West Berkshire Neurological Alliance

working with

Hampshire Neurological Alliance, Oxfordshire Neurological Alliance and Buckinghamshire Alliance of Neurological Organisations

Recommendations arising from a focus Group held on 7th November 2011 at Padworth

For the attention of NHS South Central Strategic Health Authority's Cardiovascular network project team and others.

Minimum Standards for neuro-rehabilitation

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Background

In autumn/winter 2011 the Cardio vascular network in South Central Strategic Health Authority will be developing recommendations on minimum standards for neuro-rehabilitation in the region. Some existing services in the region have been developed ad-hoc, some being well regarded by patients, with some areas having no services.

The purpose in holding this focus group was to ensure the perspective of patients, carers and the voluntary sector across the four counties of the SHA was gathered, to generate some evidence to support recommendations on minimum standards. Addressing the need for a minimum standard for neuro-rehabilitation across the region is welcome. Of the limited services in place within South Central, most therapists are regarded as providing acceptable or good quality outcomes in general, but services lack co-ordination. The Oxford Centre of Enablement is one local service indicated by patients in this focus group as a model with particular in-house merits. No local rehabilitation service is regarded as having sufficient capacity to meet needs.

It would be welcomed if acceptable minimum standards for neuro rehabilitation could be agreed, then commissioned equitably across all areas in South Central, at the earliest opportunity. Commissioning neuro-rehabilitation services should not be regarded as an exercise incurring costs, rather as one delivering value. The proposed standards should not be viewed in isolation and should be enabled by paying due consideration to GP awareness and training in particular.

Savings arising from the introduction of new neuro-rehabilitation services should be recycled into other services needed by neurology patients.

Recommendations for inclusion into a minimum standard.

Which patients need neuro-rehabilitation?

Neuro rehabilitation must be available to any neuro patient who presents as having rehabilitation need and should not be dependent upon having a diagnosis specified in a restricted list. When patients taking neuro-rehabilitation incur any medical emergency, their rehabilitation needs generally continue and holistic care should be the norm unless there are contra-indications. Therapy services need to be age-relevant and be based on a proper diagnosis and careful assessment but most importantly must be individually tailored. Services should be resourced such that patients presenting with rare neurological conditions are not at any disadvantage.

Service aims and mission

A minimum standard service should seek to maintain the functionality that people have, as well as to restore or improve functionality where possible. Prevention of deterioration should be an aim of any minimum standard. The benefits of appropriate neuro-rehabilitation are numerous and the written aims of any minimum standard should include that patients should be provided with services that work towards maintaining optimum fitness, encouraging participation in society, achievement, independence, fulfilment, improved mobility, good pain management, continence control, good diet, coping at home, access to aids and equipment, psychological support and wider advice, keeping out of hospital, keeping in work, better quality of life and similar aspirations**.**

Service Standards

The minimum standard should require neuro-rehabilitation teams to deliver patient centred, expert, listening, holistic services, using modern communications and easy to follow, effective pathways. The service should ensure, but not be bogged down in, the

need for good record keeping. Provision of a wide range of relevant, up-to-date and timely information to patients and carers is fundamental.

Composition of the neuro-rehabilitation team and links

The neuro-rehabilitation service should be a real team, not a virtual team. Posts may be a mixture of full time and part time. The team should always include the disciplines listed below. These are listed generally in the order by which capacity and need are likely to be greatest:

Specialist neuro Occupational Therapists,
Neuro Nurse Specialists (MS, Parkinson's, etc),
Neuro -physiotherapists (trained in wider aspects of physical therapy),
Speech & Language & Communication Therapists,
Neuro psychologists and talking therapists,
Continence nurse/advisors,
Pain management specialists,
Dieticians,
Vocational Support workers (especially for Head Injury).
GPs with specialist knowledge of neuro needs.

and the team should either contain or have specific and direct links to:

Pharmacy advice,
Fatigue management expertise,
Social workers,
Independent advocacy services,
Housing departments.

The team should have clear links to other services, notably: Consultant Neurologists and Consultants in neuro-rehabilitation, community nursing teams, psychiatry, equipment services, Wheelchair & Seating Service and similar.

Skills and training

Currently, individual professional skill levels of many or most rehabilitation therapists are perceived as good, although the scope of their delivered work is sometimes perceived to be too narrow. To ensure good value, the minimum standard should address ways in which some traditional roles should be restated

Many neuro-physiotherapists are perceived as working to a rigid physiotherapy code and there is a need for an expansion of their role that would enable them to provide or advise robustly on the full range of physical therapies required, rather than concentrate on traditional physiotherapy. This requirement, making specific reference to physical fitness, yoga, hydrotherapy and related physical therapies, should be clearly stated in any minimum standard, otherwise the outcomes will be less than good value.

Similarly, the traditional Speech & Language role has generally drifted in recent years into focussing over-much as a swallowing service, but should redirect towards

delivering a full speech & language plus swallowing and communications role, to ensure good value.

The skills mix in the team, and therefore in the minimum standard, should include advocacy. In addition there should be links to independent appropriately skilled advocacy for more complex matters.

The service standard should include provision of specialist training for carers. And have links to team s with expertise in working with families, children and young people.

Location of services

Where appropriate, the service should be provided in patient's homes or where patients live. Neuro-rehabilitation should be provided also in centres that are readily accessible by public transport and with good vehicle parking and be equipped adequately for the purpose. Physical access within facilities where service is provided must be suitable for wheelchair users and for those with other mobility problems. Group work can be effective and efficient, also providing an important social element, recognising that group therapy may not suit some situations. The benefits of seeing the whole multi disciplinary team in the same afternoon should be mentioned in the minimum standard. Details of where best to locate facilities should be a matter of local consultation. Full use should be made of the wide range of modern communication options, to save travelling time. Incorporating less than this into any minimum standard will deliver poor value.

Management

To achieve good value, excellent co-ordination and continuity of care, including during acute episodes is integral to achieving a minimum standard, as are effective information sharing within the team and with other service streams. The service needs to be informed about hospitalisations of those taking or needing rehabilitation.

The minimum standard must include a requirement for effective joint working with the voluntary sector in addition to statutory agency partners.

Referral routes and waiting times

GPs, neuro consultants, other consultants, nurse specialists, O/Ts and the voluntary sector should be authorized to refer patients to neuro-rehabilitation. Patient self-referral would be useful but could be abused and needs screening. Once in the system patient self-referral should be the norm.

Two streams and speeds of access should be specified within any minimum standard, namely: 'Same day/next day' and 'Within six weeks'. The minimum standard should state explicitly that words such as 'urgent', 'priority', etc should not be used, to minimise false expectations.

Same day/next day service.

Any person experiencing a loss of ability to carry out a task of daily living or incurring an equivalent neurological emergency or an acute deterioration in their neurological situation should be referred for neuro-rehabilitation on a 'same day/next day' basis. All qualifying patients should normally receive an assessment before mid-day the following day.

'Within six weeks' service.

Any person who presents as in need of neuro-rehabilitation that is not regarded mutually as being 'Same day/next day' in nature should be referred to a 'slow stream' service comprising the following five, essential elements:

Appointment notified to patients within 5 working days,
Assessments made within 1 month,
Treatment commences within 6 weeks,
Appointment communications should make it clear that patients may ask for an earlier appointment if the one offered is inappropriate,
Waiting time standards must be published,

A minimum standards recommendation should be that any rehabilitation service should use triage, to maximise outcomes from the given budget. Assessment over the phone may be acceptable in some instances, the objective being robust information gathering as quickly as possible. Motor Neurone patients must see the rapid response team.

Outcome measures and audit

The outcome measures of greatest value are those around patient and carer opinions of value. Regular patient and carer satisfaction surveys are an essential requirement of a minimum standard. Secondarily, waiting times and hospital readmission data should also be collected. Return-to-work data should be collected. The minimum standard should require regular, systematic audit of service activity and outcomes, integral to identifying opportunities to improve the value and outcomes of the services.

Implementation

The publication of minimum standards for neuro-rehabilitation should encourage commissioners to commission services of value. However, this will not be sufficient and should not be done in isolation. In tandem with commissioning services that meet or exceed the minimum standards, the commissioning system must address very strong concerns expressed by many neuro patients that many GPs have a poor understanding of neurological diagnosis, neurological need and the value of neuro-rehabilitation. Unless this is addressed at the same time, investment in neuro-rehabilitation will not realise full value.

Other recommendations

Thorough checks on trauma patients immediately following trauma should reduce the demand on some avoidable rehabilitation treatment. Recommendations on this, made by the Royal College of Physicians in 'Local Neurology Services for the Next Decade', published in June 2011 should be implemented in all areas as an adjunct to

commissioning neuro-rehabilitation minimum standards. This is an issue to address at the supra-PCT level.

Rehabilitation needs will be better met if all nurses on those hospital wards that are most likely to admit neuro patients have additional training in the care and rehabilitation needs of these patients. All nurses on all other wards should have some additional basic training in neuro needs.

The recommendation that prescriptions for long-term neurological patients should be free would help many to feel they could afford therapies and other services that the statutory sector is unable to provide.

Format of the focus group.

Attendees were briefed that the purpose of the meeting was to discuss and recommend upon ‘what should be a minimum standard for neuro-rehabilitation in any area in South Central Strategic Health Authority region?’. A minimal outline was given, suggesting no more than neuro-rehabilitation might embrace the services that individuals may need to recover lost capability to deal with tasks of daily living, or to maintain such capabilities or to return to or stay in work, as examples. The organiser indicated that there is not any universal definition of the term ‘minimum standard’, but suggested that any minimum healthcare standard was likely to be aimed at ensuring aspects of dignity, respect, good clinical outcomes and good value for money (rather than just perceived cost).

Attendees had been advised prior to the focus group of eleven questions to be discussed, which they did in four mixed groups, each led by a facilitator. Summary notes were taken at each table.

Limitations of this consultation.

Neurology conditions are many and diverse and this consultation covered an incomplete cross section, with only 23 participants representing 9 conditions, and a bias as regards age range, (all above 40 yrs) also with a female bias, (16F, 7M).

There was only 1 attendee from Buckinghamshire, 4 from Hampshire, 7 from Oxfordshire and 9 from Berkshire. There were 8 attending living with a neurological condition and 8 present in a caring role. 17 were active in the voluntary sector. 9 neurological conditions were represented directly. Two participants were wheelchair-bound and six had apparent walking difficulties. Two attendees work also as social care professionals. West Berkshire Neurological Alliance volunteers acted as facilitators and took notes of the proceedings. There was no scene-setting by service providers or by the SHA project team, of which 2 were present, aiming to encourage wide ranging and uninhibited discussion, which inevitably strayed to matters beyond the immediate SHA requirement for a minimum standards document.

Either individually or collectively, those taking part should not be thought off as ‘representative’ or ‘typical’. They were selected by local charities of which they are members because they are intelligent, good communicators, positive in outlook and interested in the way that services are provided. In addition to being able to describe

their own experiences they all also have some understanding of how others with the same condition may be affected differently.

Some recommendations cover gaps in the discussions and the validity of all the recommendations will have been through a process of crosschecks with attendees before being finalised.

Conditions Represented:
Parkinson's, including early onset Parkinson's
Polio Late Effects
Multiple Sclerosis
Motor Neurone Disease
Early onset Dementia
Traumatic Brain Injury/Acquired brain inury
Spinal injury
Charcot-Marie-Tooth
Peripheral Neuropathy

Facilitators from WBNA: Joanna Knott, John Holt, Gill Hall, Fred Davison

Composition of the mixed groups:

Table 1.

TBI carer
Polio late effects
MS
MS carer
Parkinson's x 2
SHA project manager

Table 2.

Head Injury patient
Headway volunteer
Carer MS
Carer MS
Headway volunteer
MND carer
Parkinson's and MS co morbidity

Table 3.

Parkinson's patient who is also a carer for a dementia patient
Young onset Parkinson's
MND volunteer
MS carer
Head Injuries voluntary sector
Head injuries voluntary sector

Table 4.

Parkinson's – carer
Dementia/carer for PD
Rep. Headway and Hampshire NA
MND volunteer
Hereditary peripheral neuropathology/ Hants NA
Carer for above.
SHA Project Manager

Record of the meeting and summaries, by questions and by table group.
Summary notes were taken at each table. These are reproduced below. Statements shown in quotation marks are paraphrases of what was said, they should not necessarily be taken to be direct quotes. Text in blue summarise the discussions.
Q1. Which conditions can benefit from neuro rehab?

Table 1.

'All could benefit from neuro-rehab.'

Table 2.

'All.'

Table 3.

'All neuro conditions may need neuro-rehab.'

Table 4.

'All neurological conditions can benefit from rehabilitation, including the very rare ones. There are many commonalities and these need to be identified.'

'There are problems for neurological patients who go into hospital for something other than their neuro diagnosis (e.g. a Parkinson's patient with broken hip) The neurological condition tends to be ignored when the rehab is carried out leading to increased problems and more clinical input eventually, therefore more costly for NHS.'
'Lesson: More education is needed amongst those carrying out rehab in these circumstances, of the different neurological conditions so that appropriate therapy is given.'

'Some professionals do not understand what neuro rehab is, or understand its value and importance to neurological patients.'

Summary of key matters arising from Q1.

Neuro rehabilitation must be available to anyone who presents as having need and should not be dependent upon having a specific diagnosis. When patients incur another medical emergency, rehabilitation needs continue and holistic care should be the norm. Across the NHS, staff training in these issues is important.

Q2. What are the benefits and best value arising from good neuro-rehab?

Table 1.

‘Keeping fit – maintaining optimum fitness.’
‘Long term conditions tend to be neglected.’
‘Patients tend to get kit rather than receive help, assessment and treatment. Patients need to ask the right questions of the specialists.’
‘Patients need a large amount of input and attention.’
‘Neuro-rehab needs to be holistic. Neurology is concerned with diagnosis.’
‘Need to co-ordinate between specialists.’
‘Need continuity of service.’
‘Voluntary group organises Pilates and hydrotherapy, not the NHS. Poorer members cannot afford.’
‘Physio deals with acute conditions rather than chronic.’
‘Care does not consider prevention of deterioration.’
‘Patients need to watch their weight and other practical issues.’
‘Hydrotherapy: there is a problem getting shoes and socks on afterwards – embarrassed to ask for help.’
‘Would like to book the Hydrotherapy pool at Royal Berks Hospital but cannot get co-ordination and agreement from officers. Benefits would be huge.’
‘Hydrotherapy is a big problem to obtain, but huge benefits.’
‘Some commercial gyms have wheelchair access, but are not readily available.’
‘A holistic approach is needed. A consultant laughed at the suggestion that cod liver oil for vitamins should be considered. Prescription for a six-month vitamin course are only available from hospital pharmacy, but would save money if more widely available, to prevent hospitalisation due to vitamin deficiency.‘

Table 2.

‘Companionship, achievement, improvement in mobility with physio, pain relief, Incontinence help, dietary advice, OT advice in the home, Counselling, Information given about Support Groups.’

Table 3.

‘Rare conditions need more visibility, e.g. Young Parkinson’s and those with unusual symptoms. It’s difficult to get doctors to listen. It took months to get a referral and it should have been days. I was lying on the floor screaming and calling ambulances. People and the system need to be more responsive and more listening.’
‘Services need to provide psychological support and pain relief and keep people out of hospital.’
‘We need services that lead to physical improvement and/or keep people in work.’
‘Services need to be age-relevant and be based on a proper diagnosis.’

Table 4.

‘Optimising people’s independence and so less reliance on NHS and statutory services.’

In Brain Injury; ‘this means more availability of neuro-psychology, a Vocational support worker and ongoing support. Could get more people back into work with the right support.’
For others, ‘appropriate neuro-physiotherapy earlier in the course of the disease could mean that person being able to stay in work for longer and so become less of a drain on the country’s resources.’
‘Planning end of life care needs to be done holistically.’
‘Where the disease course is more rapid, appropriate rehab can markedly improve the quality of life left to someone. Thus there are benefits to both the patient and the Society at large.’

Summary of key matters arising from Q2.

Attendees reported general difficulty in accessing rehabilitation, the more experienced being more likely to find ways to access things that help. Many do not like to ask for help. Referral times are too long. Services need to be age-relevant and be based on a proper diagnosis. Holistic therapy is needed but not often supplied. The need for co-ordination and continuity is clear. Acute treatment gets priority over chronic need. Prevention and avoiding deterioration is not given high enough priority. Hydrotherapy needs are generally unmet. The patients’ voice is often ignored; professionals need to listen more and respond better. Those with rare conditions or unusual symptoms are at risk of being sidelined. The voluntary sector is a significant source of therapy. The benefits of appropriate neuro-rehabilitation are numerous and include: keeping fit, maintaining optimum fitness, companionship, achievement, independence, improved mobility, better pain management, continence control, diet, coping at home, aids and equipment, psychological support, wider advice, keeping people out of hospital, keeping in work, better quality of life

Q3. Which are the clinical disciplines needed in every neuro-rehab team?

Table 1.

‘Specialist nurses: We need to retain specialist nurses. Rehab teams need a nursing element. A rehab neuro nurse should set individual goals and manage expectations. Specialist nurses have specialist knowledge.’
‘Continence (bladder) nurse.’
‘IAPT – psychological services.’
‘General physio or neuro physios needed’: ‘like gold dust.’
‘Specialist neuro O/T.’
‘GPs with specialist knowledge of rarer neuro conditions. May only have one GPwSI.’
‘It seems that providers avoid the opportunity to provide specialist nurses.’
‘Consultants can only see patients typically annually.’
‘Rare conditions: difficult to get recognition.’
‘Staff do not share information; they all keep their own files. We need a system of information sharing, so patients do not need to keep explaining.’
‘Need better communication with routine hospital wards.’
‘Specialist training needed for general staff.’
‘It can be degrading to be in hospital.’
‘Need info booklets on neuro conditions.’
‘Specialist teams need to know when patients with neuro conditions are being admitted to hospital.’

‘Access to facilities is a problem, as your condition gets worse: e.g. toilets, pill boxes.’
‘Free prescriptions would help people with Long Term Conditions. People often choose only what they can afford. Why do only some long term conditions qualify for free prescriptions?’

Table 2.

‘Neurologist, Specialist nurse, OT, Physio, Speech Therapist, Pain control expert, Neuro psychologist, Incontinence advisor, Pharmacist, Fatigue management.’

Table 3.

‘Psychologists, physios or physical therapists including gym trainers, O/T, Speech & Language, dietician, pain specialists, nurse specialists in the community, all providing an extended, home-based service to meet changing needs.’
‘Family pressures can distort things.’
‘Services should maintain what functionality people have, not just be aimed at improving functionality.’
One person mentioned ‘psychiatry should be part of the rehab team’.

Table 4.

‘Different for different conditions but there are some commonalities.’
‘Rehabilitation Consultant, Neuro physio, neuro-psychologist, SLT, O/T. Specialist nurse (especially for MS, PD and rare neurological conditions) and Vocational Support worker (especially for Acquired Brain Injury).’
Some also wanted Community Matrons on this list.

Summary of key matters arising from Q3.

The team should always include:

- Neuro -physiotherapists or physical therapists including gym trainers,
- Neuro nurse specialists (MS, Parkinson’s, etc),
- Continence nurse/advisor,
- Speech & Language & Communication Therapist,
- Pain management specialist,
- Neuro psychologist,
- Pharmacist,
- Fatigue management,
- Specialist neuro O/T.
- Dietician,
- One or more GPs with specialist knowledge of neuro.
- Vocational Support Worker (especially for Head Injury).

Some also wanted Community Matrons on this list.

The team should be a real team, not a virtual team.

The team should have clear links to:

- Consultant Neurologist and Consultant in neuro-rehabilitation,
- Community nursing teams,

Psychiatry,
Equipment Services, Wheelchair & Seating Service and others.

Services should maintain the functionality people have, not aim only to improve functionality.

Associated requirements include:
effective information sharing within the team and with other service streams,
specialist training in neuro matters needed for many or most general clinicians,
provision of relevant and timely information.
the team need to be informed about hospitalisations of those needing rehab.
access to facilities where teams are based must be good,
free prescriptions would help people with Long Term Conditions.

Q4. Within this, which services are needed most and why?

Table 1.

Needed most are:
'Specialist nurses for medications management.'
'Specialist O/Ts. Help get home set up, avoid accidents, and help with everybody.'
'Single point of access: see whole multi disciplinary team in the same afternoon.'
'Speech & Language needed by many with Long term conditions.'
'Parkinson's patients need help with gastro problems.'
'Continence.'
'Physiotherapy.'
'Psychological therapies treatment for anxiety and depression.'
'GPwSI would be useful for rehabilitation team. A local service or peripatetic GPwSIs who could visit regularly.'
'Patients need to see Neuro consultants and the GP should not replace consultants.'

Table 2.

'This varies depending on the condition but obviously the patient must have a diagnosis by a neurologist and should then receive the appropriate treatment from a suitably trained specialist. Continuity of care is vital.'

Table 3.

'My GP did not understand my condition and did not know which services exist.'
One person suggested the most needed were, in order: 'O/T, S&L, P/T.'
Another suggested: 'P/T, O/T, Continence Advisor.'
Another suggested 'Psychology, P/T, O/T.'
'Maintenance is just as important as regaining lost performance.'
All agreed that a 'virtual team' concept does not work. 'We need a real team.'

Table 4.

'Slightly different emphasis for different conditions'
Brain Injury: 'neuro psychologist, OT, Vocational social worker.'
Dementia: 'Neurologist, specialist nurse'

PD: ‘Specialist neurologist, specialist PD nurse with improved communication between the key people and the patient.’
Peripheral Neuropathy: ‘Neuro physiotherapy.’
MND: ‘Specialist Nurse, OT and SLT.’
All stressed need for involvement of Rehab Consultant and in some cases, a dietician.

Summary of key matters arising from Q4.

There are common interests, without being able to prescribe precisely the composition of a community neuro-rehabilitation team, but certain roles were mentioned more often than others across the four discussions:

Specialist O/Ts. mentioned six times,
Specialist nurses mentioned 5 times,
Neuro Physiotherapy mentioned 5 times,
Speech & Language mentioned 3 times,
Psychological therapies mentioned three times,
Continence services mentioned twice,
GPwSI,
Neuro consultants,
Vocational,
Consultant,
Dietician. …. each mentioned once

Several present expressed concerns about understanding of neurological diagnosis and of neurological need among the GP community. Discussions emphasised the need for a single point of access, also the benefits of seeing the whole multi disciplinary team in the same session. Maintenance is just as important as regaining lost performance.

Q5. What skill levels, staff training and ways of working are most useful?

Table 1.

‘Specialist nurses are good advocates for patients.’
‘Services should be available to care homes.’
‘Treatments should be routinely agreed with patient involvement.’
‘Need good communication between the voluntary and statutory sector.’
‘Need to have support for couples in relationships. Psychological therapies need to have active links.’

Table 2.

‘All nurses on wards which are most likely to admit neuro patients should have training in the care of these patients.’
‘All nurses on other wards should have a basic training so that patients admitted with another problem are cared for correctly.’
‘The team members must communicate with each other.’

Table 3.

‘Every GP practice needs a neuro GP specialist.’ ‘GPs should not have the choice of not being a specialist’ (was agreed unanimously at this table.)
‘We need ‘physical therapists’ more than just ‘physiotherapists’.’
It was agreed that skill levels are generally good at therapist level. However ‘there is a lack of neuro specialists within rehab teams.’
‘There should be a specialist course for carers.’
‘The charities should be used more.’
‘The minimum standard must include proper joint working with the voluntary sector. We must make maximum use of the voluntary sector.’

Table 4.

‘Request for more training in neurological conditions in all disciplines.’
‘In any PCT there should be a GP with specialist interest in Neurology.’
‘Specialist Nurses – very important.’
‘TEAMWORKING – plea for improved communication between professionals and between the professionals and their patients.’
‘Recognition that the NHS can’t do everything so need to work more closely with voluntary groups and to use the voluntary model for provision of some services like hydrotherapy, physio, SLT etc. Voluntary Groups can be experts and Commissioners should consider using them or at least, using their models of service provision.’

Summary of key matters arising from Q5.

Currently, skill levels are perceived generally as good at therapist level, although there is a lack of neuro specialists within some rehab teams. Neuro Physiotherapists should receive additional training to provide or advise robustly on the full range of physical therapies required, rather than concentrate on traditional physiotherapy. The traditional Speech & Language role has drifted into being mostly a swallowing service, but should retrain and redirect to delivering a full speech, swallowing, language and communications role. The skills mix in the team should include advocacy services. The demand for specialist neuro nursing and/or GPwSI capacity to be available within the neuro-rehab team is strong. All staff must ensure that service is patient centred and patient/care involving.

Some matters not directly part of any minimum standard for neuro-rehabilitation must be addressed if any service is to be effective. In particular, the knowledge and outlook of the GP as gatekeeper to NHS neuro-rehabilitation services needs to be addressed otherwise the local service will under-perform against its best potential.

Rehabilitation needs will be better met if all nurses on hospital wards that are most likely to admit neuro patients have training in the care of these patients. All nurses on other wards should have a basic training in neuro needs, so that patients admitted with another problem are cared for correctly.

The rehabilitation service should include a specialist course for carers.

The minimum standard must include a requirement for effective joint working with the voluntary sector.

The need for improved communication between professionals and between the professionals and their patients is central to success.

Q6. Where should services be provided to be both clinically and cost effective?

Table 1.

'Getting to services is very difficult.'
'Locations must be accessible.'
'GPs surgeries all would do.'
'Needs to be near a bus route.'
'Vulnerable people to have visits at home by a specialist O/T.'
'The service standard should be home visit. People should be seen in-situ.'
'Telephone conversation and an e-mail clinic would be useful.'
Problems were identified in getting a firm diagnosis of the condition.
One person identified having being prescribed 'five times the correct amount' of one powerful drug.
The need to have information provided to local GPs was discussed – 'people need to have backup' – 'hotline would be helpful'.

Table 2.

'In a neuro-rehab unit followed by in the patients home.'
'Continuity of care is so important.'
'Services should be local because of the problem of fatigue.'

Table 3.

'At the door, in people's homes and over the phone.'
'The movement disorders unit at John Radcliffe hospital is inaccessible. Some hospital layouts are poor. Satellite treatment units are the answer.'
'Within a 20 minute travelling time' was discussed and regarded as too optimistic.
'Important to make sure that specialist therapists are at the specialist clinics, all linking in better to prevention.'

Table 4.

'Near a good car park!'
'Need for more local sessions to cut down on travel time and cost.'
'Use of Groups.' e.g: Neuro-physiotherapists could organise groups of patients for exercise classes – obvious benefits for physio service in working with several patients at once and added social benefits to the patients. Or: SLT- organised groups for PD patients – benefits as above. 'These benefits are measurable.'
'Use of video conferencing so that neuro patients and their carers can be more easily involved in MDT meetings from home. Even the professionals would not have to be in the same room. Cost savings in journey times.'

Summary of key matters arising from Q6.

Neuro-rehabilitation should be provided in centres that are readily accessible and properly equipped for the purpose. Group work can be effective and efficient. Where appropriate, the service should be provided where the patient lives. Details of where best to locate facilities should be a matter of local consultation. Full use should be made of developing communication options to save travelling time.

Q7. What are the minimum options for patients to access or to be referred for service?

Table 1.

'The neuro rehab team should be able to cross-refer.'
'Self-referral would be useful – but could be abused – needs screening. Some expert patients know what is needed.'
'Referral criteria need to be applied.'
'Diagnosis should be confirmed before self-referral is permitted.'
'Triage of service would be useful.'

Table 2.

'This question was not understood.' *(stated the notes)*
'Any person with neurological symptoms or an acute deterioration in their symptoms should be referred immediately.'

Table 3.

'Patients should be able to be referred by GPs, neuro consultants, nurse specialists, other consultants, O/Ts and the voluntary sector. Once in the system self-referral should be the norm.'

Table 4.

'Should not just be GPs. Specialist nurses and other therapists should be able to make referrals.'
Several thought that patient self-referral should be allowed though this 'could overload services if referrals were inappropriate'. '?Less so if patients have ownership of own medical notes??'
It was noted that there are insufficient checks for brain injury in some instances of trauma, leading sometimes to unnecessary complications and the need for avoidable rehabilitation services.
'Rehabilitation services need good triage.'

Summary of key matters arising from Q7.

Any person with neurological symptoms or an acute deterioration in their symptoms should be referred immediately. Patients should be able to be referred by GPs, neuro consultants, nurse specialists, other consultants, O/Ts and the voluntary sector. Initial self-referral would be useful but could be abused and needs screening. Once in the system self-referral should be the norm. The rehabilitation services need good triage.

Better checks on trauma patients immediately following trauma should reduce the demand on some avoidable rehabilitation treatment.

Q8. What should be the referral criteria for 'same day/next day' assessment and treatment?

Table 1.

‘Needs to be patient led.’
‘GP/consultant could recommend next day.’
‘Risk of hospital admission should be an important consideration.’
‘Urinary tract infection needs urgent antibiotic treatment.’

Table 2.

‘Any acute episode or crisis.’

Table 3.

‘Referral should be ‘within a day’ when there is loss of capability to carry out essential tasks of daily living. The objective must be to prevent further deterioration as well as to restore lost abilities.’
‘Assessment over the phone for such instances may be acceptable, the objective being robust information gathering as quickly as possible.’
‘Motor Neurone patients must see the rapid response team.’

Table 4.

‘?’

Summary of key matters arising from Q8.

When there is loss of capability to carry out essential tasks of daily living, referral should be ‘within a day’. The objective must be to prevent further deterioration as well as to restore lost abilities. Assessment over the phone for such instances may be acceptable, the objective being robust information gathering as quickly as possible. Motor Neurone patients must see the rapid response team.

Q9. What should be the referral criteria for less urgent assessment and treatment?

Table 1.

Not discussed.

Table 2.

‘Any person with neurological symptoms should be referred to a neurologist promptly and be seen within 6 weeks.’

Table 3.

‘Less urgent situations should be handled to the following criteria:

1. patients should know their appointment date within 5 days of first contact
2. waiting times to assessment and treatment should be published
3. patients must be informed they may ask for an earlier assessment if the initial one is too distant’

Table 4.

‘Need for early assessment, in most neuro conditions, ‘early’ being within at least one month and treatment very soon thereafter.’

Summary of key matters arising from Q9.

Different perspectives were expressed, and a range of time-scales indicated as to how non-urgent referrals should be specified in a minimum standard. It is suggested that the following should be circulated for further consultation:

The minimum standard should be:
Appointment notified to patients within 5 days,
Assessments within 1 month,
Treatment commences within 6 weeks,
Appointment communications should make it clear that patients may ask for an earlier appointment if the one offered is inappropriate,
Waiting time standards should be published,
Words such as ‘urgent’, ‘priority’, etc should not be used, to ensure clarity.

Q10. What outcomes should be measured, to demonstrate an effective, good value service?

Table 1.

‘Patient and carer satisfaction.’
‘Long term holistic view. Look at outcomes over a period of time. Continual monitoring.’
‘Monitoring hydro patients for well-being.’
‘Being heard, being valued.’
‘Engaged with voluntary sector.’
‘Patient outcomes important. Measure outcomes for patients and families.’
‘Patients’ knowledge a huge resource.’

Table 2.

‘Any improvement in the patients’ condition.’
‘The number of patients who do not have to be admitted to hospital with an acute crisis because appropriate treatment has been given at home is a good outcome.’
‘Regular assessments of patients’ care and progress, done regularly to measure the provision of services which are provided, including their quality of life.’

Table 3.

‘Who does the measuring?’
Should measure:
‘Value, rather than activity,’
‘Waiting times,’
‘Re-admissions, noting that some variable conditions such as MS may lead to re-admission anyway),’
‘Patient surveys: (what was the service like?)’
‘Carer surveys,’
‘Returning to work, preventing marriage breakdown, enjoying life equals value,’
‘Mental health aspects, (noting that people with associated mental health issues may not understand the values),’
‘Frequency of ambulance service being called unnecessarily.’
‘Make sure that quality audits etc are published.’
‘We remain optimistic!’

Table 4.

‘Length of time getting a diagnosis.’
‘Interval between onset and death.’
‘Number of hospital admissions due to the condition.’
‘At what stage the disease leads to loss of job.’
‘Epidemiologists need to be involved.’
‘Outcome measures are necessary to measure the effectiveness of the service.’

Summary of key matters arising from Q10.

The outcome measures of greatest value are those around patient and carer opinions of value. Waiting times and hospital readmission data should also be collected. Transparency is an important part of the proposed minimum standard.

Q11. What works poorly and what works well?

Table 1.

‘Feeling being supported and listened to.’
‘Negative relationship with Consultant.’
‘Mutual respect between patient and professional.’

Table 2.

‘Lack of communication between members of the team. Communication between services is poor. Carer has to phone the TEAM when there is a problem, but the team has no knowledge of the patient.’
‘Time allowed for physio appointment is too short at only 15 minutes.’
‘The relationship between the specialist and the voluntary sector, which has an enormous knowledge, which is often dismissed.’
‘The Oxford Centre for Enablement is usually good (when it has been found) Similar should be available in all Counties to act as a hub of expert services and be in contact with community care.’

‘Neuro rehab at the OCE is exceptional, but the stuff available offered to patients after discharge (in part. community O/Ts) can be quite poor and they would benefit from more training.'
‘O/Ts are usually very good.’
‘Medication should be given on time.‘

Table 3.

‘Services are not working together. The charities are too much separated from what the statutory sector does. Need better communication.’
‘The charities work well and the statutory sector needs to link better with Branch Committees and to Local Authorities.’
‘Nurses on hospital wards are good, despite their managers.’
‘Parkinson’s Nurse Advocates on hospital wards works well.’
‘PALS works for me.’ In direct contrast: ‘PALS does not work for me; it depends on what you ask them.’
‘Flexibility: meeting individual needs rather than ‘through the pathway’: a non-prescriptive pathway.’
‘We should encourage hospitals to be more realistic about what they are.’

Table 4.

<u>Poor:</u>
‘Insufficient vocational rehab
“ neuro-psychologists
“ talking therapies
“ nutritional advice
“ SLT when needed
“ access to pain services
“ access to consultant in sleep problems
Difficulty in accessing O/Ts when needed – sometimes 6-month delays
Too few GPs who understand or know enough about neurological conditions.’

<u>Good:</u>
‘Specialist Nurses.’
‘Where it is available, IT that involves the patient and his/her family.’
One person asked why the NSF on long term neurological conditions recommendations are not being implemented.

Summary of key matters arising from Q11.

The minimum standard should set the tone for community neuro-rehabilitation teams to be patient centred, expert, listening and delivering holistic services, using modern communications and effective pathways, not bogged down in traditions and paperwork. Current capacity overall is insufficient and outcomes would be improved if the minimum standard required strong liaison with the voluntary sector. The Oxford Centre of Enablement should be studied further to identify/share good practice. The minimum standard must include requirements on joint working. The minimum standard is unlikely to make sufficient impact unless GP training and awareness issues are also addressed.

Unclassified Comments

One table listed other comments, as below.

‘Rehab is poor. There are specialists in hospital but out in the community GPs lack knowledge so care is not maintained.’
‘Rehab is given for 1 week but there is no follow up afterwards.’
‘When a patient has a crisis, there is rehab in hospital but no continuity after discharge. There used to be more voluntary sector input but patient now has to wait a long time for help. This does not happen with Motor Neurone Disease as there is a community nurse to help.’
‘Son with hydrocephalus has never seen a neuro psychologist.’
‘When diagnosis is given, all possible support should be explained, such as how to contact the specialist nurse. Leaflets must be available and given. Support groups must be identified.’
.’“Access to Work” is a group, which is very helpful but needs to be advertised more widely.’
‘It is very frustrating when seen by a new medical expert as much time is spent explaining the patient’s condition leaving little time for the consultation. They do not seem to have read the notes.’
‘All neuro patients should see a neuro physio.’
‘Professional information pack is produced by the MND group and sent to the GP when the patient has been diagnosed. Headway used to do the same. This should happen for all conditions.’
‘Carer has had to fight for help but only when he is now seriously ill has she been given it. Support for carers is essential or state has to pick up a bigger bill.’
‘Patient had an appointment with a private neuro physio for 1 hour with dramatic improvement.’
‘When a patient is supported in work there is less depression and it is financially beneficial to self and the NHS.’
‘There should be a specialist nurse for every neuro condition.’
‘There should be a person to act as a liaison between the patient and the consultant when there is an acute change, which needs immediate attention.’
‘There should be a 24-hour specialist care help line (not a charity) available 365 days of the year.’

Summary of key matters arising from the unclassified comments.

The comments above support the general thrust of recommendations.

Additional responses, following publication of the first draft report

A draft report on the focus group was circulated to attendees asking them to submit further comments, if any. Six responses were received, resulting in some minor text changes. Three comments contained information or evidence and are included below.

Response 1. ‘I didn’t see anywhere on there a view that came up on our table (table 2 I think) that was that neuro rehab at the OCE is exceptional, but that the stuff available offered to patients after discharge (in part. community OTs) can be quite poor and they would benefit from more training.’

Response 2. 'My overriding concern for MND patients at the moment is to ensure that they get an early assessment from an OT and are followed up regularly as people's condition can change dramatically over a fairly short period. I know that the policy is to do an OT assessment, make recommendations and then discharge. This isn't satisfactory for MND patients - the danger is that they deteriorate, have falls, injure themselves, go into hospital, have a miserable time where their neurological condition is not understood etc., etc., all costing the NHS more money than if an OT was keeping an eye on the situation and intervening at an earlier stage thus avoiding all this drama, discomfort and expense. They are expected to re-refer themselves when they have concerns, but a lot of the older plwMND don't like to bother professionals, and when they do, they don't see the original OT. One plwMND requested an OT as the result of a recommendation by Dr Jeddi (this was done in August) and she STILL hasn't been given an appointment. The service seems to be in a state of flux at the moment with people leaving or retiring and no one knowing who is responsible for what. Clearly more O/Ts are needed. The other major shortage is in the psychology service.
As doctors can't do much for neurology patients then much more money should be put into the therapy services as this is where a real difference can be made.'

Response 3. *(include or have links to ..)* 'Talk Therapies (an ongoing emotional support when neuro psychology services stop such as CBT therapy for ABI and other talk therapies for all neuro conditions. Independent Advocacy services, Housing departments.'

'We had a discussion about the importance of hand held records and also perhaps a personalised Carers Passport which can go with a patient into hospital giving information about any behaviours, needs, special diets, etc. associated with the neurological condition when in a general ward for example.'

All six responses indicated full contentment with the first draft, other than to suggest that some typographical errors should be corrected and some minor additions and clarifications to recommendations should be made, all now incorporated.

Ends

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