mnda
motor neurone disease
association

# Submission to the Specialised Services Commission

## Specialised services, wider care services and funding

i. It is important that specialised services are not eroded in favour of generalism. NICE guidance, academic research and research commissioned by us all point towards the involvement of MND specialists being beneficial in MND care. In particular, based on the weight of available evidence we recommend that people with MND should be seen at a dedicated MND clinic, overseen by a neurologist with appropriate specialism.

ii. Defining ‘specialised’ is more difficult: we have used the term with reference to clinical expertise, but for NHS purposes the use of planning populations with reference to disease prevalence, although a crude approach, may still be useful. That said, the boundary between specialised and local commissioning is currently proving to be an obstacle to effective care within the NHS, and *mutatis mutandis* the same can be said for the barrier between the NHS and social services. Eliminating the obstacles thrown up by these boundaries is desirable, and ideally changes to the planning and funding of all these services will make the boundaries less marked and the definition of ‘specialised’ less critical. We explore these points further below.

iii. We must further observe at this point, however, that a properly funded social care system is essential to the good functioning of specialised NHS services as it is to all others. The 2015 Spending Review did not provide adequate funding for social care, and therefore did not meet the demands of the Five Year Forward View, despite its up-front extra cash for the NHS. We do not believe it is either sustainable generally, or in the interests of people with MND specifically, for the proportion of our GDP spent on health and care to decline as currently planned. There is little need for further debate on the subject of sustainable funding mechanisms for health and social care: reviews such as the Barker and Dilnot Commissions have studied the issues exhaustively. We wish to see reliable and sufficient funding of the entire health and care system, based on the appropriate sharing of risk across the population as a whole.

iv. We anticipate that spending on specialist care for rarer and more complex diseases will certainly need to increase substantially. In respect of MND, the ageing population and the growing uptake of the life-prolonging intervention non-invasive ventilation (NIV) are likely to be driving an increase in both incidence and survival times at present. In the near future (within five to ten years), we would hope to see new treatments targeting specific genetic mutations, which will mean that a sub-set of people with MND will live for much longer, with the disabling effects of the condition slowed or even halted. The recent discovery of biomarkers for MND will hopefully lead to a diagnostic test, which MND currently lacks: with quicker diagnosis the overall number of people known to have MND will see a one-off increase, and earlier commencement of treatment with the drug riluzole should extend survival time, and therefore the MND population, slightly as well. The recent draft guideline published by NICE noted that longer survival times in MND increase costs to the NHS very considerably, because the condition is so complex and demanding. While new care models may be able to allow for the more efficient and effective delivery of general care, it is hard to see how they could make the expensive drugs and specialist input required for many aspects of MND care cheaper to deliver.

**Quality assurance, national standards, and accountability**

i. We support the continued use of national standards for specialised services. Best clinical practice is not, other than at the frontier of knowledge, a matter of controversy and it is right that clear statements of what patients can expect should be set out. These should of course have sufficient flexibility to be adaptable to local circumstances, but no more latitude than is necessary for that.

ii. Since 2013, quality assurance has been a major problem in specialised services. Commissioners have entirely lacked the resources or wherewithal to identify what their money is paying for. In the case of MND, this means that mandated services are simply not being funded by the NHS. See Case Study 1, below.

iii. It is also clear that NHS England is fundamentally unaccountable for failures to implement national standards, when they occur. It is clear that nobody will be held accountable for the major failings in specialised augmentative and alternative communication (AAC) from 2012 to 2014 outlined in Case Study 2.

iv. Strong new accountability measures should be introduced, preferably parliamentary in nature. If ministers are not to be held directly to account by Parliament for the provision of services, then NHS England directors should be instead. Matters of policy should remain between NHS England and ministers, but major operational failures should be within the remit of parliamentary accountability.

**Recommended approach for MND**

i. The final version of NICE's MND guideline will be published in February 2016. We will be making recommendations to the NHS based on this, research we have commissioned into models of MND care, our Outcomes Standards for MND care and other best practice guidance. As the NICE guideline and Models of Care report are currently unpublished, we offer the below recommendations for MND care on a provisional basis.

ii. Our Models of Care report identifies four key characteristics of effective MND care:
    - It is multidisciplinary
    - It involves an MND clinic
    - Community services are sufficient and involve MND specialism
    - Care is coordinated.

iii. The draft NICE guideline also found that multidisciplinary care both extends survival and is cost-effective at a threshold of £30,000 per QALY.

iv. We suggest that MND care should be planned with a line of sight along whole pathway, from a position of specialised knowledge; a capitated budget / year of care approach would probably be appropriate. We believe that the necessary knowledge of MND must come from the provider side: neither specialised nor local commissioners have proved capable of securing the necessary oversight of these services. In the context of the Five Year Forward View ‘vanguards’ this might mean one of the new primary care organisations taking responsibility for planning MND care, and provision being by a mix of that organisation and one or more of the new multispeciality community providers. In principle, such an arrangement should be capable of securing care with all the necessary characteristics – indeed, the proposed organisations would appear better suited to the task than the current ones.

v. Similar recommendations may hold good for other highly debilitating neurodegenerative illnesses such as progressive supranuclear palsy and multiple system atrophy, and possibly some muscular dystrophies. We see no reason why this approach would be incompatible with a measure of regional devolution, barring the deployment of wholly different provider (or commissioner) models in such areas.

**Case study 1: specialised MND clinics and inadequate quality assurance**

i. Specialised neurology services have been dogged by system design and implementation problems since 2013, and there is every sign of these problems continuing. In respect of MND, this has translated into a failure by NHS England to fund services mandated in the service specification (D04: specialised neurology).

ii. The neurology service specification states that all neurology services are specialised. This is contrary to NHS England’s identification rules, and clearly at odds with clinical practice: support from community-based therapists and clinicians is an integral part of MND care, as for many other neurological conditions. This led some CCGs to believe that they had no responsibility for neurology: while we never received any clear-cut reports of services used by people with MND being de-commissioned, some other condition areas did see services cut back. This appears to illustrate how little detailed oversight of services local commissioners really have: on one occasion, a Freedom of Information request prompted a CCG commissioner to ask a regional member of MND Association staff what services they commissioned in respect of MND, as they did not know. These shortcomings in local commissioning probably proved fortuitous: without them, more CCGs might well have seized the apparent opportunity to save money by cutting supposedly specialised neurology services.

iii. In respect of MND specifically, the service specification is generally sound: it gives a fair description of a specialised multidisciplinary MND clinic. The wording was drafted by the MND Association at short notice on request from the responsible commissioner – while we are still generally happy with it, we would prefer to have had chance to fine-tune it and consult more widely on the specifics. Unexpectedly, it contains an additional, erroneous, statement that all MND care is specialised – this is over and above the similar stipulation made in respect of neurology services generally. This was the only wording in the description not drafted by us.

iv. However, despite the clear description in the service specification of a specialised, multidisciplinary MND clinic, NHS England has not moved to commission any such clinics. Many are already in operation in designated neuroscience centres, but only as part of the MND Association's care centre programme. Under this scheme we have, since the early 1990s, instituted specialised clinics by arrangement with individual hospital trusts and/or universities: we have funded, and in most cases continue to fund, a coordinator to facilitate access to multidisciplinary care; the neurologists and other specialists are funded by the NHS or universities. NHS England has not attempted to assume this funding responsibility, and in meetings with commissioners we have learnt that they lack sufficiently detailed oversight of the services they commission: effectively, they commission a bundle of specialised neurology services from a hospital, and leave the hospital to distribute the money. The assurance exercise conducted soon after the new specialised commissioning regime came into effect relied on self-certification by hospitals, and did not examine every service. Hence the Association's charitable funding (approximately £1million per year, albeit this total includes a centre each in Northern Ireland and Wales) remains in the mix, despite the unambiguous funding obligation on NHS England.

### Case study 2: specialised augmentative and alternative communication (AAC) and a failure of accountability

i. Specialised augmentative and alternative communication (AAC) has been one of the most egregious areas of failure in specialised services since 2013, although a reasonably convincing recovery from this is now underway.

ii. The service specification first published in draft form in 2012 proposed a highly promising new system for specialised communication support. Unfortunately, when NHS England assumed responsibility for these services in 2013, the specification simply was not implemented. The new specialised hubs promised in the specification did not exist. Worse still, a combination of confusion about possible new arrangements and cuts or reconfigurations by CCGs led existing services and pathways in some areas to collapse. People with MND began finding themselves with no communication support at all; by spring 2014, reports of this were reaching us regularly, and demand on our support services was growing. The then CEO of NHS England, Sir David Nicolson, wrote to assure us definitively that the new system was about to get up and running; but it simply did not happen. Towards the end of 2014, his successor Simon Stevens wrote in similar terms; again, the picture he painted did not match what people with MND reported to us.

iii. The leadership of NHS England was not responsive to our concerns. In early 2015, the All Party Parliamentary Group on MND published a report outlining the problems in detail; this led to an intervention at Prime Minister's Questions and eventually a ministerial meeting before we were able to secure a meeting with senior officials in NHS England.[1] Since then, happily, NHS England has been more responsive and we have an ongoing dialogue with them, although its promised follow-up on actions agreed in meetings remains tardy.

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[1] http://www.mndassociation.org/get-involved/campaigning-influencing/appgreport/

iv. At the same time, NHS England’s commissioners finally managed to gain some traction in setting up the new system. Although £15million in convergence funding, to upgrade some existing services to the new ‘hub’ standard, was agreed in April 2014, it took until the turn of the year for the providers to agree contracts with NHS England; thereafter, they had to undertake recruitment (some posts remain unfilled). However, most of the planned hubs are now operating at or close to the level intended, albeit that most are still dealing with substantial case backlogs.

v. Despite this undoubted progress, it must be observed that the service specification was drafted in 2012, yet contracts were not fully in place with providers until 2015. The need to establish these services was eminently foreseeable, but NHS England failed firstly to do it, and secondly to recognise or acknowledge its failure.