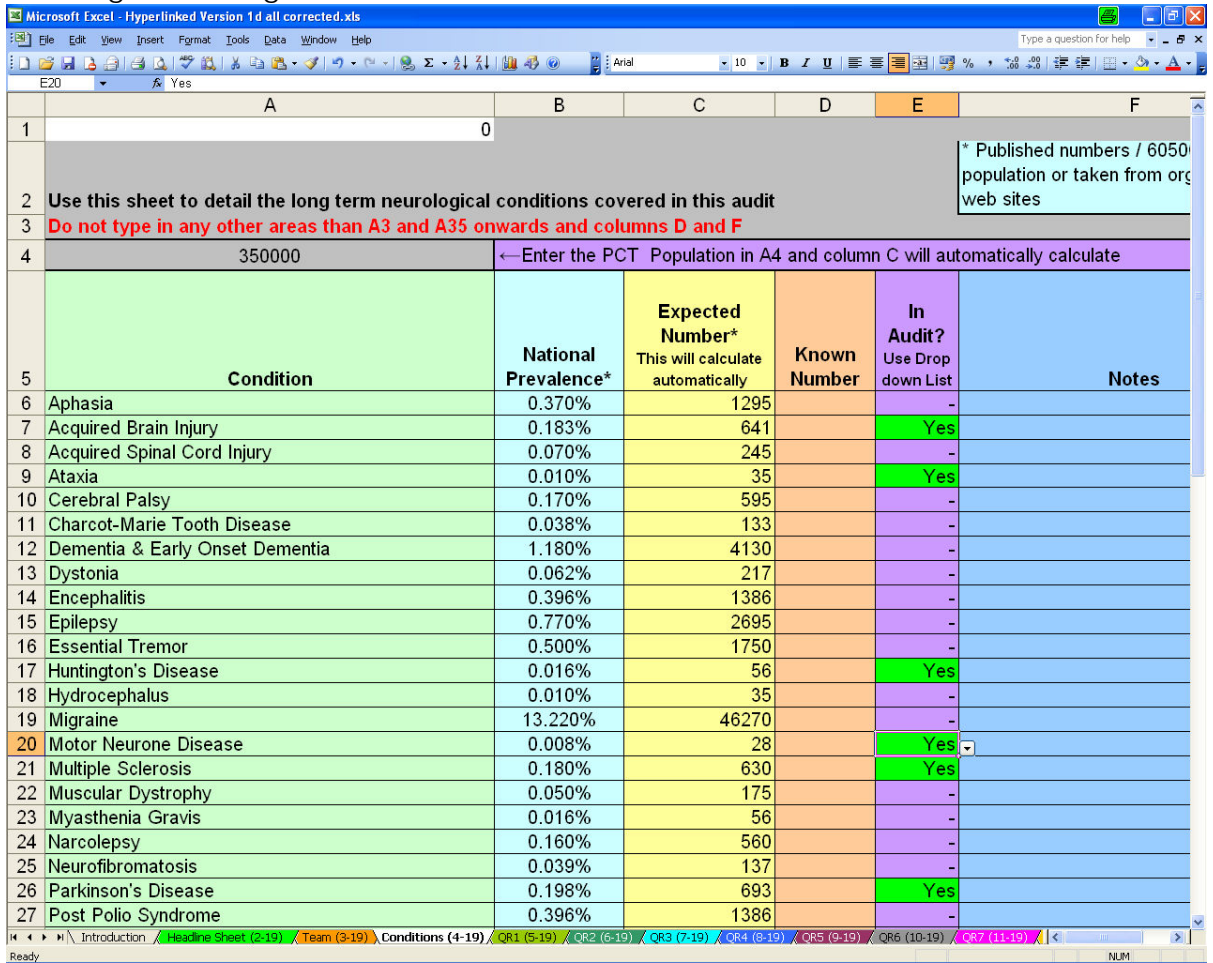
On all QR and Overview pages a column is available for auditors to make notes and the cells automatically expand to accommodate the text. This allows for auditors to elucidate on their assumptions and interpretation of the questions and to make notes about inclusion, exclusions or specific areas of service that do not fit with the 'Met', 'Part Met' or 'Not Met' category selected for the sub element of the EBM.

Hyperlinks were embedded in the tool to allow for swifter navigation between work tabs, elements within tabs and to external links such as the National Service Framework LTNCs and World Class Commissioning.

The basic formula to drive the EBM was made on the premise that all sub elements had to be met to drive the EBM to be 'Met' (Green) and that if all were 'Part Met' then the EBM would be 'Not Met'. Any sub element that

was 'Met' would make the EBM 'Part Met'. (Fig 4). The same applies to driving the Overall score for the QR

Fig 1 Showing Conditions List



5	Condition	National Prevalence*	Expected Number* This will calculate automatically	Known Number	In Audit? Use Drop down List	Notes
6	Aphasia	0.370%	1295		-	
7	Acquired Brain Injury	0.183%	641		Yes	
8	Acquired Spinal Cord Injury	0.070%	245		-	
9	Ataxia	0.010%	35		Yes	
10	Cerebral Palsy	0.170%	595		-	
11	Charcot-Marie Tooth Disease	0.038%	133		-	
12	Dementia & Early Onset Dementia	1.180%	4130		-	
13	Dystonia	0.062%	217		-	
14	Encephalitis	0.396%	1386		-	
15	Epilepsy	0.770%	2695		-	
16	Essential Tremor	0.500%	1750		-	
17	Huntington's Disease	0.016%	56		Yes	
18	Hydrocephalus	0.010%	35		-	
19	Migraine	13.220%	46270		-	
20	Motor Neurone Disease	0.008%	28		Yes	
21	Multiple Sclerosis	0.180%	630		Yes	
22	Muscular Dystrophy	0.050%	175		-	
23	Myasthenia Gravis	0.016%	56		-	
24	Narcolepsy	0.160%	560		-	
25	Neurofibromatosis	0.039%	137		-	
26	Parkinson's Disease	0.198%	693		Yes	
27	Post Polio Syndrome	0.396%	1386		-	

Fig 2 Showing 'Met', 'Part Met' and 'Not Met'

Quality Neurology Excel Monitoring Tool			
By Practical Participation (tim@practicalparticipation.co.uk) & Alun Davies MS Society			
Evidence based markers of good practice for Quality Requirement 1			
Overall			
Action Plan		Not Met	
<p>A person centred service: People with long term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.</p> <p>Questions Asked by Service Users</p>			
1	1	There is timely integrated assessment involving all relevant agencies leading to individual care plans which:-	Part Met
1.1.1	1.1.1	Cover current and anticipated needs (including health, social, emotional, psychological, physical and cultural needs)	Met
1.1.2	1.1.2	Are held by the person and regularly evaluated and reviewed with them by the clinical / community / social care team. Review is based on clinical need including self assessment (See QR2)	Part met
1.1.3	1.1.3	Ensure that staff have access to all relevant records and background information about the person's condition, test results and previous consultations and care issues	Not met
1.1.4	1.1.4	People at the end of life have their needs and preferences (particularly the preferred place of death) properly assessed	Met Part met Not met Select

Fig 3 Showing Overview Tab

QR	EBM 1	EBM 2	EBM 3	EBM 4	EBM 5	Notes
QR 1	Not Met	Part Met	Not Met	Not Met	Not Met	
QR 2	Not Met	Not Met	Not Met	Select	Not Met	
QR 3	Not Met	Not Met	Not Met	Not Met	Not Met	
QR 4	Not Met	Not Met	Not Met			
QR 5	Not Met	Not Met	Not Met			
QR 6	Not Met	Not Met	Not Met			
QR 7	Not Met	Not Met	Select	Not Met	Select	
QR 8	Not Met	Not Met	Select	Select	Not Met	
QR 9	Not Met	Not Met	Not Met			
QR 10	Not Met	Not Met	Not Met	Not Met	Not Met	
QR 11	Not Met	Not Met	Not Met	Not Met		

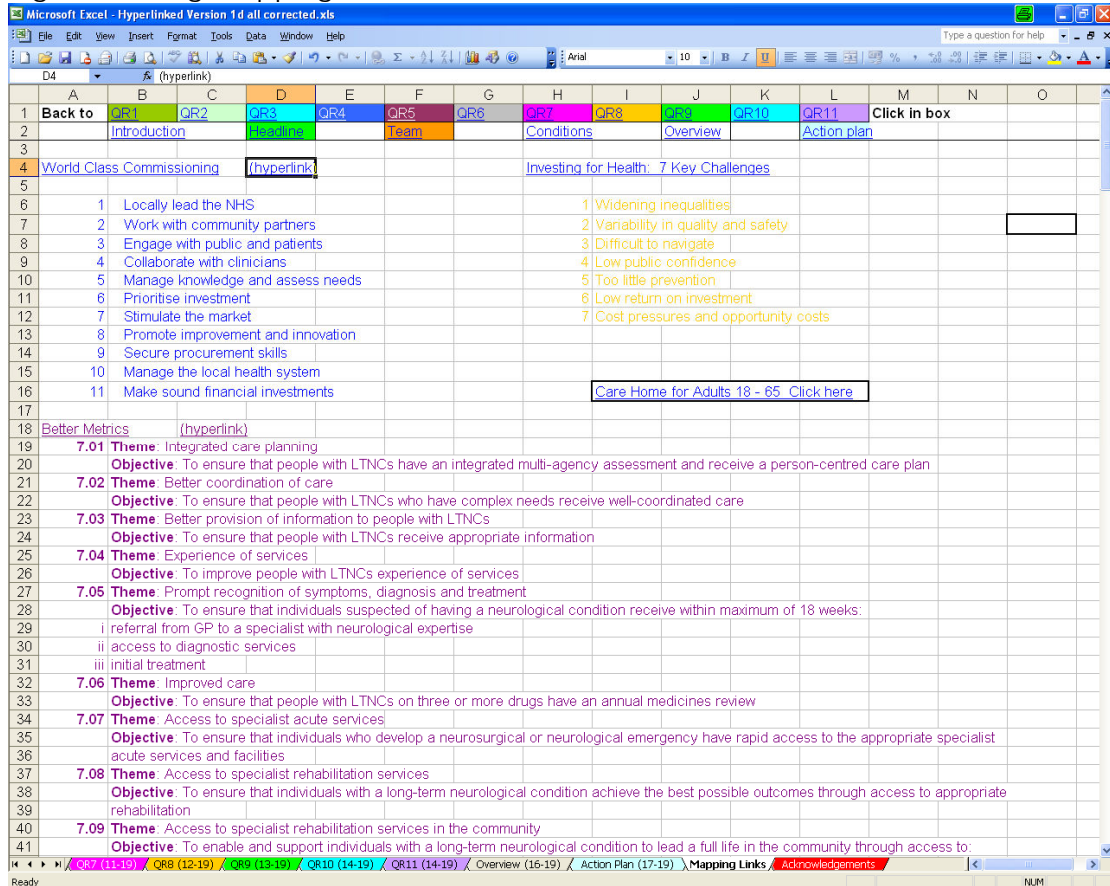
Fig 4 Showing drivers

Quality Neurology Excel Monitoring Tool			
By Practical Participation (tjm@practicalparticipation.co.uk) & Alun Davies MS Society			
Overall: Part Met			
Emergency and acute management: People needing emergency 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.			
Questions Asked by Service Users			
1	Acute and emergency management of sudden onset neurological conditions complies with :	Met	QR3
3.1.1	NICE Guidance where available	Met	QR3
3.1.2	takes account of nationally agreed standards and guidelines	Met	QR3
2	Local hospitals accepting people with a neurosurgical or neurological emergency have appropriate resources to treat, manage and review individuals presenting with a sudden onset neurological condition including:	Part Met	QR3
3.2.1	trained staff/teams (A&E, medical assessment, acute medical, neurological/neurosurgical) to ensure that people with acute neurological symptoms receive prompt neurological assessment.	Met	QR3
3.2.2	appropriate facilities and links to specialist neuroscience centre and spinal cord injury centre for prompt expert opinion	Part Met	QR3
3.3.3	protocols of agreed care with specialist spinal cord injury and neuroscience and neuro-rehabilitation centres.	Part Met	QR3
3	There are protocols in place which comply with:	Not Met	QR3
3.3.1	Nice Guidelines on head injury	Part Met	QR3

Fig 5 Showing the Action Plan Tab

Action Plan					
	Aim	Outcome	Actions	Lead responsible	Achieve by
QR 1	Not Met				QR 1
QR 2	Not Met				QR 2
QR 3	Not Met				QR 3
QR 4	Not Met				QR 4
QR 5	Not Met				QR 5
QR 6	Not Met				QR 6
QR 7	Not Met				QR 7
QR 8	Not Met				QR 8
QR 9	Not Met				QR 9
QR 10	Not Met				QR 10

Fig 6 Showing Mapping links Tab 18 of 19



	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
1	Back to	QR1	QR2	QR3	QR4	QR5	QR6	QR7	QR8	QR9	QR10	QR11	Click in box		
2		Introduction				Team		Conditions		Overview		Action plan			
3															
4		World Class Commissioning		(hyperlink)				Investing for Health: 7 Key Challenges							
5															
6		1	Locally lead the NHS					1	Widening inequalities						
7		2	Work with community partners					2	Variability in quality and safety						
8		3	Engage with public and patients					3	Difficult to navigate						
9		4	Collaborate with clinicians					4	Low public confidence						
10		5	Manage knowledge and assess needs					5	Too little prevention						
11		6	Prioritise investment					6	Low return on investment						
12		7	Stimulate the market					7	Cost pressures and opportunity costs						
13		8	Promote improvement and innovation												
14		9	Secure procurement skills												
15		10	Manage the local health system												
16		11	Make sound financial investments												
17															
18	Better Metrics			(hyperlink)											
19		7.01	Theme:	Integrated care planning											
20			Objective:	To ensure that people with LTNCs have an integrated multi-agency assessment and receive a person-centred care plan											
21		7.02	Theme:	Better coordination of care											
22			Objective:	To ensure that people with LTNCs who have complex needs receive well-coordinated care											
23		7.03	Theme:	Better provision of information to people with LTNCs											
24			Objective:	To ensure that people with LTNCs receive appropriate information											
25		7.04	Theme:	Experience of services											
26			Objective:	To improve people with LTNCs experience of services											
27		7.05	Theme:	Prompt recognition of symptoms, diagnosis and treatment											
28			Objective:	To ensure that individuals suspected of having a neurological condition receive within maximum of 18 weeks:											
29			i	referral from GP to a specialist with neurological expertise											
30			ii	access to diagnostic services											
31			iii	initial treatment											
32		7.06	Theme:	Improved care											
33			Objective:	To ensure that people with LTNCs on three or more drugs have an annual medicines review											
34		7.07	Theme:	Access to specialist acute services											
35			Objective:	To ensure that individuals who develop a neurosurgical or neurological emergency have rapid access to the appropriate specialist acute services and facilities											
36															
37		7.08	Theme:	Access to specialist rehabilitation services											
38			Objective:	To ensure that individuals with a long-term neurological condition achieve the best possible outcomes through access to appropriate rehabilitation											
39															
40		7.09	Theme:	Access to specialist rehabilitation services in the community											
41			Objective:	To enable and support individuals with a long-term neurological condition to lead a full life in the community through access to:											

5. Focus groups

Purpose of the focus groups

As described earlier, the MS Society's audit tool, Measuring Success, included the use of focus groups to gather the views of service users and it was agreed that a similar process should form part of the Quality Neurology audit. As well as validating the self-assessment findings emerging from the spreadsheet, the groups (of both service users and carers) would inform on priorities for service development and improvement against the outcome of the self-assessment.

Assumptions

Number of focus groups

Initially the intention was to hold one focus group in each pilot site. However, during initial discussions with the pilot sites, some of the leads expressed an interest in having several groups. In one case, this was to take account of a large minority ethnic population where one of three proposed focus groups would not be conducted in English. In other cases, additional groups were to be run to take account of large geographical areas; or where there were significant differences in availability and delivery of services across a pilot site due to NHS re-organisation.

Composition of focus groups

The aim was to have groups of between eight and 12 people in order to have enough people to promote discussion but not so many that some people might not get enough opportunities to take part, or that the group might be difficult to manage. It was hoped that 8 – 12 would enable a reasonable spread of conditions, ages and ethnicity. The intention was also to recruit participants who had been diagnosed for varying lengths of time but with an emphasis on people who were newly diagnosed or diagnosed within the last three years.

Basis for discussion

As outlined above, it was originally intended that the experiences of the focus group participants would confirm or negate the assessment of the local organisations emerging from the spreadsheet. However, because of the way the responses were recorded and scored on the spreadsheet, it was difficult to identify clear-cut, discrete topics that the focus groups could either confirm or challenge. It was therefore decided to use a range of subjects that broadly reflected the NSF, allowing for some flexibility depending on how discussion was progressing.

This would draw out issues of greatest importance and meaning to service users and carers, identifying gaps in services and where they wanted improvements to be made. A sample list of topics is given in **Appendix 2**.

Piloting the focus group approach

In order to try to ensure that the focus groups would be as effective as possible, the approach to running them was trialled in an area that was not a pilot site.³ Ten people took part: seven service users and three carers. This group provided useful learning, for example, on timings, topics and inclusivity. The focus group also acted as a ‘dummy-run’ for the practicalities of providing refreshments, paying travel expenses and giving out gift vouchers, which were a means of thanking people for taking part. Participants were asked to complete a short evaluation form before they left.

Planning the pilot site focus groups

A schedule of dates was drawn up with the leads in each pilot site, dependent on their timescale for completing the audit tool. The number of focus groups to be arranged was agreed at the same time.

A flyer was produced to act as an invitation to take part in a focus group and was agreed with the leads in each pilot site. It described the purpose of the groups, how they would be run and how to apply. A sample flyer is

³ We are grateful to the North West Neurological Alliance for all their efforts in pulling a group together.

attached at **Appendix 3**. Having the contact points at the MS Society would ensure confidentiality.

The local leads took responsibility for disseminating the flyers and the process was broadly the same in each pilot site: the flyers were sent out directly to a wide range of individuals e.g. heads of service in the PCT, local authority and NHS Trusts; to voluntary organisations and carers' centres; and indirectly via members of Local Implementation Teams or other groups with a remit for long-term neurological conditions. However, in site 8, the lead asked the local Council for Voluntary Services to take the process forward.

In some cases, local voluntary organisations also undertook to circulate flyers on their networks or to approach individuals to see whether they would be interested.

Once it was agreed that a focus group would take place, the people who had expressed an interest in attending were phoned and given details of the venue, timings and other arrangements. Confirmation of the groups with service users and carers often happened twice.

Where a group was not being run, would-be participants were also telephoned to let them know.

Process for running the focus groups

The following points summarise the approach for conducting the groups i.e. this is the running order that participants were given at the beginning of the session:

1. Brief background to the Quality Neurology project.
2. Purpose of the focus group.
3. Ground rules – how the session would be conducted.
4. How people would be asked to introduce themselves:
 - a. Your first name;
 - b. Whether you're a service user or carer;
 - c. Your neurological condition(s) and how long you've been diagnosed;
 - d. Any other significant health conditions;
 - e. One thing about the services you use that you really like/value.
5. Discussion of topics.
6. Final word – one thing that would make a big improvement in living with your condition (or your caring role).
7. Payment of expenses and vouchers.

8. Evaluation forms⁴.

The focus groups were recorded, participants having signed a consent form, and transcribed by an external company. The transcription was then developed into themes by the project team and a report forwarded to the pilot sites for consideration when action planning.

6. Peer Review

The original intention of peer review was to:

- Enable services to validate their self-assessment findings in a non-threatening environment; and
- Share learning and ideas.

As the project progressed more slowly than originally planned, it became apparent that would be extremely difficult to the health and social care commissioners and providers to field a small team for brief visits to another pilot site and review the data required beforehand. The focus of the peer review element was therefore shifted to focusing on the outcome of the process i.e. - the action plan.

To achieve the new aim of reviewing the action plan, participating pilot sites were to be given the profile of another pilot site, the results of the audit – that is the completed audit tool – and the report of the focus groups along with the completed action plan. They would then be asked to comment on the action plan, asking: ‘if they had the information to hand, would they have made the same or similar action plans?’

However, as a result of the different ways in which both the audit and the action-planning were undertaken in the pilot sites, there was a significant disparity of formats of the final outputs from the project. At the same time the pilot sites, in effect, disengaged from the project, as they wanted to concentrate their efforts on implementing their action plans. It was therefore not possible to implement the peer review process within the timescales of the project.

7. Action plans

The audit tool allows for actions to be recorded against the individual QRs under headings of:

- Aim
- Outcome
- Actions
- Lead Responsible
- Achieved by

It was anticipated that each site would identify the main themes and challenges from the audit, and that focus group information would be

⁴ Participants were asked to complete an evaluation form before leaving. (Appendix 4)

synthesised into one or two key issues for which an aim of service improvement / development could be identified. The result of what achieving the aim would look like would be entered in the outcome box, allowing for future audit of implementation to take place. The person responsible for leading on the work and a reasonable timescale of completion would also be entered.

8. Results: Audit tool

Completing the tool

The SPRU and the Project Manager between them observed the sites completing the audit tool.

All of the sites used the audit tool. Sites completed the tool using the methods set out below. The Project Manager had informed them that the recommended way to complete the tool (based on the experience gained from many audits using the NICE audit tool) was to set aside a half day or, failing preparatory discussion of the tool, a whole day to populate the workbook. It was also advised that as many stakeholders as possible attend and reach a consensus opinion as to the status against each EBM criterion.

Site one: Completion of the tool was led by a Primary Care Trust (PCT) lead for Long Term Neurological Conditions (LTNCs) with input from the Local Implementation Team (LIT). Information based on input from local professionals provided for a recently conducted 'gap analysis' was also used.

Format of the meeting: two hours were allocated for the completion of the tool which had previously been discussed at the LIT meeting earlier that week. The tool was projected onto a large screen and was completed by the PCT lead during the meeting. The meeting was focused around specific QRs that were of particular relevance for those staff in attendance.

Only the PCT lead and two occupational therapists (OTs) - one from a local acute setting and one from the community setting - attended the full meeting (both of whom were on the LIT). A further OT (also based in the community but in a different service) attended for the final hour.

Some of the QN audit tool had already been completed by the PCT lead. The PCT lead had also filled in some parts of the tool with information provided by senior commissioning/provider/ managerial staff. Staff at the meeting identified additional people/organisations who should be invited to contribute to the completion of the tool.

By the end of the meeting (2.25 hours) only three QRs were completed, with QR1 taking over an hour to complete. Those present arranged additional meetings with the PCT lead to continue to complete the tool.

Site two: Initially three PCT commissioners led on completing the tool. (The LIT group was not at that time meeting.) The tool had previously been emailed to the Head of Neurology Services (PCT provider side) and the Clinical Director of Neurology (acute trust). It was later decided that a face to face meeting with the Head of Neurology Services (PCT) would be more useful.

Format of the meeting: two of the three PCT commissioners attended but the Head of Neurology Services was unable to attend (she had completed several sections of the tool and emailed this to the commissioners instead). The audit tool was viewed on a PC and worked through page by page.

The commissioners present decided to email it to the third (absent) PCT commissioner as well as the Head of Disability Services in the local authority.

Site three: The initial approach was to fill it in during a meeting of LIT members. No parts of the audit tool had been completed prior to the meeting.

A laptop showing the tool was linked to an overhead projector so everyone could see the questions and the answers could be typed in during the meeting. One hour was allocated for the meeting and the following LIT members were present: Deputy Director of Nursing and Patient Safety (Chair), NSF LTNCs Development Manager, GP, Consultant Rehabilitation Therapist, representative from Carer's UK and also a lead for Clinical Audit and Quality. Note that the NSF LTNCs Development Manager was there to facilitate completion of the tool but did not attempt to answer many of the questions herself – this was the job of the LIT members.

Once the tool had been introduced to the group there remained approximately 40 minutes to work on it. Three QRs were covered in this time. It was agreed that a half day workshop would be necessary to cover all the QRs which was subsequently held. In addition it was suggested that the tool be emailed to all those invited so that people would be familiar with the questions before the workshop in order to save time in the session.

Site four: Multiple audits were undertaken, one in each of the five former

PCT catchment areas that made up the new PCT.

In the multiple sites, the tool completion was led by the Neurology lead for the PCT. The tool was completed during meetings that were arranged with the specific aim of gathering information/completing the tool. Meetings were held in five locations in the PCT area and a QN audit tool was completed per meeting. Global invitations were sent to NHS and social service staff in the locations including GPs and neuro-consultants; all relevant voluntary organisations were invited to send staff and/or carer and/or service user representatives. The first meeting was intended as a pilot for the process of QN tool completion throughout this site.

The meetings were run in groups, each working on a chosen QR and on paper, with this being transferred to the Excel spreadsheet at a later date. The exception was QR 11 which was completed by the whole group with the tool projected and notes added contemporaneously.

A morning was allocated for completion of the tool (9:30-13:00), broken into two sessions.

Site 5 had only partly completed the tool before it withdrew from the pilot.

Site 6: Here the tool was projected to a large meeting of clinicians and service users from the LIT group. Tool was populated over several hours and extensive use made of the notes areas to qualify answers and to explain assumptions. Not all clinicians remained for the whole of the exercise.

Site 7: The Quality Neurology Project Manager facilitated the population of the audit tool with a large group of clinicians, service managers and the lead commissioner for LTCs. The tool was completed over five hours with extensive use made of the notes sections. All bar one person stayed throughout the process. Some sections were left unanswered due to lack of input from the acute unit and some aspects of social care.

Site 8: Completed the tool over several hours, using their LIT which had good representation from all service providers across health and social care as well as service user representation and the LTC commissioner.

A projector was used so everyone could see the responses and reach a consensus.

Site 9: Had done major work on four of the QRs prior to agreeing to be part of the QN project, so they used the previously collected data to populate the audit tool QRs that were relevant and concentrated on those remaining QRs where no work had been undertaken.

Evaluation of the tool and learning from its use

The following learning points summarise feedback from the evaluations undertaken by the University of York about the tool and its use.

Learning point 1: The chair of the group completing the audit tool needs to have a good understanding of the QRs and local services. Service users and/or carers have valuable experience to contribute in completing the QN audit tool and should be included.

Learning Point 2: Input from the *full range* of practitioners, service managers and commissioners is crucial.

Learning Point 3: A meeting of representatives *from across the patch* is fundamental to identifying areas of good practice and gaps in service. Participants must be familiar with local services.

Learning Point 4: It takes time to discuss each of the questions under each of the 11 QRs. One hour is not enough. As stated, the tool needs a minimum of a half day and a full day is recommended.

Learning Point 5: Emailing the audit tool to potential contributors before a meeting gives preparation time and enables more time to be devoted to discussion and completion of the tool during the meeting.

Learning Point 6: Even where contributors have received a copy of the audit tool in advance a face to face meeting is still necessary to discuss possible answers and come to a consensus.

Learning Point 7: Discussion of gaps and areas of good practice through the completion of the audit tool in a meeting with the full range of contributors helps to identify priorities and ways of taking things forward.

Themes arising from feedback from the pilot sites.

Some specific issues about the tool were raised during completion, many of them common to most sites. These were addressed by amendments to the tool as sites reported them. They can be summarised as follows (**nb** notes in *italics* are the actions taken to amend the tool as the process went on, in response to the feedback from the pilot sites):

Who completes

- A service manager in site 2 had marked several areas 'met',

whereas at the meeting it was felt the requirement was only met for people who used her particular service. Something to be aware of: met for whom?

- In site 3 it was useful to have a GP at the meeting as he knew what happened for people who were not linked in to specialist services (for example those in nursing homes).

Guidance/instructions

- None of the sites referred to the guidance notes or instructions during the meetings. Where people were confused they tended to guess or move on. Given the limited time available during these meetings it would be useful to include some basic instructions in the body of the tool. *In the Excel version this functionality would be limited to drop down or pop up boxes with information to assist, but only minor changes have been followed up at this stage of development.*

Understandability

- At points, the intention of the quality markers was questioned ('Do we need a multidisciplinary team involved in diagnosis – isn't this more important in rehabilitation?' etc). It might be useful to have some information about the rationale for each point on the page (or at least a link or reference to it) so that people can make an informed decision about whether this is a priority for them. *This is an issue with the wording within the NSF LTNCs itself and needs to be addressed.*
- There was also some misinterpretation of quality markers (for example, one site thought the question about running culturally appropriate services meant they should be dedicated to particular cultures, which they felt was unrealistic in areas with high levels of cultural diversity). Again, links to more information so people understand what the markers are actually asking them to do might be useful. *The intention was for those completing the tool to make these assumptions and record their interpretation in the notes section.*

Usefulness of the tool

- Sites 2 and 3 were under the impression that completion of the tool would produce an action plan ready for them to use. *This was never implied at any stage in discussions with the pilot sites.*
- Most of the questions will be answered 'part met' because it is likely that, even where a measure is met in one geographical location, or for one condition, it may not be met for another. *The notes section*

can be used to qualify the answer making it clear that some areas do meet the criteria, but the service as a whole does not.

Conditions page

- There was concern with this page as many of the figures in question were not known, and where information was available it was about the numbers of people using services, not the numbers in the population as a whole. If the purpose of the page is to highlight the difference between those using services and those expected to reside in the catchment area then this might need to be made more explicit. *This page was developed as a direct request of pilot site 9 and formatted to their initial requirements.*
- In one site participants were concerned that the population statistics may not be relevant for their locality because of the nature of the population (predominantly young and transient) and may, therefore, lead to misinterpretation (or not) of service provision. *The conditions page is meant to be a guide only and not definitive.*
- One site asked whether some secondary neurological manifestations of non-neurological conditions should also be included e.g. amputations; brain tumour. *These are not within the NSF LTNCs conditions as stated in the NSF LTNCs document so were not included.*
- There was concern at the risk of double counting (e.g. there is a section for both aphasia and stroke). This isn't a problem as long as it is made clear that the purpose of the page is not to come up with a total number of people with LTNCs. *The conditions were lifted directly from the NSF LTNCs and the author was aware of the element of potential double counting.*

Service user perspective sections (at the end of each QR page)

- Only have a choice of 'yes' or 'no' – the view may not be this clear cut. *This has been amended and now there are more options such as 'Yes', 'No', 'Some', 'Not always' and there are pop up menus to assist in clarifying how these should be answered.*
- Participants in site 1 and 4 thought these questions were to be completed by service users, misunderstanding that they had been posed by service users. *In the revised tool this section changed from being titled 'Service User Perspective' to 'Questions asked by service users'*

Notes sections

- All sites made extensive use of these sections, as generally most

elements were part met.

- A lead for quality and audit in one site suggested including hyperlinks from notes pages to evidence where markers are claimed to be met (e.g. protocols, job descriptions, results of audits.). *This could be done within the web based version that is in development.*

9 Results: Focus groups

Service user and carer participation

In all, 51 people took part in seven focus groups; three people took part in telephone interviews; and three people completed questionnaires. The telephone interviews, and separate questionnaires for service users and for carers, were introduced in order to get the views of people who are 'hard to reach' because of the nature of their neurological condition;⁵ or people who might otherwise not have an opportunity to contribute. The draft questionnaires are attached at **Appendix 5**.

Outcome of arrangements

Appendix 6 sets out the schedule of events, action taken and outcomes for each pilot site. The sites are listed in the order in which the original focus groups were planned.

Focus groups took place in six of the eight pilot sites, with site 7 having two. In one site a focus group was held in a service setting used by a range of people with long-term neurological conditions and was organised by members of the staff. This meant that confidentiality was compromised, although neither the PCT nor the Council were involved. In that site, telephone interviews were also carried out with people who had responded to the first invitation, following a phone call arranging a time to talk and seeking agreement to record the calls. The questionnaires were used in pilot sites 2 and 9 when it was agreed that viable focus groups wouldn't be possible.

Focus groups were postponed in three pilot sites because of the low number of responses to the first invitation; one group was run in a site where two had been proposed; and in two sites three groups had been proposed but only one was run in each of them.

Questionnaires were sent out to four people in pilot site 2 after they had agreed to complete one. Despite their previous agreement only three questionnaires were returned. Similarly, questionnaires were sent out to four people in pilot site 9 but they weren't phoned beforehand and none of

⁵ These might be, for example, people with significant physical impairments or people in the later stages of progressive conditions. Some people with communication difficulties or cognitive impairments might find it difficult to participate fully in a group.

the questionnaires was returned. However, telephone feedback on the questionnaire itself was given by one of the recipients.

Reports

Six sites were given themed reports based on focus groups and one based on a questionnaire. One site was also given a further report based on telephone interviews. A sample report is attached as **Appendix 8**.

Reports were developed against standard themed and weighted methodologies from verbatim transcripts of the recorded focus groups. Most were undertaken by the two project workers, but one was conducted with a private sector professional reader and transcriber. The themed report in appendix 9 was professionally produced by a private sector company specialising in medical themed analysis.

Issues arising from the focus groups, telephone interviews and questionnaire

As set out in **Appendix 2** *Sample topics for discussion*, the subjects introduced were broadly the same for each group and interview (slightly different in the questionnaire). However, the discussions didn't all follow the same pattern because of the mix of conditions; local provision; the interaction between group members; and, of course, the personalities and interests of the participants. Nevertheless, there were many common issues not only within groups, but also across the groups and **Appendix 9** provides a summary of the key themes, illustrated by specific comments of group members. The themes were:

- Experience of diagnosis
- Accessing information
- Experience of staff groups
- Experience of services
- Access to services
- Support groups
- Continuity of care
- Care in hospital
- Person-centred care
- Carers and families
- Access to work
- Access to benefits

Common finding amplified in Appendix 9 were:

- Lack of information at diagnosis, both historically and currently; problems with accessing information at appropriate times post-diagnosis and lack of emotional support at this time. There were also issues concerning frequency of follow-up with neurological services especially neurologists. General Practitioners received a mixed reaction and were cited as either being supportive and knowledgeable or non-supportive and unhelpful. Many found that

GPs always attributed any co-morbidities as being a result of their neurological condition. It was found that not everyone had access to specialist nurses, but those who did were very positive about them. The experience of specialist Neurological teams was also viewed positively.

- Service users' experience of physiotherapy varied widely, and although being viewed as key professionals keeping people with neurological conditions mobile and independent, most service users cited insufficient input from physiotherapy is a major problem. Occupational Therapy services were also considered inadequate.
- In terms of social care there was a mixed response with those with higher levels of disability receiving acceptable levels of social care, whilst those with lower levels of disability struggled to remain independent whilst falling outside the eligibility criteria. There was major confusion around the differentiation between health and social services' occupational therapists. There was also severe confusion concerning home adaptations and grants for alterations. In terms of aids, equipment and adaptive technologies, with the exception of wheelchairs and access to splints where people were no longer seeing physiotherapists or occupational therapists, most were supplied in a timely manner.
- Access to appropriate housing was also a major issue for those expressing an opinion. Physical access to services due to lack of adequate parking, accessible transport, and considerate timing of appointments were also cited as issues.
- Local and national support groups were considered essential for people with long-term neurological conditions.
- Lack of continuity of care, communication and coordination between services was seen as an issue especially during transitions between children and adult services and adult and elderly care services. The inconsistencies in continuity of social workers were also raised as a major issue.
- It was generally agreed by service users that if admitted to hospital for co-morbidities, then often their neurological condition was ignored and their insight into their own conditions overlooked. Patients with Parkinson's disease often had their pleas for their medication on time refused.
- Few in the community had care plans although there was confusion about what constituted a care plan. However, most service users claim to know who they would contact if their needs changed despite few having a key worker or care coordinator.
- Most service users said that their carers received little or no support.
- Several service users highlighted difficulties in finding work. They claimed that there was insufficient help them to find appropriate work.
- There was general confusion concerning eligibility for and access to benefits.

Learning from the process and outcomes of engaging service users and carers

- A variety of mechanisms to engage service users and carers is needed e.g. focus groups, visiting service-specific environments, using meetings of condition-specific groups, questionnaires.
- Where staff are being asked to help with recruiting for focus groups, they need to be able to spend time explaining what a focus group is, and why service users and carers are being invited to take part.
- Where there is increased risk of service users having a greater degree of cognitive impairment (as was the situation with a particular focus group with a large number of participants with acquired brain injury), then reminders of the date, time and venue close to the date of the meeting are important, especially for people who might have difficulty in remembering, or time and date referencing.
 - If it's known that there are participants with cognitive impairments or communication difficulties:
 - More time should be allowed for discussion; and
 - Support needs should be considered to ensure people can have opportunities to contribute.
- Some flexibility in timing of focus groups needs to be built in to allow for interaction between participants (an immediate benefit for some group members was learning from others e.g. about Direct Payments, local services).
- Sufficient time needs to be allowed for telephone interviews, which can be very intensive.

10 Results: Action Plans.

To complete the action planning effectively it became clear that it was essential to have the same chair person and some members of the group that completed the original audit and were in a position of authority within the organisation to be able to make decisions to undertake the evaluation of the audit outcomes, and action plan development.

Several pilot sites were reacting to other drivers, such as Strategic Health Authorities requiring Self Assessment Frameworks to be completed and ongoing work on neurological services re-design.⁶ This work incorporated whatever information was available from QN at the time and, in some pilot sites, the work overtook the QN project, especially where the audit tool was completed but there were delays in running focus groups. However, the QN tool was an integral and essential part of the process acting as the initial catalyst.

Site 1 had other drivers running alongside the QN project and produced an action plan with alternative headings of: *Suggested action, Feasible?*

⁶ In pilot site 4, the QN project was linked to work being undertaken by the clinical neurological champion's service re-design and also supported an MSc dissertation.

Population number affected, Possible to best learn from practice locally or elsewhere? Addresses top priorities? Potential improvement to patient experience?, Score & recommendation. See Appendix 10

Site 2 (still awaited) Appendix 11

Site 3 produced an extract from their Annual Work Programme from their LIT, *'Incorporate the recommendations from the Quality Neurology Focus Group for all long term neurological conditions'* and headings of: Work area, Action, Lead, Date, Progress report. (See **Appendix 12**). They also had an external driver from their Strategic Health Authority who required some output on neurological conditions ahead of local progress on the QN project.

Site 4 The Long Term Conditions Service Improvement Board sub group produced: *Progressive Neurological Conditions Strategy*. See **Appendix 13**. At this site, the work was also being used to populate the evidenced based element of the Champion's MSc submission.

Site 5 didn't participate beyond early involvement.

Site 6 produced an action plan with headings of *Activity, Action, Outcome, Timescale, RAG and Lead* in which all 11 QRs had at least one objective. (See **Appendix 14**).

Site 7 produced an action plan as per the given template for QRs 1,4,5,6,7,8,10 & 11 but only QR1 included detail of the outcome and actions. (See **Appendix 15**).

Site 8 produced a full strategy document which took account of, and acknowledged, the work from QN and its influence. (See **Appendix 16**).

Site 9 was unable to complete the full process within the timescale. However, they did complete the audit as part of ongoing work on the NSF LTNCs where they had already gathered data on several QRs. They found the tool useful for capturing data for those QRs they had not yet worked on.

All the sites that reflected the QN work in Neurological Service Strategies, said that the QN tool was the major catalyst in recognising service shortfalls and identifying areas of good and poor practice across their PCTs. The input from service users was deemed to have been invaluable in helping set priorities and for identifying 'quick wins' and low cost – mainly around the areas of information.

11. Conclusions

With the evidence from the University of York study concerning the patchy implementation of the NSF LTNC, this project demonstrates that the audit

tool is a robust, vehicle with which to measure progress against the NSF LTNCs and can be used as a means to drive progress with the engagement of service users. . However, there are issues around the questions using the words lifted directly from the NSF LTNCs (**see Appendix 17**). Work will need to be done to refine these questions and add guidance notes regarding interpretation and parameters for assigning the scores.

The tool has the potential to be developed into a web based application that also becomes the knowledge store and evidence base for implementing the NSF LTNCs. This has been proven for QR1 using a platform developed by the commercial company 'Gaiasoft'⁷. (**See Appendix 18**). The value of this approach is to allow multi-speed tracking of progress and audit on a micro and macro level.

All the functionality issues from the Excel tool could be addressed within the web based framework with easy pop up guidance and ability to specify the scoring criteria.

It also has the potential to enable contact between areas to benchmark and share best practice and for service users and carers to directly input their views on specific aspects of services related to the NSF LTNCs.

It should be noted that to be successful, the audit should always have the engagement of services users as an essential element.

13. Recommendations:

This project has demonstrated that the audit tool is a robust vehicle for both auditing progress against the QRs of the NSF LTNCs and highlighting its implementation and ongoing development of services for those affected by long term neurological conditions.

Recommendation 1

The tool / process is actively promoted as a robust means of enabling GP commissioning clusters to understand the neurology services that they will need to commission; and to assist them in creating their neurology commissioning strategy for service consolidation, improvement and development in line with the needs, wishes and priorities of people affected by a long-term neurological condition.

The tool / process is also actively promoted as a robust means of enabling providers – both public and private – to fully understand the neurology services that they should be providing for people affected by a long-term neurological condition; and to enable well-facilitated, constructive dialogue between provider and commissioner within any given area.

⁷ <http://www.gaiasoft.com>

Recommendation 2

That investment⁸ is sought to develop the web enabled version of the tool, which would then be made available (on a licence) to commissioners and service providers who wish to evidence their compliance and track the development of their neurological services related to the QRs of the NSF LTNCs. The web tool will support the full lifecycle of improvement from assessment, to improvement planning, action taking, review, re-assessment and learning.

The web enabled tool would also have a portal by which service users and carers could have an overview of progress and leave comments and suggestions. This would provide an additional opportunity for engagement of service users and carers.

If the web version is developed, then sharing of information and best practice between localities could be monitored and used as a surrogate peer review process.

Recommendation 3

The tool is promoted to the DH, the Care Quality Commission, the anticipated Commissioning Board, and any new emerging regulators / influential bodies as a robust vehicle with which to audit and evaluate neurology services, monitor compliance with the NSF and other national initiatives, and demonstrate active involvement of service users and carers in service development / evaluation.

Recommendation 4

That, should the Excel version of the tool be developed and be adopted, work would be done to clarify the wording of some questions and to develop guidance in drop down comment boxes concerning the criteria for completion of 'Met', 'Part Met' and 'Not Met'. An 80% formula would need to be developed to increase the number of areas that could be regarded as 'Met' and reduce the demoralisation element of so many areas being 'Part Met'.

Recommendation 5

That the draft service user and carer questionnaires be further developed and tested to ensure that they meet the needs of commissioners and service providers in both delivering feedback on services and highlighting issues of greatest importance to service users and carers.

Recommendation 6

That different ways are explored of enabling:

- 1) Service users and carers to complete the questionnaires e.g. web-based or hard copy, and that these allow complete confidentiality.
- 2) Commissioners and service providers to collate their responses.

(nb. Both of the above would be covered if the web enabled tool is developed).

⁸ Currently estimated at less than £230,000.

Recommendation 7

That a specific format is not used to completion of action plans as the audit outcome can be used in a range of ways.

If the web enabled version is developed then this action will be taken care of in the reporting abilities of the tool.

If the Excel version is adopted, then commissioners and service providers can use the results from the audit and focus groups in the 'house' style to fit with emerging drivers and initiatives.

Alun Davies
Project Manager

December
2009

Marilyn Ekers
Project Worker

15. Acknowledgements.

The project manager and project worker wish to acknowledge the input and assistance from the following people and organisations.

Fiona Aspinal, SPRU, York University
Michael Bassey, Carer representative & former steering group member
Penny Bassey, Service user representative & former steering group member
Sylvia Bernard, SPRU, York University
Joanna Black, National Council for Palliative Care
Val Buxton, Director of Policy Campaigns and Information, PDS Steering group member
Lesley Carter, Steering group member
Tim Davies, Practical Participation
Morel Forman, Chief Executive. Gaiasoft International Ltd
Mike Godfrey, Service user representative, Steering group member
Kate Gridley, SPRU, York University
Robert Gurney, Service user representative & former steering group member.
Mandy Hassall, Assistant Director of Services [NSF] Headway - the brain injury association.
Tricia Holmes, Motor Neurone Disease Association & former steering group member.
Sheila Lakey, Former project manager
Heidi Macleod, Motor Neurone Disease Association, Steering group member
Lucy McCulloch, Health Care Commission Steering group member
Sue Millman, Chief Executive. Ataxia UK Steering group member
Robyn Noonan, DH User Led Organisations Delivery Programme.
Michelle Procopi, Project Administration support
Charlie Rees, Project Administration support
Chris Reynolds, Consultant, Gaiasoft International Ltd
Janice Russell-Taylor, Service user representative, Steering group member
Paul Smith, Executive Director, Spinal Injuries Association.
Yvonne Trace, Greater Manchester Neurological Alliance.
Geraldine Walker, Community Care Development Officer, Dudley Council for Voluntary Service
Jon Whiting, DH User Led Organisations Delivery Programme.
Barbara Williams, Director of Operations, MS Society, Steering group member (chair)
Maggie Winchcombe, Adviser, LTNC RI
Darran Winfield-Stanesby, Service user representative, Steering group member
All the service provider staff who undertook populating the audit tool in each pilot site
All the service users who took part in the patient focus groups, filled in questionnaires or were interviewed face to face or by telephone.
Service users and carers from: Ataxia UK, Headway, The Motor Neurone Disease Association, The MS Society, The Parkinson's Disease Association, The Spinal Injuries Association.

Appendices

	Page
1 Bid document	33
2 Sample list of topics for focus groups	47
2a Focus group running order	48
3 Sample flyer inviting participation in focus groups	49
4 Evaluation of focus groups form	51
5 Questionnaires	
Carers	55
Service users	67
6 Schedule of focus groups events, actions taken and outcomes from pilot sites. <i>(We also undertook evaluations of the questionnaire , the feedback forms of which are not included in the appendices)</i>	84
7 Feedback on the draft audit tool proforma	87
8 Sample focus group report	93
9 Thematic summary from six focus groups	98
10 Site one action plan	108
11 Site two action plan	111
12 Site three action plan	112
13 Site four action plan	113
14 Site six action plan	118
15 Site seven action plan	121
16 Site eight anonymised strategy <small>(with its own appendices)</small>	125
17 Evaluation of wording of NSF LTNCs questions within the audit tool	208
18 Web based audit tool screen shots	211
19 Profile of Funding Charities	227
20 Excel based audit tool (as separate Excel file)	

This page is deliberately blank