Briefing: the new NHS in England and implications for MND

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The NHS reforms so far

The current phase of reforms to the NHS in England began in June 2010 with the publication of the white paper 'Equity and Excellence: Liberating the NHS'. It proposed far-reaching structural changes to the NHS, the centrepiece of which was the abolition of PCTs and the transfer of their commissioning role to smaller, clinician-led (principally general practitioner-led) Clinical Commissioning Groups (CCGs).

Alongside this, it proposed to create a new NHS Commissioning Board (NHSCB), which would make the central operation of the NHS independent of the Department of Health. The Board would also have responsibility for commissioning some NHS care, including specialised services.

Since then we have been engaging with the Government's numerous consultation exercises to try to secure answers on what this means for healthcare services used by people with MND. The publication of draft service specifications on December 12th was the first firm indication of the NHSCB's intentions toward MND.

The new system comes into operation on April 1st 2013.

Implications for care centres

It is likely that, for the first time, there will be a formal obligation on the NHS in England (and only in England) to commission multi-disciplinary MND clinics and associated services. In practice, these are not specifically commissioned at present, but included in the package of services provided by the hospitals in which they are located. Their existence has therefore been down to arrangement with a hospital, and not to formal commissioning. It seems likely that this will change.

Research carried out in care centres and funded or part-funded by the Association will not be directly affected. While this paper will not address research in detail, it should be noted that the Government's Mandate to the NHSCB contains a clear instruction that associated treatment costs for clinical trials must be paid.

What we are doing and have done so far

Our immediate priority is to respond to a short (six week) but significant consultation on several draft service specifications for specialised services. These specs will then be considered by the NHSCB, and some elements of them – but not all, necessarily – will be adopted as commissioning priorities for the next year. Detail on these is included below, and we invite your comments to inform our response.

This public consultation follows substantial behind-the-scenes work by the Association and others. The fact that multidisciplinary MND clinics are described in the draft spec for adult neurosciences is in part due to our earlier work to influence the NHSCB: we established contact with the Clinical Reference Group (CRG) with responsibility for adult neurosciences, and they subsequently came to us for a draft definition.

We also continue to press the Government for a NICE guideline and quality standard on MND – both have now been promised, but not currently scheduled to begin development before 2014 (we are working to secure an improvement to this

schedule). The Strategic Clinical Network on dementia, neurology and mental health was created following our lobbying, as part of the Neurological Alliance, for an improvement to the NHS's provision for people with neurological conditions, after the identification of shortcomings in last year's report by the National Audit Office (which in turn was conducted as a result of our suggestion to the NAO).

We also will be making direct contact with appropriate personnel in the Commissioning Board, to make the case further for prioritising MND services. This will include presenting evidence on the importance, efficacy and cost-effectiveness of care centres in the context of the current problems with some aspects of NHS neurology services (as identified by the NAO and PAC reports), and present them as an opportunity to provide person-centred, integrated and well planned care – all of which the NHS is officially keen to implement.

Specialised service specifications

There are now draft service specifications for most areas of specialised commissioning. The NHSCB is consulting on all of those that are available. There are five draft specs with relevance to MND:

i. adult neurosciences
ii. complex specialised wheelchair and seating
iii. AAC / communication aids
iv. environmental control equipment for patients with complex disability
v. specialist rehabilitation for patients with highly complex needs
vi. Complex home ventilation

We will be making formal responses to these draft specs. The hyperlinks above will take you to the full documents, and access to all draft specs is available on the NHSCB website. Key extracts and background details are set out below.

i) Draft service specifications on adult neurosciences

The dividing line between specialised and non-specialised services was drawn by a Clinical Advisory Group (CAG), which looked at all areas of specialised commissioning under the current system and assessed whether they should remain specialised for the new arrangements, and whether new areas of care should be treated as specialised in future.

The most crucial recommendation in respect of MND was that for regarding neurology:

Suggested text for regulation:
Adult Specialist Neurosciences Services

Suggested Description:
Adult Specialist Neurosciences Services will include services provided by Adult Neurosciences or Neurology Centres. This will include:

- *All Neurosurgery activity*
- *All Interventional procedures within neuroradiology*
- *In-patient neurology*
- *Specialist diagnostics (including neurophysiology, neuroradiology,)*

- *Associated services (Neuropsychology, Neuropsychiatry, Neurorehabilitation, Neuro Critical Care)*
- *Neurology Out-patients*

The service will include out-reach when delivered as part of a provider network.

After the CAG report was published, the Clinical Reference Group looking specifically at adult neurosciences approached us for a description of what a neurology outpatient service for someone with MND should look like. We drafted this on an extremely tight turnaround, and are grateful to Prof. Ammar Al-Chalabi for assisting us with it (any problems or errors with it are of course either the Board's responsibility or ours, not Ammar's).

Our intention was to provide as comprehensive a description as possible of the type of care that a person with MND might access via a care centre. If anything, the draft spec includes a more extensive description than even we had expected.

The description of a specialised MND service in the draft service specification therefore reads:

> *Motor Neurone Diseases*
> *The description of a specialised motor neurone disease service is where care for a patient with motor neurone disease involves a multi-disciplinary approach from MND specialists. including a specialist neurologist. to direct care and provide diagnostic certainty, a specialist nurse / care co-ordinator and specialist provision in respect of: respiratory support, speech and language therapy, dietetics and physiotherapy, saliva management, respiratory secretion management, neurorehabilitation, occupational therapy, gastroenterology and gastrostomy, chiropody, management of cognitive impairment, riluzole safety blood tests, palliative care, end of life care, counselling / emotional support, telephone support.*
>
> *It is important to note that MND is among the most demanding neurological conditions. It is degenerative, often rapidly so, and requires complex and anticipatory care significantly above what a general neurology service can provide.*
>
> *People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis.*
>
> *All services for people with motor neurone disease should be commissioned as a specialised service.*

The final paragraph is unusual, and not replicated for other conditions. It suggests that the divide we had expected between specialised services commissioned by the NHSCB and community service commissioned by CCGs may not be applicable to MND.

It should also be noted that there are restrictions on when a neurology outpatient service qualifies as being 'specialised':

Service Description
A neurology service should be regarded as specialised when a patient is referred from a consultant or a professional with specialist training in the condition to a consultant neurologist with sub specialist expertise for investigation or treatment that requires the special expertise that is contained within that pathway of care that lies out with the expertise of the referring consultant .This would include that referrals such as those to a neurologist with a special interest in neuro-ophthalmology by a consultant ophthalmologist (i.e. a specialty out with neurology). Furthermore, referral from a physiotherapist assessing patients in a musculoskeletal service to a consultant neurologist in the MS clinic would be included. Neither of these are uncommon and represent ways in which patients "find their way" to subspecialist clinics.

AND/OR

Where best practice e.g. NICE guidance, would require multiprofessional care that might include involvement of more than one other professional group within the defined service e.g. specialist nurse, allied health professionals, orthotists, dieticians, speech and language therapists, psychologists or psychotherapists, continence services, pain relief services and respiratory care services.

AND/OR

Where there are joint arrangements with specialists in rehabilitation medicine, cardiology and clinical genetics, ophthalmology, otology, interventional radiology, neurosurgery, orthopaedic and spinal surgery where their involvement is an integral part of patient care e.g. patients with neuromuscular disorders, ataxia.

AND/OR

As part of care where the patient's condition is such that it involves assessment for potential elective neurosurgical procedures or interventional radiography, (e.g. patients with epilepsy who have seizures resistant to medical treatment, or those with complex movement disorders,) and their subsequent follow up after surgery.

AND/OR

As part of care that involves drugs for which special funding or expertise is required e.g. botulinum toxin for dystonia or spasticity management, apomorphine for PD, intravenous immunoglogulin for accepted neurological indications, disease modifying therapies in MS and other neuro-inflammatory disorders, recently licensed drugs for epilepsy and drugs on the current high cost drugs list.

The neurosciences specification also references other disease areas of relevance.

Specialist Clinic for Cognitive Disorders

Includes patients presenting with memory and other disorders of cognition, e.g. Alzheimers disease, non Alzheimer dementias (frontal temporal dementia), Creutzfeldt Jacob Disease, dementias of vascular and metabolic origin. Specialised services for cognitive disorders should include: diagnostic services for younger patients (under 65 years) and inherited dementias, joint therapy services with mental health services teams and joint working with neuropsychology services, and with neurosurgeons, and include patients in whom the cognitive disorder is post-neurosurgical.

Neurogenetics Diseases
Neurogenetic services are provided through a partnership between neurology centres and specialist genetic centres. Clinical counselling and predictive genetic testing for neurological disorders that have a genetic or familial association are included in this definition where this activity takes place within a neurosciences or neurology only centre.

The other key part of the draft spec related to the service model, as set out below.

<u>Generic Service Model</u>
Specialist services will operate at three levels:

Tier 1: Local community and primary care services e.g. physiotherapy and community nursing where skills can be developed with the assistance of specialist staff from the Hub centres in order to provide ongoing basic maintenance for people with neurological conditions

Tier 2: Multidisciplinary specialist outreach clinics to be developed in main population centres. These outreach services, provided by the members of the multidisciplinary team visiting from the hub centres, will constitute the "subspecialist spokes"

Tier 3: Specialist Care provided at a tertiary centre acting as a 'Hub' and fully equipped to carry out the full range of neuro-related procedures, investigations and treatments such as muscle biopsies and early access to other neuromuscular specialist clinical services such as respiratory, cardiac and orthopaedic.

This model would be supported by the following:
• A ' virtual' Clinical Network - to support multidisciplinary and cross organisational working to provide effective and efficient treatment, care and support to patients and their families.
• Shared care with services delivered as close to home as possible as well as access to a specialist centre, supported by multidisciplinary team working - each person will be supported by an individualised package of care.
• Availability of support within each region and will offer emotional support, care coordination and to translate medical information into a format families can understand
• Individualised care supported by ongoing care coordination from the point of diagnosis.
• Close working between paediatric and adult services to ensure smooth transition between services

Population cover

The service outlined in this specification is for patients ordinarily resident in England; or otherwise the commissioning responsibility of the NHS in England (as defined in Who Pays?: Establishing the responsible commissioner and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges).*

** - Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP Practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP Practice in England.*

The population served should be covered by the existing neurology / neurosurgery and neurology only centres and should not include populations served by neurologists who do not have governance links with either of the above. Included in this specification are those whose needs are outlined in [Service specification / care pathway] above.

Any acceptance and exclusion criteria

Location(s) of Service Delivery Each region will have a directory of services that will highlight:

• Specialist adult and children's neurology specialised services available within the Region

• Specialist neurology centres that take referrals from the main children's and adult units

• Availability and location of specialist Neurology Rehabilitation Services

• The existing model of neurology and neurology /neurosurgery centres should be preserved and neurologists should not be appointed unless they have contracts that include as a minimum 2 PA's for continuing professional development and governance at such a centre

Referral Route

Between a consultant or a professional with specialist training in the condition to a consultant neurologist with sub specialist expertise for investigation or treatment that requires the special expertise that is contained within that pathway of care that lies out with the expertise of the referring consultant.

Discharge Criteria and Planning

Many patients will have long term, deteriorating conditions where discharge is rare. If patients feel they are sufficiently supported locally and are stable, they will be given open appointments for them to be reviewed as needed and every patient requiring specialised follow up must be given an emergency care plan, including how to access the specialist service.

Interdependencies with other services

The following services are integral to the care of people with neurological conditions and the commissioning of specialised neurology services should integrate with the commissioning arrangements for neurology / neurosurgery intensive care.

• Neurosurgery

• *Neuroradiology*
• *Neurophysiology*
• *Neuropsychology*
• *Neuropsychiatry*
• *Neuropathology*
• *Neurological rehabilitation*
• *Specialised Equipment Services*

We would like your views on how well this model will work for MND. We have some initial thoughts and questions:

- existing care centres fit within the definition of a specialised MND service and can therefore be commissioned by the NHS
- how would care centres interact with tiers 1 and 2 of the generic model, particularly in light of the stipulation that all MND services should be commissioned on a specialised basis? Would care centres wish to expand to take a more direct hand in these services, once suitable funding is available?
- how might the referral restriction affect care centres? Referral routes into care centres can vary – but this will be true of many other services, so will it make a significant difference in practice? If all MND services are commissioned on a specialised basis, is the point moot?

There is one major exception to the view that care centres can be commissioned under this new model: the Peninsula Network is not based in a Centre as per the definition, so may not be commissioned in the same way. As it is a network, however, central commissioning may not be the most appropriate model for it – the Association is keenly aware of this issue, and exploring it.

In late November, the NHSCB published a 'commissioning manual' for specialised services, which gives a little more background detail on the above. The relevant content is reproduced in Appendix 3 to this document.

ii) Draft service specification on complex specialised wheelchair and seating

The main CAG report recommended that the following services should also be commissioned by the NHSCB:

Specialist Services to support patients with complex physical disabilities

Suggested Description:
Specialist Services to support patients with complex physical disabilities will include the specialist assessment for, and provision of (if indicated):

- *Prosthetics (limb and artificial eyes)*
- *Specialist wheelchairs (including complex postural seating and powered wheelchair controls)*
- *Specialist Augmentative and Alternative Communication Aids*
- *Environmental Controls*

This applies to patients with complex physical disabilities. This applies to provision in adults and children.

Term “specialist wheelchairs” here includes complex postural seating and powered wheelchair controls.

More detail is given on these services in the commissioning manual; the relevant content is reproduced in Appendix 3.

Following on from the above, three draft service specs have been published from this list which pertain to MND. The first is the spec on specialist wheelchairs and seating. Key extracts from the spec are reproduced below.

Service description/care pathway

• A complex specialised wheelchair and seating service will address the postural needs of adults and children facilitating comfort and function as well as their mobility needs. It will also provide the base to which other assistive technologies can interface e.g. communication aids or environmental controls

• The complex specialist assessment team should consist of a core group: a doctor specialising in rehabilitation medicine, a specialist therapist and a clinical engineer/scientist all of whom have appropriate skills and experience. The team will have access to a physiotherapist, an occupational therapist, a tissue viability nurse, rehabilitation engineers and engineering technicians, with workshop facilities to manufacture/test/modify and design equipment.

• The specialist team will work closely with the individual, their families/carers, other medical and surgical teams, local therapy staff (including speech and language therapists) as well as staff from social services, community nursing and education /employment. The specialist team will also liaise with external suppliers of equipment.

• Assessment should be undertaken in a specialist centre, equipped with appropriate equipment for physical examinations, driving assessments and pressure measurement plus suitable facilities for moving and handling. Trial wheelchair/seating equipment should also be available. Alternatively, individuals may be seen in other environments such as child development centres/schools for children or familiar/non-threatening surroundings such as a home for people with cognitive or learning difficulties.

• The multi-disciplinary team (MDT) at a Specialised Spinal Cord Injury Centre (SCIC) is a complex specialised assessment team for the purpose of this specification. Where appropriate workshop facilities are not co-located on the SCIC site, the SCIC team will work in partnership with the complex specialised wheelchair and seating service to manufacture/test/modify and design equipment.

• Each prescription will be individually formulated following a detailed assessment of the disabled person's needs and lifestyle, using a standardised assessment procedure. A specification will be drawn up in conjunction with the disabled person, and his/her carers if appropriate, and based on his/her goals. The prescription may comprise off-the-shelf components, bespoke manufactured items or any combination of these.

• The service will offer regular reviews of the wheelchair prescription as an individuals needs may change due to their medical condition.

• A referral may be made from professionals in specialist medical teams such as rehabilitation medicine, neurology, orthopaedics and paediatric teams or from local NHS wheelchair service providers (see criteria for referral set out in the document "Wheelchair Services for children and adults with noncomplex requirements -Access to Prescription") Referral may be for assessment and provision or specialist opinion.

Interdependencies with other services
The Complex Specialist Wheelchair Service will be co-located and provide or sub contract Rehabilitation Engineering Services. The service will provide or sub contract services to:
• Design bespoke equipment and modifications for individual users as required
• Review stability issues and advise on technical implication of wheelchair prescriptions, accessories and modifications
• Advise on risk management in relation to transportation, and oxygen related risks
• Advise on safety, maintainability and flexibility of new equipment available to the service

Relationships are required to the following:
• Environmental control and communication aid services to allow for systems to be incorporated within complex seating packages
• Local wheelchair services to ensure a seamless pathway of care for patients and will offer advice and support to local wheelchair providers. These local services will be commissioned through their CCG and close liaison will be required with local commissioners to ensure any local development or service redesign considers the implications for the complete patient pathway

We would be grateful for comments on the above, and also on the proposed timescales for the service: the specification cites an aim to, "see all patients within the agreed timescale of 18 weeks" (the meaning of "see" is unclear).

We are concerned that this is far too long: for comparison, the Oxford wheelchair service aims to see all new referrals within one week and have an appropriate wheelchair supplied to the individual within three or four. While a slower service may result in some cash savings to the NHS, it comes at both an unacceptable personal cost to the person with MND, and a high risk of further cost to the NHS arising from the need for extra treatments to cope with pain or injury arising from unaddressed posture and mobility problems. We are minded to make this point strongly in our response, and would appreciate comment on it.

iii) Draft service specification on AAC / communication aids

Below are key extracts from the draft spec on AAC and communication aids.

Service description/care pathway

The proposed service model is a hub and spoke model.

The recommendation for a hub and spoke model is based on existing good practice which has in turn been recommended by many high level reports such as the reports from the Communication Champion and AAC Synthesis for Commissioners from the RCSLT, and in the previous SSNDS.

The term 'specialised AAC hub' indicates a range of activities to be undertaken (see service model section) rather than a presumption that there must be a centralised hub location or provision of hub services by a single organisation.

Taking into account the SSNDS document and the OCC report recommendations on the activities to be undertaken by specialised AAC hub services, the following areas of service will be undertaken:
• Specialised assessment of AAC needs
• Regional management, including procurement, of high tech AAC systems
• Training and service development of local spoke AAC teams
• Regional co-ordination of care planning, service standard development, quality assurance and improvement of local AAC teams.

In order for a specialised AAC hub service to deliver the required range of activities, in addition to those administrative and management staff required by any organisation, the hub team should include staff with the following competences:
• Electronic assistive technology (clinical scientists, clinical technologists, specialist occupational therapists, specialist speech and language therapists or equivalent):
• Speech and language therapy with AAC specialism;
• Learning and educational development competence to support the AAC assessment and intervention service to younger clients (often a teacher);
• Seating and positioning (often a physio or occupational therapist);
• Access and control methods and mounting of equipment (often a physio or occupational therapist);
• Equipment procurement and stock management;

The hub team should also be able to evidence that it has processes and contracts in place to access, in a timely way, staff with the following competences:
• Competence in personalisation and customisation of equipment (software, electronic and mechanical);
• Cognitive assessment competence to support AAC assessment and intervention service to older clients;
• Health informatics , quality improvement and research methodology competence;
• Training and workforce development competence to support the development and competence of local AAC spoke services.

The specialised AAC hub services will work with the developing local AAC spoke teams to provide training and to establish a collaborative approach to outcomes measurement and data gathering on which to base quality assurance, service development and to inform future commissioning practice.

Specialised AAC services will work with their local AAC spoke teams to build their capacity to manage directly the needs of 90% of the region's AAC population and to jointly manage the needs of the 10% of the region's population that require specialised AAC services.

An individual for whom a specialist AAC service is needed would have/be (a combination of):
• Severe physical disability especially of the upper limbs.
• Additional sensory impairment to the communication impairment.
• In need of specialist switch access, which may need to be bespoke.
• In need of a device that integrates spoken and written communication, as well as environment control. Able to understand the purpose of a communication aid
• Developed beyond cause and effect understanding.
• Multiple disabilities which in combination impact on the individual's ability to communicate.
• Communication technology needs beyond the competence of the local AAC service.
• Experience of using low tech AAC which is insufficient to enable them to realise their communicative potential.

A 'specialised service' would provide:
• A multi-disciplinary team (MDT) assessment including SLT's, Clinical Scientists and Technologists, OTs, Specialist Teachers and access to Physiotherapists, Psychologists and other relevant professionals.
• Technological and engineering facilities for customisation and modification to the individual. An assessment and loan bank of possible technologies offering a diverse range of solutions.
• An extremely wide range of software, vocabulary packages and resources.
• Expertise in procurement and equipment management. An ability to issue, monitor, maintain, recall and refurbish equipment.
• An ability to manage, aggregate and analyse user information to enhance the service and streamline day to day operations.
• An ability to integrate services and equipment with other assistive technologies such as Environmental Control.
• An ability to educate and train a wide range of stakeholders from the user, families, spoke service members and local team members.
• An ability to take account of Co-morbidity issues such as Postural support needs. 6 NHSCB/D1b
• Work with local health and social care professionals in areas where service uptake is low to facilitate referral of those who could benefit from specialist assessment and equipment provision.
• Experience, capacity and remit to deliver services across a wide geographical region

The care pathway will be as follows:
• Referrals will be accepted from health, education and social care professionals working in local teams
• Additional information to the referral may be required from other health, education or social care agencies or the individual's GP, especially for self referrals or those from non- health professions
• All referrals will be acknowledged within 10 days of receipt by the service and it be stated if there is reason to delay the assessment or referral acceptance, such as insufficient referral information

• Otherwise, the service will assess all patients fulfilling the acceptance criteria, typically within 6 weeks from the date of acceptance of the referral
• Patients will be assessed in the most effective location e.g. their home, place of residence, hospital, school, or workplace by competent, experienced personnel and in collaboration with other services where necessary
• Equipment shall only be provided after the assessment. The assessment recommendations shall be confirmed in writing to the patient, referrer, GP and other stakeholders as appropriate
• Opportunity for a temporary trial of suitable sample equipment shall be recommended and made available when indicated, such as when there is doubt over the patient's motivation or ability to use the equipment. The outcome of the trial, either to continue with or to cease provision shall be based on suitable outcome measurement
• When equipment provision is recommended at the assessment, this shall normally be available for use by the patient within 12 week of the assessment, or within 18 weeks of acceptable referral. Exceptions to this target may occur due to dependencies on other agencies or when the recommended solution involves custom or bespoke or integrated equipment
• All patients provided with equipment shall receive adequate training in its use with necessary information in an appropriate format to them. Additional tuition shall be available as required, in consideration of the possible cognitive impairment of some users
• Each user of equipment shall receive ongoing support in case of its malfunction, an annual service maintenance visit including statutory testing of equipment and timely review of equipment appropriateness for them
• In response to reported malfunctions of the equipment, the service shall ensure that the user is contacted as soon as possible and remedial action for critical functions taken within a clinically appropriate time
• The frequency of user and equipment review shall be determined on a case by case basis by service personnel with the ability to respond appropriately to changes in clinical conditions (e.g. people with rapidly progressing neurological conditions)
• Adjustments, modifications or change of the equipment provision shall be provided when indicated following review due to change in patient clinical condition, functional impairment or circumstances. A full reassessment of their needs shall also be available when appropriate
• Equipment no longer required by users due to change in their circumstances, shall be reclaimed, decontaminated and refurbished to standards agreed with manufacturers prior to becoming available for reissue.

Exclusion criteria for provision of equipment by the service would be:
• No/mild physical disability
• Minimal upper limb impairment

As with wheelchairs, we feel the proposed timescales (assessment within 6 weeks of referral, and equipment provision within 12 weeks) are inappropriately slow for people with MND.

iv) Draft service specification on environmental control equipment for patients with complex disability

Key extracts from the draft spec on environmental control equipment are reproduced below.

Service description/care pathway

The service will deliver environmental control and other electronic assistive technology equipment such as computer access as the specialist hub serving a catchment population typically in excess of two million people (Section 2.3). Principle elements of the EAT service;

• Staffing:

o The assessment and provision of EAT equipment will be carried out by a multi-disciplinary team consisting of experienced professionals from a clinical / AHP background to ensure appropriateness andindependence of prescription. All EAT provider services will employ, or have reliable access to, properly accredited and experienced clinical scientists, rehabilitation physicians, rehabilitation engineers, occupational therapists and speech and language therapists. Patterns of staffing will be determined by local requirements and the availability of skilled personnel.

• Commissioning and clinical governance:

o The service will have as Clinical Lead an established clinician with relevant, proven competences and well versed in service organisation, innovation and research. The service will keep user related documentation securely in accordance with Trust and NHS guidelines

• Training:

o The service will ensure that they offer training packages, seminars and symposia to inform professionals (esp community occupational therapists, social workers, speech and language therapists) and voluntary sector personnel within its catchment. This will ensure that patients who could benefit from EAT provision are referred to the service. EAT services across the country will collaborate to ensure equity of standards in prescription.

Care Pathway for EAT service delivery

o Referrals will be accepted from health and social care professionals, charity support workers.

o When treating children, the service will additionally follow the standards and criteria outlined in the Specification for Children's Services (attached as Annex 1 to this specification)

o Additional information to the referral may be required from other sources and primarily the patient's GP, who is responsible for the care of the patient in the community, and is to be informed about the referral and its outcome.

o All referrals will be acknowledged within 10 days of receipt by the service and it be stated if there is reason to delay the assessment or referral acceptance, such as insufficient referral information.

o The service will assess the EAT needs of all patients fulfilling the acceptance criteria.

o Patients will be assessed at their home, place of residence, hospital, school, or workplace as appropriate, by competent, experienced personnel and in collaboration with other services where necessary.

o The assessment recommendations shall be confirmed in writing to the patient, referrer, GP and other stakeholders as appropriate.

o Opportunity for a temporary trial of suitable sample equipment shall be recommended and made available when indicated, such as when there is doubt over the patient's motivation or ability to use the equipment.
o When equipment provision is recommended at the assessment, this will normally be available for use by the patient within 18 weeks of acceptable of the referral. Exceptions to this target may occur due to dependencies on other agencies or when the recommended solution involves custom, bespoke or integrated equipment.
o All patients provided with equipment shall receive adequate training in its use with necessary information in an appropriate format to them. Additional tuition shall be available as required, in consideration of the possible cognitive impairment of some users.
o Patients using the equipment shall receive ongoing technical support in case of its malfunction, an annual service maintenance visit including statutory testing of equipment.
o In response to reported malfunctions of the equipment, the service shall ensure that the user is contacted as soon as possible and remedial action for critical functions taken within 48 hours of notification.
o The frequency of user and equipment review shall be determined on a case by case basis by service personnel. Patients with rapidly deteriorating conditions, like MND, will require more frequent reviews.
o Adjustments, modifications or change of the equipment provision shall be provided when indicated following review due to change in patient clinical condition, functional impairment or circumstances. A full reassessment of their needs shall also be available when appropriate
o Equipment no longer required by users due to change in their circumstances, shall be reclaimed, decontaminated and refurbished to standards agreed with manufacturers prior to becoming available for re-issue.

• General Paediatric care When treating children, the service will additionally follow the standards and criteria outlined in the Specification for Children's Services (attached as Annex 1 to this specification)

<u>Population covered</u>
The service is to be available to persons of all ages, diversities, medical conditions (acquired or congenital) and place of residence (independent living, with family, residential care, nursing home), who have a severe disability, which restricts their ability to operate independently standard handsets and technologies for control of the environment and access to computer.

A particular service will normally serve the population within a determined geographical area with a population size sufficient to generate the critical mass of referrals to support the service. Typically, this is a population of greater than 2 million.

<u>Any acceptance and exclusion criteria</u>
Most people requiring EC equipment have significant upper limb impairments that result in them being unable to use standard controls, for example remotecontrol handsets or telephones. Many are neurological conditions resulting in tetra-paresis, often with a progressive component varying from moderate to rapid and combined with fatigue. Many will also have impaired cognition and or communication function.

The commonest diagnoses are as follows; Multiple sclerosis, Spinal Cord Injury (level C5/6 & above), Motor neurone disease, Cerebral palsy, Muscular dystrophy, Severe arthritis, Acquired Brain injury and Muscular dystrophy.

• Environmental Controls provision will be for people who meet the following criteria:
o Profound and potentially complex physical disability, such that they are unable to operate standard controls for functioning independently in the home.
o Where simpler and cheaper non customised solutions are not suitable or appropriate.
o Cognitively and physically able to operate EC equipment consistently. o Able to demonstrate sustained motivation to use the EC equipment.
o Individuals requiring multiple control functions integrated into a single means of access as multiple devices are inappropriate (including also potential for integrating functions for communication, computer access and/or powered wheelchair control.

• Exclusion Criteria (for equipment provision by the service);
o Where simpler and cheaper non customised solutions to the identified needs of the patient are available and appropriate for the individual.
o The individual patient does not have the cognitive ability or motivation to operate the EC equipment. This shall normally be established though a period of trial of some sample solution of equipment.
o Provision of equipment is inappropriate due to social, environmental or other circumstances.

Certain aspects of the potential provision are outside the funding remit of the specialist service and require referral for funding and provision by other agencies. If these are not available, then this may or may not preclude the benefit of provision of the EC equipment, these are:
o door, window and curtain openers
o page turners
o building adaptations
o electrical, joiner/carpentry or other minor adaptation
o telecare equipment

<u>Interdependencies with other services</u>
Relationships are required with other services and agencies where collaboration on assessment and/or provision for an individual patient is necessary, notably:
o Wheelchair services and communication aid services where equipment is required to be inter-connected or integrated
o Local Community Equipment and Telecare services where equipment is required to be interconnected to allow its control by the patient through the EAT equipment.
o Social services, housing associations or departments where minor adaptations works are required (eg: electrician or joinery/locksmith services)
o Specialist Nursing homes for patients with complex disabilities where they are likely to be resident for a significant period of time. The following represent the additional stakeholders potentially involved in EAT service provision:
o Community Social Services, especially Occupational Therapy Service
o Community Rehabilitation Service/ Physical Disability Support Team
o Specialist Rehabilitation or treatment centres (Spinal Injury Units, RRU, National Hospital)

o Palliative Care Team & Consultant o Consultants In Rehabilitation Medicine and Neurology o Clinical Nurse Specialists (eg: Multiple Sclerosis)
o Charity support workers & organisations (eg: Motor Neurone Disease Association)
o Hospice & Respite centres
o Nursing & residential care homes
o Continuing Care Managers o School, Colleges and Universities- Special Educational Needs

EAT services across the country will collaborate to ensure service standards are maintained with equity. Collaboration is also required between EAT service regarding individual patient equipment users who move place residence, so that their equipment and its support can be transferred

EAT equipment may be obtained from suppliers in accordance with National Framework agreement for EAT operated by the NHS Supply Chain (Contract Ref: NF001365), which specifies the agreed process for the installation and ongoing support of the equipment. Where utilised, EAT services are therefore required to liaise and work collectively with suppliers who provide equipment and services in accordance with the framework agreement and monitor their performance against this.

As above, we feel that the proposed timescales (acknowledgement of referral within 10 days and provision within 18 weeks) are too slow for people with MND.

v) Draft service specification on specialist rehabilitation for patients with highly complex needs

MND is also referred to in the specification on specialised rehabilitation for patients with highly complex needs. Brief extracts are provided below.

A small number of patients with highly complex needs (Category A) will require the support of tertiary 'specialised' services (Level 1/2a), which are the services covered by this definition.

'Tertiary specialist' rehabilitation services (Level 1) are high cost / low volume services, which provide for patients with highly complex rehabilitation needs following illness or injury, that are beyond the scope of their local general and specialist services.
• These are normally provided in co-ordinated service networks planned over a regional population of 1-3 million through collaborative (specialised) commissioning arrangements.
• Level 1 services may be further divided into:
o Level 1a – High Dependency - a complex caseload with mainly high physical dependency
Level 1b – High Risk - a complex caseload of mainly 'walking wounded' patients with cognitive / behavioural problems who may be a danger to themselves or others, and/or at risk of wandering / absconding.

Service Description

Tertiary specialist rehabilitation services include a combination of individual and group based interventions to support appropriate social interaction, communication, life and work skills. They are primarily offered as time-limited in-patient / residential programmes, but may include associated activity in follow-up day-patient / out-reach / community programmes (again in time-limited) to extend support for patients with particularly complex needs to ensure carryover of gains in their community context.

Some of the conditions that commonly give rise to complex disability as classified by the Long Term Conditions National Service Framework
Progressive and intermittent conditions: Neurological and neuromuscular conditions (e.g. multiple sclerosis, motor neurone disease, Huntingdon's disease, muscular dystrophies, inherited metabolic disorders)

vi) Draft service specification on complex home ventilation

Key extracts are below.

1.1 National/local context and evidence base

This specification relates to the tertiary hospital infrastructure necessary to enable the safe and sustainable establishment and maintenance of home care packages for patients with complex ventilation needs. This infrastructure includes:

- *assessment of new patients and care of established patients with acute or chronic deterioration*
- *diagnostic services for the assessment of patients with suspected complex ventilatory needs*
- *multi-disciplinary teams (MDTs) to provide holistic assessment of care for patients with multi-system disease (to include dedicated ventilation physicians, physiology technicians, physiotherapists, dieticians, speech and language therapy and occupational therapy)*
- *24-hour emergency access to advice for local centres and to cover equipment failure.*

The patient population served by this specialised service comprises tracheostomy-ventilated patients, individuals requiring diaphragm-pacing and those patients requiring sophisticated non-invasive ventilation.

Specialist Centres

The overall aim of the specialist service is to establish and support patients with long-term breathing difficulties on the least intrusive ventilation modality possible. This will enable them to have a longer life of better quality than would otherwise be possible. Patients likely to need long-term support should be identified from at risk groups (e.g. those with neuromuscular disease, severe scoliosis or chest wall deformity, morbid obesity or end stage respiratory disease causing hypercapnic respiratory failure) before that need becomes absolute. The aim should be to avoid admission to Intensive Care with respiratory failure through elective initiation of effective domiciliary ventilation. Whilst most of these patients will be identified by local services, periodic diagnostic assessment at specialist centres may be required.

A proportion of patients requiring long term ventilatory support present acutely, often via ICUs. Frequently these patients are difficult to wean from assisted ventilation and require domiciliary packages of care to be arranged prior to discharge.

National Drivers

National Guidance for the provision of aspects of specialist non-ventilation services to patients exists for some individual patient groups e.g. Motor Neurone Disease (MND), Duchene's Muscular Dystrophy; for broader categories of patients e.g. weaning guidance; and around specific technologies e.g. diaphragmatic pacing and tracheostomies. There are some national standards available and some specialist society guidance. Provision of complex home ventilation services also falls within the NHS Outcomes Framework Domain 1 - preventing people from dying prematurely where Improvement Area 1a specifically identifies reducing mortality from respiratory disease, and Domain 2 – enhancing quality of life for patients with long term conditions.

Guidance supports delivery of care by respiratory specialists working within MDTs. For example, NICE clinical guideline around use of NIV in MND states that "multidisciplinary teams should coordinate and provide on-going management and treatment for patients with MND, including regular respiratory assessment and provision of non-invasive ventilation. The team should include a neurologist, a respiratory physician, an MND specialist nurse, a respiratory specialist nurse, a specialist respiratory physiotherapist, a respiratory physiologist, a specialist in palliative care and a speech and language therapist". The guidance also outlines the support and training which need to be provided to the patient and their family and carers: "support and assistance to manage non-invasive ventilation which should include training on using non-invasive ventilation and ventilator interfaces, for example emergency procedures, night-time assistance if the patient is unable to use the equipment independently (for example, emergency removal or replacement of interfaces), how to use the equipment with a wheelchair or other mobility aids if required, what to do if the equipment fails, assistance with secretion management, information on general palliative strategies, an offer of on-going emotional and psychological support for the patient and their family and carers".

Ensuring NIV is delivered by competent respiratory professionals is emphasised in NICE MND guidance and also in the National Patient Safety Agency (NPSA) alert which identified cases where problems with administering NIV were stated as causing at least moderate harm: key issues included shortage of staff skills or staff time to set up and monitor NIV. Further recommendations are likely to result from the National Tracheostomy Safety Project.

2.2 Service description/care pathway
Currently the management and diagnosis of complex respiratory failure is directed by a number of guidelines (see section three). Specialised centres will interface with local and regional networks which together will deliver a holistic diagnostic and domiciliary ventilator service. It is anticipated that local units will maintain a diagnostic and treatment service for sleep disordered breathing and will be capable of managing simple nocturnal respiratory failure. Local centres will also be able to provide local surveillance monitoring of patients attending specialist centres.

Current coding is unable to reliably identify patients requiring specialist care. Patients will be identified as those requiring referral from a local ventilation service, Respiratory Physician, or from a Consultant Intensivist for patients failing to wean on ITU, to the Specialist Centre. Patients will also be identified from databases held by Specialist Centres.

Specialist Centre (Complex Home Ventilation and Weaning Centre)
Will provide diagnostic and multi-disciplinary assessment and management of all patients requiring complex home ventilation. Each Complex Home Ventilation and Weaning centre will serve a population of approximately 5 million; they will already have at least 400 patients currently on home NIV and at least 15 ventilated via tracheostomy. The centres will provide inpatient weaning facilities, and outpatient or day case multi-disciplinary assessment and treatment services.

Complex Home Ventilation

Outpatient or day case multi-disciplinary assessment will be provided at specialist centres for the following groups of patients:

- *Tracheostomy ventilated*
- *>14 hours/day non-invasive ventilator dependent*
- *<14 hours/day non-invasive ventilator dependent patient with associated complex medical diagnoses (e.g. neuromuscular disease, cardiomyopathy, morbid obesity awaiting bariatric surgery) needing other specialist input and / or complex home care package with associated co-morbidities.*
- *Diaphragm pacing*
- *Patients with sub-optimal control of sleep disordered breathing*
- *Those transitioning from paediatric services*

Care centres and NHS trusts

Care centres currently exist by arrangement with provider trusts. These adult neuroscience or neurology centres will continue to wish to provide services to the NHS under its new arrangement. They may not, however, realise that the NHSCB will be specifically seeking to commission MND clinics, as up to now commissioners have not made a point of doing this – rather, the care centres have been included as part of the overall package offered by the provider.

It is therefore important that the trust understands that the NHSCB (specifically, one of its Local Area Teams – see Appendix 2) will be looking to commission an MND clinic, and therefore that it is in the trust's interest to keep the clinic going and offer it to the Board as a service they can provide.

New NHS institutions

In addition to the new commissioning bodies – CCGs and the NHSCB – many new bodies will be created. These will often be in the form of networks or similar structures, and are intended to co-ordinate and integrate activity across the NHS. More detail is given in Appendix 2 below, but in summary the key bodies are:

- Strategic Clinical Networks – new regional networks, including one covering dementia, neurology and mental health
- Operational Delivery Networks – their role is to coordinate patient pathways between different providers
- Clinical Senates – regional bodies operating across all areas of care
- Academic Health Science Networks – their role is to drive innovation in the NHS, both by promoting the spread of innovation and best practice, and by coordinating care and research.

Appendix 1: Background and further detail - specialised commissioning

Specialised commissioning is relatively new within the NHS. It arose from the Carter Review of 2006, which identified services that could be commissioned on a more specialised basis in order to improve both clinical and cost-effectiveness. Its threshold was a planning population of a million people – any service requiring a planning population of this size or greater could, broadly speaking, be called "specialised". This approach has been maintained in the new approach to commissioning.

The Carter Review did not lead to all the identified services being commissioned on a specialised basis, however. About half of those services began to be commissioned by ten Specialised Commissioning Groups (SCGs), operating on the same geographical boundaries as Strategic Health Authorities. The other half of the supposedly specialised services remained the responsibility of PCTs. SCGs, SHAs and PCTs are all being abolished as part of the NHS reforms.

The list that defined specialised services was known as the Specialised Services National Definitions Set (SSNDS), and went through several iterations. The SSNDS listed all specialised service areas, and gave some detail on what services should look like; unusually however, it included no detail on specialised MND services beyond simply including them on the list. Accordingly, SCGs tended not to commission the clinics specifically; where they have been provided, they tend to be in place by virtue of an arrangement with a provider and bundled up within that provider's commissioned package of services (though that overall package may be commissioned on a specialised basis).

The move to commissioning by the NHSCB will, we hope, move MND clinics out of this curious 'below the radar' position to being formally commissioned and fully NHS-funded services, and by doing so extend further the scope and quality of NHS services for people with MND.

Appendix 2: Background and further detail - the new NHS structures

1. NHS Commissioning Board (NHSCB) and its Local Area Teams (LATs)

Officially, from April 1st all specialised services will be commissioned by the NHSCB to national standards, to be met immediately everywhere; derogations from these standards are expected to be time limited, and very much the exception.

The NHSCB will be embedded locally within the NHS: it will have a 'matrix' structure involving many local offices, a relatively small central headquarters, and its work and responsibilities being spread across all its different outposts.

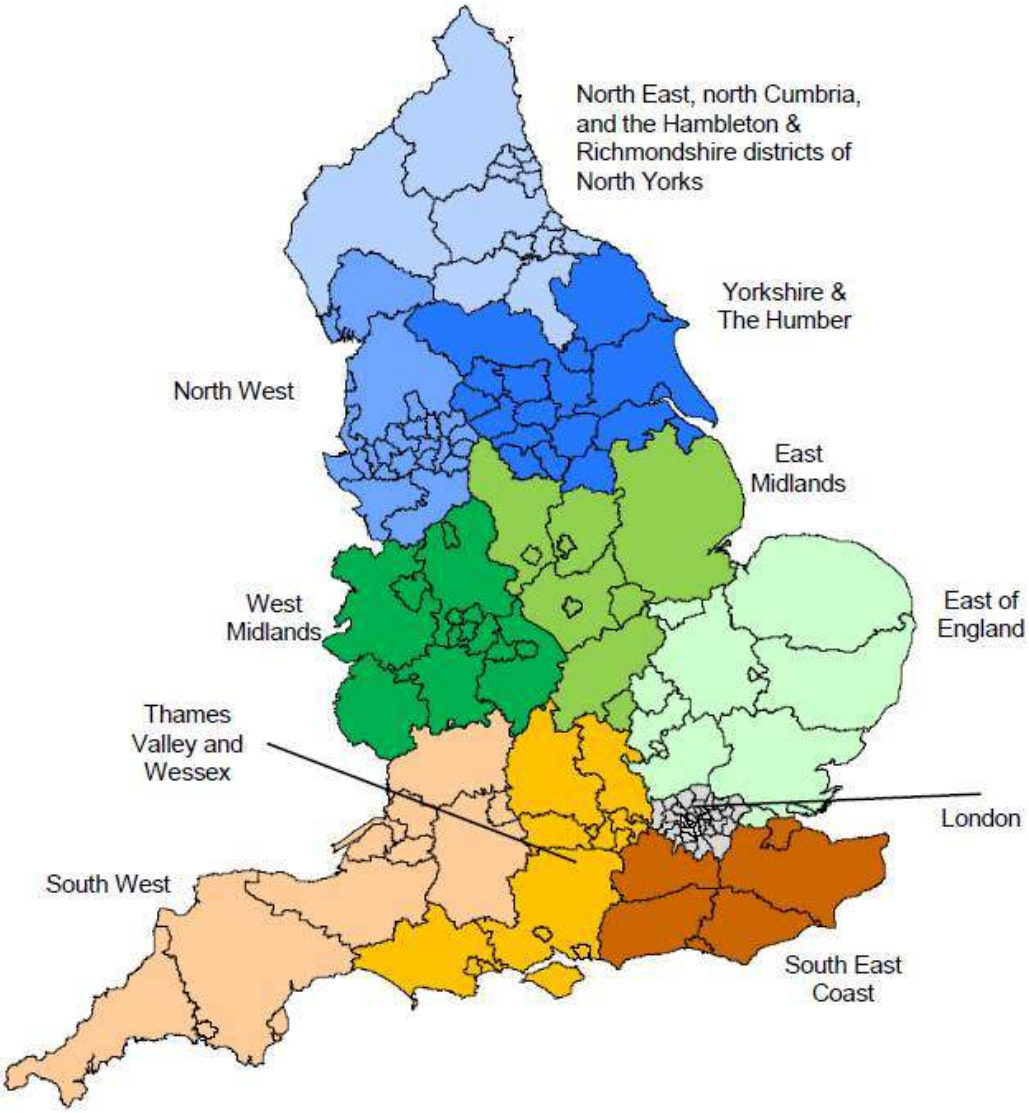
It will have three tiers:

- A National Support Centre – its 'central' offices in Leeds and London
- Regions – four of these, covering north, central, southern and London (two each based in Leeds and London)
- Local Area Teams – 27 of these.

Decisions about what is commissioned by the Board will be taken centrally. This framework will then be implemented by ten of the Local Area Teams (LATs). These will be called "enhanced LATs" and, because of their commissioning budgets, will be very large organisations.

The ten "enhanced LATs" are listed, and their geographical areas shown, below:

• Cumbria, Northumberland, Tyne and Wear
• South Yorkshire and Bassetlaw
• Cheshire, Warrington and Wirral
• East Anglia
• Leicestershire and Lincolnshire
• Birmingham and the Black Country
• Bristol, North Somerset, Somerset and South Gloucestershire
• Wessex
• Surrey and Sussex
• London



There is a subtle but important change from the old model of specialised commissioning to the new one:

- Previously SCGs contracted across the country for provision in their area
- Now LATs will contract with providers in their area for provision across the country, ie taking into account patient pathways.

In other words, an LAT might be commissioning services for people who live in neighbouring LAT patches, but whose care pathway brings them into their area to visit a particular specialist centre.

Health and Wellbeing Boards are expected to be a key arena in which the two streams of commissioning (CCG and NHSCB) will have an interface, as both are statutory members of HWBs (note that the simplified NHS structure diagram at the end of this appendix should properly have a purple arrow from the Board to HWBs, as well as from CCGs to HWBs).

2. Networks (i): Specialised Clinical Networks

It has become clear that a plethora of new networks and similar structures is being created in an effort to ensure that the new NHS structures cohere.

The most high-profile, or at least self-explanatory, of these are the Strategic Clinical Networks. These are hosted by LATs, mainly the same LATs that have responsibility for specialised commissioning. They include networks on the combined topic of mental health, dementia and neurology. Their geopgraphic areas and host LATs are listed below.

Geographical Area	Host Local Area Team
Cheshire and Merseyside	Cheshire, Warrington and Wirral
East of England	East Anglia
East Midlands	Leicestershire and Lincolnshire
Greater Manchester, Lancashire and South Cumbria	Greater Manchester
Northern England3	Cumbria, Northumberland, Tyne and Wear
London	London
South East Coast	Surrey and Sussex
South West Coast	Bristol, North Somerset, Somerset and South Gloucestershire
Thames Valley	Thames Valley
Wessex	Wessex
West Midlands	Birmingham, Solihull and the Black Country
Yorkshire and the Humber	South Yorkshire and Bassetlaw

3. Networks (ii): Operational Delivery Networks

Far less has so far been published about Operational Delivery Networks, but a publication is expected from the NHSCB before the end of 2012. Existing documentation describes them as, “focused on coordinating patient pathways between providers over a wide area to ensure access to specialist resources and expertise. Provider clinicians dominate their membership and work closely with patients and other stakeholders. ODNs will be provider hosted and funded in the long term, with transitional arrangements in the short term. ODNs typically cover areas such as adult critical care, neonatal critical care, trauma and burns.”

These are therefore not hosted by the NHSCB.

1. Networks (iii): Clinical Senates

While senates are not technically ‘networks’ they are clearly intended to function as part of the same package of structures. Unlike networks, which will have a specified clinical focus as well as a geographical one, senates will be purely geographic. Their stated aim is to, “help CCGs, HWBs and the NHSCB to make the best decisions about healthcare for the populations they represent by providing advice and leadership at a strategic level.”

The boundaries of the 12 senates will be aligned with those of the 10 LATs with responsibility for specialised commissioning (ie two LATs will have responsibility for two senates, the rest will have one each). A further publication on the detail of senates’ operations is expected before the end of 2012.

2. Networks (iv): Academic Health Science Networks

These networks are intended to link treatment and research endeavours, to facilitate research and also to identify and spread best practice. The first 'wave' will go live in April 2013, though it will be a little while before they cover all parts of the country. These are to be provider-run, but with some funding from the NHSCB, and it is intended that all providers should join one.

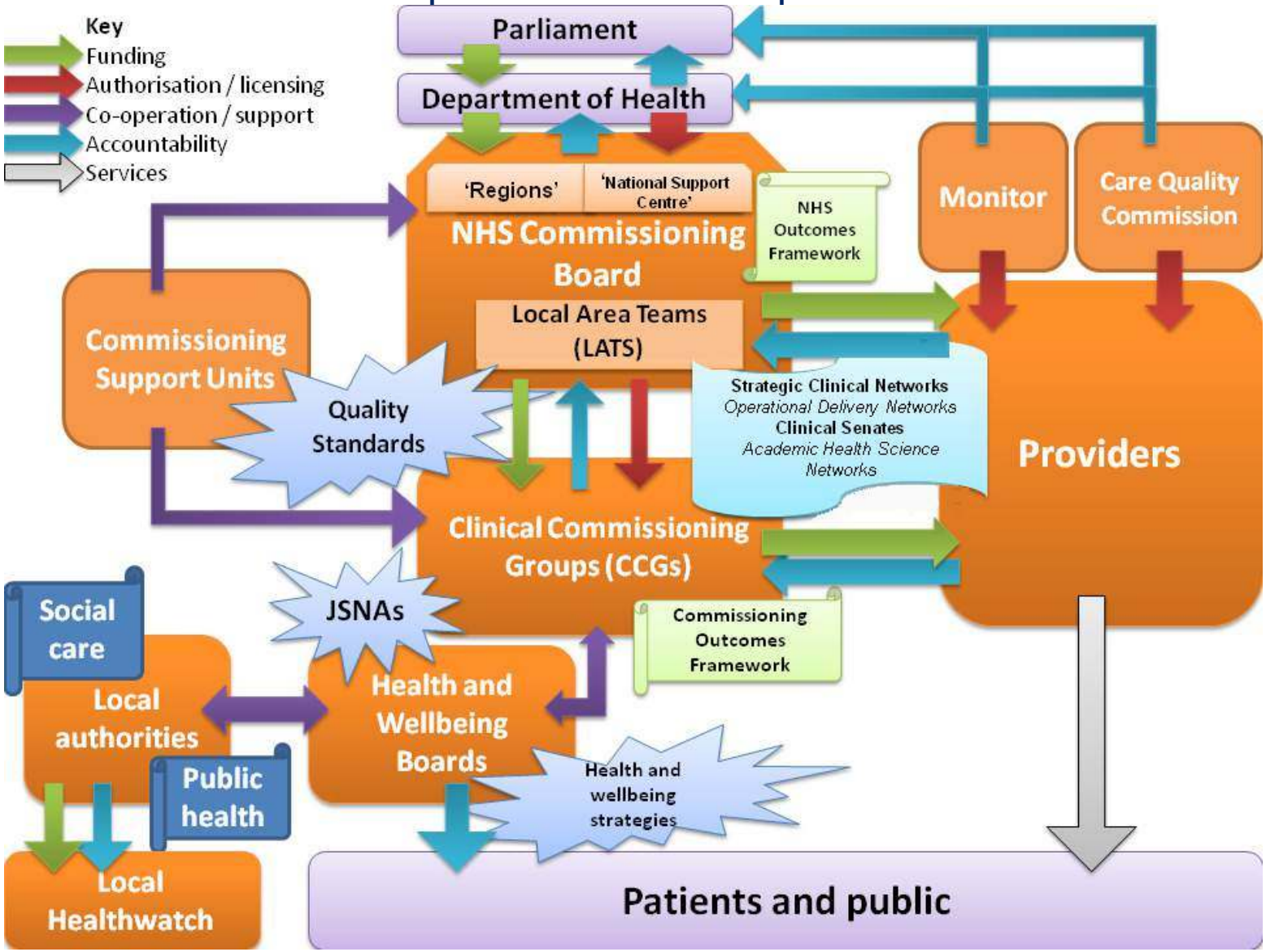
3. Clinical Reference Groups

Originally created to advise on the detail of what should count as "specialised" services, CRGs are set to continue as advisory bodies to the NHSCB, and are expected to have a role in service reconfiguration. While this may be a positive, there are several problems with CRGs:

- The process for the appointment of their chairs and other members is not transparent
- There are two spaces reserved per CRG for patient representatives, and these must be service users rather than representatives of an organisation
- They are not clearly accountable for their work.

A "stakeholder engagement map" is being created to allow patient organisations to engage with CRGs, in light of the fact that they may not sit on them (a decision reportedly taken largely to avoid tensions over managing which organisations should be allowed a seat on a CRG).

Simplified NHS structure from April 2013



Appendix 3: relevant material from the Commissioning Manual for specialised services

12. Adult specialist neurosciences services

About the condition/service
Clinical neurosciences include both medical and surgical neurology as well as diagnostic support and neurological rehabilitation services. The services are interdependent and the care pathway for many patients with neurological problems may span several neurosciences sub-specialties.

How the service is organised
Adult Specialist Neurosciences Services are provided by about 25 Adult Neurosciences Centres and 10-15 Adult Neurology Centres. Some services are delivered as outreach.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions all adult specialist neurosciences services provided by Adult Neurosciences or Neurology Centres, including services delivered on an outreach basis as part of a provider network.
The NHS CB commissions:
- All neurosurgery activity
- All interventional procedures within neuroradiology
- Inpatient neurology
- Specialist diagnostics (including neurophysiology, neuroradiology)
- Associated services (neuropsychology, neuropsychiatry, neuro-rehabilitation, neuro critical care)
- Neurology outpatients

CCGs commission neurology inpatients and neurology outpatients where these are provided at local hospitals that are not Adult Neurosciences or Neurology Centres.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:
- the number of individuals requiring the service is small;
- the cost of providing the services is high because of the specialist interventions involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes ALL activity at specified centres.

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134. Specialist services to support patients with complex physical disabilities (all ages)

[D1 – Complex Disability Equipment] Service summary
Specialist services to support patients with complex physical disabilities (including those with a combination of physical, sensory, intellectual, learning or cognitive disabilities) include the specialist assessment for, and provision of (if indicated):

• Prosthetics (limb and artificial eyes)
• Specialist wheelchairs (including complex postural seating and powered wheelchair controls)
• Specialist augmentative and alternative communication aids
• Specialist environmental controls

This applies to provision in adults and children

B. SPECIALIST WHEELCHAIRS (INCLUDING COMPLEX POSTURAL SEATING AND POWERED WHEELCHAIR CONTROLS)

About the condition/service
There are estimated to be about 500,000 wheelchair users in England but with only about 5% (about 25,000) requiring specialist services. These are patients who have the most profound disabilities and/or an unstable medical condition, who can only function adequately in a wheelchair with unique personalised modifications, often incorporating bespoke manufactured items. All aspects of provision (assessment, objective setting, specification, prescription, design, manufacture, commissioning, on-going support and maintenance) require greater knowledge and expertise than is available in most local wheelchair services. The specialist service addresses postural needs (facilitating comfort and function) as well as mobility**.**

People (adults and children) requiring specialist wheelchair services have a complex and /or fluctuating medical condition and multiple disabilities, which may include physical, cognitive, sensory and learning aspects. The most common diagnoses that need specialist wheelchair services are: cerebral palsy, muscular dystrophy, multiple sclerosis, brain Injury, motor neurone disease, high level spinal cord Injuries (with/without ventilation support).

How the service is organised
Although there are about 150 providers of wheelchair services in England, only about 30 of these are able to provide specialist services.

The specialist assessment team consists of a doctor specialising in rehabilitation medicine, a specialist therapist, a clinical engineer and a clinical scientist, all of whom have appropriate skills and experience. The specialist team works closely with the individual, their families/carers, other medical and surgical teams, local therapy staff (including speech and language therapists) as well as staff from social services, community nursing and education /employment. The specialist team also liaises with external suppliers of equipment.

Specialist centres are equipped with appropriate equipment for physical examinations, driving assessments and pressure measurement plus suitable

facilities for moving and handling. Trial wheelchair/seating equipment is also available. Alternatively, individuals may be seen in other environments such as child development centres/schools for children or familiar/non-threatening surroundings such as homes for people with cognitive or learning difficulties.

Each prescription is individually formulated following a detailed assessment of the disabled person's needs and lifestyle, using a standardised assessment procedure. A specification is drawn up in conjunction with the disabled person, and his/her carers if appropriate, and based on his/her goals. The prescription most likely to meet the specification may comprise off-the-shelf components, bespoke manufactured items or any combination of these. Advice may be given about other aspects of mobility/postural management such as use in vehicles, static seating, standing frames, etc.

Specialist centres are equipped with technological and engineering facilities for assembly/set-up of the prescribed equipment and for customisation/modifications often necessary to complete an episode of care successfully

individuals as their needs may change at irregular intervals due to their medical conditions. Access to engineering facilities ensures that changes can be managed in a timely manner.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist wheelchair services for individuals who meet the following criteria:

- Have posture or mobility needs that can only be met with a high level of specific design input
- Are 'active' individuals requiring special expertise
- Have the ability to control a powered wheelchair but are unable to use standard joystick controls
- Require multiple items of integrated equipment

The NHS CB commissions the following drugs/devices: specialist wheelchair packages, special seating packages.

Clinical Commissioning Groups (CCGs) commission services for those wheelchair users who do not meet the criteria for specialist wheelchair services.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS Commissioning Board because:

- the number of patients requiring the services is relatively small;
- the cost of providing the service is high because of the specialist equipment involved;
- the number of doctors and other expert staff trained to deliver the service is small; and
- the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

C. SPECIALIST AUGMENTATIVE AND ALTERNATIVE COMMUNICATION AIDS

About the condition/service
The Office of the Communication Champion estimates that approximately 6,000 children and adults require assessment and provision by specialist communication services each year.

Communication is fundamental to independence, achievement and quality of life. A communication system enables people who have lost, or never had speech or language to interact with their world, often allowing them to engage and be successful in education, vocation and work.

Augmentative and alternative communication (AAC) equipment allows for:
• Output of synthesised (artificial) voice, digitised (recorded) voice or text
• A vast array of ways in which vocabulary is organised and selected by the user
• Many different means of accessing and controlling the equipment

People requiring specialist AAC assessment have a combination of physical, sensory, intellectual, learning or cognitive disabilities. This includes children and adults born with a communication impairment (for example, cerebral palsy, developmental disorders, learning disabilities and other disorders such as autism) and children and adults who become communication impaired (for example through stroke, cancer, brain and spinal injury and neurological diseases such as Parkinson's, Alzheimer's, multiple sclerosis or motor neurone disease).

How the service is organised
There are 10-12 specialist centres in England, either NHS or voluntary sector (funded via NHS or education sources). Assessment models and the services offered vary but most provide:
• A multi-disciplinary team including specialist speech and language therapists, clinical scientists and technologists, occupational therapists, specialist teachers and access to physiotherapists, psychologists and others
• Technological and engineering facilities for customisation and modification to the individual
• An assessment and loan bank of possible technologies offering a diverse range of solutions
• An extremely wide range of software, vocabulary packages and resources
• Expertise in procurement and equipment management
• An ability to issue, monitor, maintain, recall and refurbish equipment
• An ability to manage, aggregate and analyse user information to enhance the service and streamline day to day operations
• An ability to integrate services and equipment with other assistive technologies such as environmental controls
• An ability to educate and train a wide range of stakeholders from the user, families, spoke service members and local team members

• An ability to take account of co-morbidity issues such as postural support needs

Referrals for an AAC needs assessment originate from local services, including health care professionals in the community and acute medical settings, staff within the education sector, staff within the social care sector and specialist and local rehabilitation teams.

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions services for patients that require specialist assessment for AAC aids:

Where there is a severe/complex communication difficulty associated with a range of physical and/or cognitive, learning and sensory deficits.
• Where goals are achieved by the input of a multi-disciplinary team to include speech and language therapists, clinical scientists, occupational therapists and education professionals (as a minimum), with specific competencies and access to a wide range of specialist equipment.
• Where individuals require multiple assistive technologies, integrated into a single means of access and functionality (for example communication, environmental control, computer access and/or powered wheelchair control)
• Where communication solutions are dependent upon special engineering and adaptation.

Clinical Commissioning Groups (CCGs) commission AAC aids for those patients who do not meet the criteria for specialist AAC aids.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:
• the number of patients requiring the services is small (about one patient registered at each GP practice requires access to the service);
• the cost of the service is high because of the specialist equipment involved;
• the number of doctors and other expert staff trained to deliver the service is small; and
• the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCG.

D. SPECIALIST ENVIRONMENTAL CONTROLS

About the condition/service
There are about 6,000 users of environmental control systems (ECS) in England. These systems enable people with profound physical disability to gain a degree of personal independence, often enabling them to continue living in their own homes with carer support and relying on their ECS to achieve single switch access to operate multiple functions such as:

• Summoning help in an emergency or calling a carer
• making and receiving telephone calls
• controlling door access for visitors and the EC user
• adjusting room temperature, ventilation and lighting
• adjusting position in riser/recliner chair or profiling bed
• operating electrical appliances in home (television, satellite, audio visual equipment).

A significant proportion of users make use of these technologies to provide safety and security, gain remunerative employment, maintain social contacts and access information and services. The current EC equipment has a modular format with systems prescribed and assembled to meet individual need. However, they are only available from specialist suppliers and may require a customised means of access to accommodate the individual's functional abilities.

Most people requiring ECS have significant upper limb impairments that mean they are unable to use standard controls, for example remote-control handsets or telephones. Many are neurological conditions resulting in tetra-paresis, often with a progressive component varying from moderate to rapid and combined with fatigue. The commonest diagnoses are: multiple sclerosis, spinal cord injury (level C5/6 & above), motor neurone disease, cerebral palsy, muscular dystrophy, severe arthritis and acquired brain injury. Besides having severe physical impairments, some of the users may also have co-existing cognitive and communicative impairment.

How the service is organised
There are about 20-25 providers of ECS, with over 70% of the population being covered by 12 major service providers.

The specialist centres providing ECS: conduct assessment of the individual's needs, usually in their place of residence; prescribe equipment solutions to meet these needs; and undertake or oversee their installation. A stock of relevant equipment is available to demonstrate ECS and computer access to patients and carers and, if needed, a trial can be arranged.

The services are also responsible for: on-going support of the equipment, including initial tuition; clinical review with additions and modifications to suit changing needs; equipment maintenance; and service support, including emergencies.

Specialist ECS services achieve the required medical and technical competencies through the multi-disciplinary approach of clinical scientists, clinical technologists, specialist occupational therapists and input from medical personnel (most commonly rehabilitation medicine consultants). They work closely with the community and other specialist teams who may be involved with individual patients. Thus is especially needed for patients who require multiple assistive technologies that need integration into a single means of access (for example, environmental control, computer access, communication aid and/or powered wheelchair control).

What the NHS Commissioning Board commissions
The NHS Commissioning Board (NHS CB) commissions specialist environmental controls.

The NHS CB commissions the following drugs/devices: specialist environmental control devices

Clinical Commissioning Groups (CCGs) do not commission any services relating to a patient's specialist environmental control but commission any general health services required by that individual. Local authorities commission non-specialist environmental controls.

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:
• the number of patients requiring the services is small (about one patient in each GP practice requires access to the service);
• the cost of providing the service is high because of the specialist equipment involved;
• the number of doctors and other expert staff trained to deliver the service is small; and
• the cost of treating some patients is high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.

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3. Adult highly specialist respiratory services
[A3D – Specialised Respiratory] Service summary
Adult highly specialist respiratory services include services provided by Highly Specialist Respiratory Centres for patients with specified rare conditions or specified common conditions with complex needs. The service includes outreach when delivered as part of a provider network.

A. COMPLEX HOME VENTILATION

About the condition/service
Assisted ventilation is used in the management of acute and chronic respiratory failure. In the acute setting it is typically delivered in high dependency or intensive care units. However, the development of effective portable ventilators has resulted in a rapid increase in the use of assisted ventilation in the domiciliary setting as a treatment for chronic respiratory failure. It allows patients with complex ventilatory needs and/or a high degree of ventilator dependence, many of whom would have previously died or remained in hospital, to be managed in community settings.

How the service is organised
Complex home ventilation is delivered by about 12 providers catering for patients who: are difficult to wean from invasive ventilation following an acute illness requiring

intensive care; those admitted to hospital with an acute decomposition in their chronic respiratory failure; and outpatients with complex ventilatory needs and/or requirement for ventilatory support for more than 14 hours per day. Conditions resulting in the need for long term ventilation include end-stage lung disease, neuromuscular conditions and severe skeletal deformity.

What the NHS Commissioning Board commissions
The NHS CB commissions complex home ventilation services from Highly Specialist Respiratory Centres.

D. ALL ADULT HIGHLY SPECIALIST RESPIRATORY SERVICES
Clinical Commissioning Groups (CCGs) commission all other respiratory services, including:
• All asthma services that are not defined as 'difficult'
• Sleep disorder breathing that fails to respond to simple therapy, except where patients fall under the scope of complex home ventilation
• Advanced pulmonary function testing, except where the patient falls under the scope of one of the four areas commissioned by the NHS Commissioning Board
• Occupational lung disease, except where the patient falls under the scope of interstitial lung disease
• Alpha 1-antitrypsin deficiency
• Existing secondary and primary care services supporting the local care of patients with PCD, ILD, complex home ventilation and severe and difficult-to-control asthma as determined by the specialised centres
• Patients requiring non-invasive ventilation, but falling outwith the criteria for complex home ventilation, managed in Home Ventilation Units
• Ventilatory equipment and individual home care packages for all ventilated patients supported in the community, in liaison with local social services, education and housing departments

Why the service is commissioned by the NHS Commissioning Board
This service is commissioned by the NHS CB because:

the number of patients requiring the service is small (there is about one patient across six GP practices with difficult to control asthma and one patient across two GP practices with interstitial lung disease);
• the cost of providing the service is high because of the specialist equipment, drugs and interventions involved;
• the number of doctors and other expert staff trained to deliver the service is small; and
• the cost of treating some patients is very high, placing a potential financial risk on individual CCGs.

How the activity for this service is identified
This service includes specified activity at specified centres.

Review of the service commissioner
There are no plans to review whether this service should be commissioned by CCGs.