A rapid response to a rapidly degenerative disease

The case for a National Strategy for MND
A rapid response to a rapidly degenerative disease –
The case for a National Strategy for Motor Neurone Disease
People with MND face unacceptable delays and inequities

MND may be a disease of low prevalence, but it is one of high need. The rapid progression and wide range of symptoms mean that people with MND have complex and demanding care and support requirements. The NHS and social services can find it challenging to meet the care and support needs of people with MND in a timely and equitable way. The often unsatisfactory, and at times totally unacceptable, experiences of people with MND demonstrate that rapid and significant improvements are required to drive-up national and local standards in the provision of health and social care services, and in the care provided by clinicians and health and social care professionals.

Care provided by the NHS and social services is fragmented and of variable quality; primary care trusts and local authorities lack the road map of services (and their associated costs) that people with MND need from diagnosis to death. Clinicians, and health and social care professionals outside areas and centres of expertise in MND, rarely have occasion to care for people with MND. Even for those regularly working with people with MND, providing high-quality care can be complex and challenging. These professionals are without official national guidance or direction on acceptable standards of care.

Research is hampered by bureaucratic and regulatory burdens

The economic burden of MND alone provides a sound basis for increased investment in MND research. It is estimated that the maximum direct costs to the health and social services for a person with MND is approximately £200,000 annually, and represents a maximum cost to health and social services in UK of £373 million a year in addition to indirect costs to the economy of approximately £1.1 billion.

There has never been a better opportunity to realise the benefits of medical research for people with MND. The UK is well-placed to realise such benefits including morbidity reduction and efficiency gains in the care of people with MND. Yet the national situation is one of missed opportunity. While interest by the medical research community is rapidly increasing thanks to recent major advances in understanding the causes of the disease, research remains poorly funded when compared to the study of other long-term conditions, with clinical research in particular hampered by bureaucracy and regulatory burdens.
Why is the MND Association calling for a National Strategy for MND?

Urgent, national action is required to improve the quality of life and achieve dignity in death which people with MND need and have a right to expect, no matter where they live.

Urgent, national action is required to realise efficiency gains and value for money in the spend on care for people with MND, and research into the causes and cure of this disease.

The existing National Service Framework for Long Term Neurological Conditions successfully sets out what shape care for a neurological condition should take, but it has not been implemented. A National Strategy for MND will close the gap between the framework’s vision and delivering that vision for people with MND.

A National Strategy for MND will provide a road map and set standards for the co-ordinated, holistic care of people with MND, from diagnosis to death. It will lend weight to efforts to address bureaucratic and regulatory burdens that currently delay much needed research. A National Strategy for MND will support effective resource planning and allocation, thereby realising efficiency savings.

Best practice in relation to MND is already well-developed, not least by the MND Association’s Year of Care Pathway, Standards of Care and Clinical Guidelines. We will happily work with the Government to ensure this expertise is imported into the new National Strategy for MND.

Imagine a healthy and alert mind trapped inside a body that can’t move, but can still think and feel. That’s the devastating reality of MND for many of those who develop it. By joining our call for a National Strategy for MND, you can help make a real difference to the lives of people with MND.

Take action: what you can do to help

- Write to the Prime Minister and Secretary of State for Health highlighting the need for a National Strategy for MND
- Encourage your party to endorse the call for a National Strategy for MND
- Sign Early Day Motion number 198 supporting a National Strategy for MND
- Sign up to our Pledge in support of a National Strategy for MND
- Speak to the social service and healthcare providers, and commissioners in your constituency to ensure that they are aware of, and addressing the everyday care issues facing people with MND
- If you are a councillor, raise these issues within your local authority structures and investigate the services provided to people with MND against those outlined in this manifesto – if you need support and advice on how to improve local services, please contact us.

To find out more about services for people with MND in your constituency or ward, please contact the MND Association at mndstrategy@mndassociation.org or telephone 01604 611842.
National Strategy for MND – the case for a co-ordinated approach

A holistic approach – what might a National Strategy for MND look like?

National Strategy for MND: Meeting the needs of a person with MND

- **Equipment and Adaptations**: Wheelchairs and other equipment are essential for people with MND to maintain their quality of life.
- **Faster Diagnosis**: Many people with MND have an extremely long wait to be diagnosed; this time needs to be reduced.
- **Continuing Healthcare**: The regime for providing continuing healthcare does not currently meet the needs of people with MND.
- **Disability Benefits**: The slowness of the benefits system fails many people with MND; it must be improved.
- **Emotional Support and Counselling**: Maintaining emotional and psychological wellbeing is as crucial for quality of life as managing physical health.
- **Respiratory Management**: MND can significantly affect breathing; treating this can make a huge difference.
- **Key Workers/Specialist Nurses/Care Co-ordinators**: It is vital that care for people with MND is co-ordinated – up to 18 professionals can be involved at a time.
- **Supporting Carers**: Carers are vital for maintaining the quality of life of people with MND: their needs, including for respite care, must also be taken into account and met.
- **Clinical Research**: The UK must remain a leader in research into MND and other conditions.
- **Palliative and End of Life Care**: High quality palliative and end of life care must be made more widely accessible so that people with MND can die with dignity in this country.

**National Strategy for MND – the case for a co-ordinated approach**

A holistic approach – what might a National Strategy for MND look like?
Luke is a young man with MND who has received appropriate, timely and co-ordinated care over a five-and-half-year period. Despite progressing to significant disability, since diagnosis he has been able to live independently with his wife, has had three children and exceeded all expectations of survival and quality of life due to the support he has received. This case demonstrates that when services interact in co-ordinated way they can deliver the rapid response to an individual’s needs and the broad range of specialist services required in a timely and anticipatory manner.

Luke has been clear that he wishes to be in control of the timing of interventions and that these should be made according to his own pace. The local care team has to balance respect for these wishes with professional responsibility to plan care so that it is timely and crisis situations are avoided.

1This person’s name and geography has been changed to protect his anonymity.
Luke is currently living at home with his wife and children. He is provided with district nurse and twilight care, which are co-ordinated by a local specialist nurse. He has a review at his local care centre every six months, but there is regular contact between the care centre co-ordinator and the local services that he uses. Luke is supported with NIV, PEG and a cough assist device.
Onset of symptoms to diagnosis

Length of time taken for diagnosis and from diagnosis to death: The average time from the onset of symptoms to diagnosis is 17 months, and from diagnosis to death, 14 months.

Low awareness of MND and neurological conditions among GPs: When a patient visits their GP, they are generally being dealt with by a medical professional who may only see one or two cases of MND in their career, and it can take GPs many months to recognise a neurological condition as the cause of symptoms, and make a referral to a neurologist.

Neurologists: Awareness of MND and of advances in care and support amongst neurologists, particularly those outside areas of MND expertise, needs to be significantly improved to ensure that diagnoses are made appropriately, and that follow-up care and support by neurologists is provided and is of a high standard.

The low number of neurologists in the UK compounds delays to a diagnosis: one for every 170,000 people, compared with to one for every 18,000 – 35,000 people in other European countries. More neurologists are clearly needed.

Responding to the challenge with a National Strategy for MND – Faster, better diagnosis

- GP awareness programmes: A multi-agency approach is needed to ensure GPs are supported to develop a greater awareness of neurological conditions.

- Improved diagnosis delivery: A multi-agency approach is needed to ensure diagnoses are made sensitively with support and appropriate information. Referrals to designated key workers who specialise in co-ordinating care for MND, and to the MND Association should also be made.

  A multi-agency approach is needed to increase awareness of MND among neurologists, especially those working outside areas of MND expertise.

- Increased neurological resources: A national target is needed to ensure that patients are seen by a neurologist within four weeks of being referred by a GP. While much progress has been made under the 18 week target introduced from November 2008, the rapid nature of MND warrants an even shorter timeframe than this.

  Multi-agency led, proactive measures are needed to increase the number of neurologists practising in the UK.

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CHALLENGE 1

Case study:

Del Deanus, 34, Welwyn Garden City

In 2006 Del went to his GP who referred him to hospital. Two months later he received his hospital appointment. At that time Del thought it was a brain tumour. Del went in for tests. His wife Emma called the hospital to ask if she should be there for the results and was told that there was no need.

During the respiratory tests Del was given his notes to take back up to the ward. Del looked at his notes and saw a letter from his GP to the neurologist that suggested MND. A return letter from the neurologist to the GP confirmed the diagnosis as a ‘good spot’.

When Del got back to the ward he asked the neurologist what was wrong with him. He said they didn’t know and had to do more tests.

When Del returned to the hospital after the weekend the neurologist diagnosed MND. He was on his own.

Two days later the hospital called Del and told him that he had hepatitis B and that he and his partner would have to be checked for HIV. He was told to stop taking riluzole and not to have unprotected sex.

Unsurprisingly this caused problems within the relationship and fears of infidelity. Del had three tests to prove he was negative. There was no apology, just an explanation of a mix-up in the lab.

1 Riluzole (trade name Rilutek) is the only drug known to have any effect in slowing the progression of MND.
Brian Gray, Northallerton  

Brian cared for his wife Diane until her death in May 2007. Diane had been in hospital being treated for pneumonia just before she was diagnosed with MND and in total she was in hospital for nearly 22 months. Brian said: “She should never have been in hospital for so long. After already spending 12 months in hospital, she had to remain in hospital for a further nine months whilst a team was put together to look after her at home. The carers needed to be able to deal with Diane’s breathing machine, as well as other specialist equipment she needed. This also included making adaptations to the house.” By the time Diane came home she had already had MND for two years. She was to die two years later. Something else that took a long period of time was getting a specially adapted wheelchair. Brian said that dealing with the wheelchair department at social services was very upsetting. Social services said Diane could not have the chair she needed because it was too expensive (£10,000). In the end they got the chair but it took 18 months. The chair itself only took three months to build. In the meantime they gave them a wheelchair originally made for a man six feet tall. Brian modified it, but it meant he had to push her for 18 months, so Diane had little independence. In the end, by the time she got the specialised chair she could only use it for four months. Brian said: “I know MND is a difficult disease to live with. However time is precious, so long stays at hospital, or long delays in securing vital pieces of equipment is literally robbing the time the person has left.”

**Care and support after diagnosis**

*Achieving quality of life and dignity in death*

**Equipment and adaptations:** People with MND experience unacceptable delays and inequities when seeking to access equipment and home adaptations from health and social services. Equipment and home adaptations delivered in a timely way are essential to enable people with MND to maximise their independence and quality of life. However, the MND Association has identified over 25 areas of concern across England with regards to wheelchair provision.

The MND Association routinely supplies key pieces of vital equipment for people with MND including riser/recliner chairs, light-writers, suction units, profiling beds and washer/dryer toilets, where the statutory service response is simply too slow to meet the needs of people with MND. The Association believes it is unacceptable that statutory services deliberately and repeatedly allow the financial burden of vital equipment and adaptation provision to fall on a charitable organisation.

**Responding to the challenge with a National Strategy for MND**

- **Prompt supply of appropriate equipment:** A significant improvement in the way statutory services respond to rapidly progressive diseases like MND is needed to ensure that people with MND receive appropriate equipment in a timely way. To meet the needs of people with MND, an assessment of need and the supply of equipment should take place within a month or so of referral at the most; at present, most NHS wheelchair services are a long way from being able to meet these standards.

- **Responsive wheelchair provision:** The MND Association has developed a partnership model with Wheelchair Services in eight areas to ensure people with MND can have timely access to a wheelchair that meets their needs. However, this only works because we provide additional funding: a national Government and MND Association Partnership should be established to ensure that this solution can be effectively implemented across the country, and statutory services must provide proper levels of funding in order for this to succeed.

- **Fast track for home adaptations:** A national ‘fast track’ procedure needs to be instituted for the Disabled Facilities Grant, and a person diagnosed with MND should automatically be dealt with under this procedure.
Respiratory management: Respiratory insufficiency is one of the most severe and distressing symptoms for many people with MND. There are wide fluctuations in the availability of respiratory support, with perhaps as few as 5% of people with MND having access to non-invasive ventilation which significantly improves quality of life and can extend survival by seven months. In England the MND Association has identified 44 areas where respiratory support for people with MND is of serious concern.

Responding to the challenge with a National Strategy for MND
• Consistent and co-ordinated approach to respiratory management:
A comprehensive multi-faceted, respiratory management service must be established or made available to people with MND, and reflect the person’s journey from diagnosis to death, with specialist support in the community and at the end of life.

Palliative care and end-of-life care: The provision of appropriate palliative care for people with MND enables them to secure as high a quality of life as is possible, for as long as possible. However, people with MND experience unacceptable inequities in access to specialist palliative care across the country. In 2005 only a quarter of palliative care services were providing care to people with MND within six months of diagnosis, and only a third of palliative care services were providing care in the ‘terminal’ phase of the disease. Only 39% of people with MND had been referred to specialist palliative care services.

Responding to the challenge with a National Strategy for MND
• High quality palliative care: People with MND must be offered the opportunity to access specialist palliative care services as soon as possible after diagnosis. Effective palliative care provision needs to be responsive and adapted as the condition progresses and the needs of the person with MND change.
  Palliative care for people with MND must be co-ordinated by professionals with a good knowledge of MND, and delivered by professionals with a range of specialist skills.
  Hospices must be supported to offer places to people with MND and other neurological conditions.

• Integrated approach to end of life issues: Care professionals support people with MND, their families and their carers to understand the options available at end of life and help them assess which might be right for them. This should happen before the person with MND loses the ability to communicate effectively. Systems such as Advance Care Planning must be put in place to ensure that these decisions are known to all professionals involved in caring for a person with MND, even in an emergency scenario such as admission to hospital by ambulance.

case study:
Mark Carr, 46, Wakefield
Mark had to wait nearly a year before getting his wheelchair. During that time he was confined to the top floor of his house and was virtually a prisoner in his own home. Mark had to wait over two months for wheelchair services to do an assessment. It took a further three months for them to come out with a chair. However Mark’s needs had progressed since the initial assessment so the chair was not suitable. He says that if you are not a standard size and need alterations it starts causing problems. Mark’s upper body was getting progressively weaker so he needed something that would help his posture and support his head. Mark also needed his chair to hold the ventilator that he uses 24 hours a day.
During this time Mark could no longer use the stairs so he had to remain on the top floor of his house. He spent six months in total living this way. The chair eventually arrived 10 months later.
Mark said: “That’s the problem with this disease, you’re always needing adaptations.”
Mark is also the first person in his area to be given his own budget by social services. Social services pay him £70,000 a year to pay for his care. He then pays the care agency. He describes it like running a small business. He really likes this approach because it gives him greater control.
Inconsistent support for carers: MND is a rapidly degenerative condition. A person with MND will often begin to require assistance even with trivial tasks from an early stage, and become totally dependent on others before they die. Appropriate and timely respite care is vital for carers as is high quality and consistently available formal care. Both respite and formal care remain unacceptably inconsistent and of varying quality across England.

Responding to the challenge with a National Strategy for MND
- Formal recognition and support for carers: Local arrangements for formal care, respite care and counselling and bereavement services need to cater appropriately for people with MND and their carers. These services must be accessible, appropriate, and available in a timely manner. The carers ‘annual health check’ must be made appropriate for a carer of a person with MND.

Clare Mills

Clare Mills received support from palliative care nurses in 2007 to ensure that her husband Steve died at home, peacefully, as he wished.

‘After Christmas Steve was really struggling. He said, ‘I can’t do this anymore. I want to talk to the nurses about my end of life plan’

‘We called the nurses and explained how Steve was feeling and that he wanted the suffering to end. The nurses arrived and insisted on interviewing Steve alone so that he could feel free to speak his mind.

‘I contacted Dr Allen who reiterated what he said to us when Steve was first placed on NIV: that NIV is not a life-support machine, it is a treatment and that Steve has the right to refuse it. Steve also had to see a psychologist who assessed Steve’s mental capacity twice. Our local PCT had to meet with their solicitors to check that the whole process was within the law.

‘By this time Steve was unable to take anything but small amounts of water, given with the greatest of difficulty. He was on a syringe driver to ease the discomfort of being starving and dehydrated.

‘Steve decided that he wanted to die on Saturday morning. The Friday evening was spent waiting to hear from the PCT solicitors concerning their decision to let the palliative care nurses attend on the Saturday morning. Eventually they called at 7.30pm to say that the nurses were able to attend.

‘On Saturday all the family arrived. I felt very uncertain, I had no idea how long it would take or what would happen.

‘Everything had to be very exact. For example we weren’t allowed to inject Steve with drugs before the mask was removed. I knew I could remove the mask to re-arrange Steve and that Steve had the right to ask for the mask to be left off.

‘Removing the mask was very difficult. When I did Steve became very distressed. He was not ready. He needed more sedation to alleviate the suffering caused by the withdrawal of the NIV.

‘I put the mask back on him. The palliative nurses gave Steve an injection which was just enough to send him into a more relaxed state and ease his evident agitation. People came into the room, held Steve’s hand and cuddled him.

‘I took the mask off Steve and held him. He didn’t gasp or struggle. It only took a couple of minutes, his lips went blue and he went very pale.

‘The nurse took his pulse which was still there but very faint. After 10 minutes he slipped away peacefully in my arms.

‘I know there was no more I could have done for Steve. I made Steve a promise when he was first diagnosed that he would die at home peacefully and I’m pleased I was able to fulfil that promise.’
Systemic issues

Putting the needs of people with MND at the heart of the health and social care system.

Lack of designated key workers, specialist nurses and multi-disciplinary teams (MDT): The complexity of the symptoms presented by MND means a large number of health and social care professionals may be involved in the care of someone with MND. It is common to have up to 18 professionals involved in caring for a person with MND at any time, and a total even higher than this over the entire course of their illness. 3

Good practice in co-ordinating this care can take a variety of different forms, and different models suit different local situations. The models which work the best for people with MND are typically those which involve a designated key worker, often themselves a Clinical Nurse Specialist, MND Care Centre Co-ordinator, or other specialist clinician, co-ordinating care across different services. This key worker often achieves the best results by bringing together and co-ordinating a multi-disciplinary team to care for a person with MND.

The key worker's role is to anticipate and co-ordinate services for the person with MND, ideally through the establishment of a community-based multi-disciplinary team, and ensure they and their carer are provided with specialist information.

This co-ordination of care and treatment is vital: if care is poorly co-ordinated, untimely and without specialist knowledge of MND, this can result in treatment being missed and the person's condition becoming more acute more rapidly, leading to greater expense and suffering, as more intensive treatment and care is then needed.

Co-ordination limits duplication of services, makes the best use of existing resources and ensures that services are delivered as effectively and efficiently as possible.

Responding to the challenge with a National Strategy for MND

Designated key workers and MDTs:

- To ensure that people with MND receive the highest quality of life possible and die with dignity, a single point of contact, i.e., a key worker, is needed. A key worker should always be a clinician with specialist knowledge of MND. It may be that different key workers, with different professional specialisms, are required at different stages of the progression of the disease.
- MDTs, ideally located within communities, need to be embedded into practice and become a routine part of care delivery for people with MND.

The Sinclairs, Great Yarmouth and Waveney

Following Mr Sinclair’s diagnosis with MND, his wife contacted the MND Association because of the lack of a co-ordinated service for people with MND in East Anglia.

Mrs Sinclair described the hardships she faced when her husband was diagnosed and continues to face because there is no one to co-ordinate care for people with MND in her area. Mrs Sinclair has struggled as none of the professionals (GP, social worker) have any knowledge of MND; there has been no one point of contact for co-ordination; Mr Sinclair waited five months for a wheelchair and had repeated problems before he eventually obtained NHS continuing healthcare; Mrs Sinclair has had to pursue palliative care herself without any support or clinical advice. This situation has been ongoing with little improvement since Mr Sinclair’s diagnosis in April 2007. Although new specialist nurses for the area have been promised, many aspects of Mr Sinclair’s care continue to be unmanaged.

Personalisation: Personalisation could offer greater choice and control for individuals by enabling them to choose the services they receive, when and where they receive them. However, arranging your own care can be time-consuming and complex and it is important that people can ‘opt out’ of direct payments for social care, personal health budgets and other personalised arrangements, and access their care in the traditional way if they so choose. There must be equity between delivery models.

Responding to the challenge with a National Strategy for MND

Making personalisation work for people with MND

- The MND Association wants to ensure that the introduction of personal health budgets does not disadvantage people with rapidly progressing and unpredictable conditions like MND where a flexible and rapid response is necessary to meet the needs of patients.
- It is important that budgets are flexible and can react to a sudden change in circumstances. Personalisation should endeavour to meet needs and achieve value for money, it should not be used as a mechanism through which to make cost savings.
- Currently, some people with MND arrange their own social care using direct payments, but lose the ability to do this when they move into NHS continuing care, where personalised options are not currently available. If personalisation is to be fully implemented across health and social care, transitions between the two must be seamless.

1 The MND Association’s MDT Best Practice Guide suggests that there should be 11 key team members with an additional 14 members co-opted on from time to time to deal with specific issues e.g., housing.
Difficulty accessing NHS continuing healthcare: NHS continuing healthcare is the system that provides funding for patients who need round-the-clock medical care. Timely access to NHS continuing healthcare is vital for a person with MND to maintain as high a quality of life as is possible once the disease is at an advanced stage.

There is a lack of expertise regarding MND on the multidisciplinary panels that assess NHS continuing healthcare needs, and the process lacks transparency and accountability. Often the panels do not appreciate that MND is a rapidly degenerative condition. While appeal procedures exist, they are slow and lengthy: given the rapidly degenerative nature of MND, this is not acceptable.

Instances of particular concern pertaining to MND include: multidisciplinary panels disbelieving or disregarding the evidence presented to them; serious cases being branded ‘stable’ and denied NHS continuing healthcare; in extreme cases, patients who had previously received continuing NHS healthcare having it withdrawn, after they are assessed as having improved, and their needs reduced: given the degenerative nature of MND, this is currently a medical impossibility. These problems often stem from the lack of a specialist key worker.

The time and effort expended by NHS continuing healthcare panels in evaluating, rejecting, and listening to appeals may be considered an inefficient use of professional time, which could be saved by appropriate guidance, awareness and education.

Responding to the challenge with a National Strategy for MND

• Assessment for NHS continuing healthcare by someone with knowledge of MND: The system needs to be amended so that a person with MND is given a full assessment for NHS continuing healthcare by somebody with knowledge of the degenerative nature of MND, so that their care needs are properly taken into account.

Barriers in the benefits system: People with MND and their carers are typically entitled to two key benefits: one of either Disability Living Allowance (DLA, for those under 65) or Attendance Allowance (AA, for those over 65); and Carers’ Allowance (CA). All are prone to slow payments and difficulty of access which causes anxiety and places undue stress on people with MND and their carers.

Responding to the challenge with a National Strategy for MND

• A flexible and responsive benefits system: The existing six-month life expectancy threshold for access to the fast-track ‘special rules’ needs to be more flexible. A diagnosis of MND should automatically result in placement within the special rules system.

Commissioning: As evidenced by the wide variations in care provision across the country, local and regional commissioning often does not take into account the needs of people with a neurological condition or the particular needs of people with MND.

Responding to the challenge with a National Strategy for MND

• Needs-led commissioning: Quality standards and mechanisms governing and auditing commissioning must ensure that services procured meet the needs of those with neurological and rapidly degenerative conditions such as MND.

• MND Year of Care Pathway: To support commissioners to meet the needs of people with MND, the MND Association has produced the MND Year of Care Pathway. The pathway is an invaluable commissioning tool which supports anticipatory and efficient commissioning for people with MND by providing in an accessible format, the disease milestones, health and social services required as well as detailing the associated costs of each service per person.

Case study: John Francis

John Francis was granted continuing NHS healthcare funding in October 2007. In December 2008, aged 72, and having been diagnosed with MND for nine years, he had his continuing NHS healthcare removed. The panel’s decision came despite John having had numerous emergency admissions to hospital.

John’s GP had given written evidence to the panel that his needs had increased against all the relevant assessment criteria. The panel instead concluded that his needs had decreased. John’s son and daughter felt in particular that the panel had greatly overstated his father’s ability to communicate.

The panel seemed to reach its conclusions on the basis that John’s condition was relatively stable; this was broadly true, but only as a result of the high standard of care he was receiving. Without it, his condition would undoubtedly have appeared far less stable. It certainly makes no medical sense to suggest that the condition of a person with MND might have improved – it is a degenerative disease, and once a function has been lost it cannot return.

The decision was appealed, and eventually overturned in May 2009 after a lengthy and distressing period of uncertainty for the whole family.
### CHALLENGE 3

**Clinical research:** Clinical research in the UK can be intensely bureaucratic, with significant time and resources spent on administration. The burden falls disproportionately on rarer diseases like MND which require multi-centre participation in clinical research because of their low prevalence.

The UK is currently at the forefront of clinical research into MND, providing clear benefits for patients, however this position is generally perceived to be under threat.

There are clear risks that academic researchers will either move away from MND research to more fruitful areas such as other neurodegenerative diseases or cancer, stop trying to translate their laboratory findings into clinical measures, or move to other territories.

Pharmaceutical companies or biotechs developing the treatments commercially are likely to conduct trials in other parts of the world where it is easier to conduct this research. This would have an impact on the UK economy, where the pharmaceutical and biotech sectors are currently among its strongest.

Addressing the challenges faced by the research community will ultimately support the establishment of an international research programme leading to a World Free of MND.

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<td>• Funding needs to be increased to accelerate advances in finding the causes of MND</td>
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<td>• Increased funding is needed to pursue the translational opportunities arising from advances in basic research.</td>
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<td><strong>Streamlined bureaucracy and increased funding for clinical research:</strong></td>
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<td>• Measures need to be put into place to relieve the bureaucratic burden and ensure that the UK remains at the forefront of research into MND</td>
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<td>• The regulation of multi-centre clinical research needs to be streamlined so that rarer conditions do not bear a disproportionate bureaucratic burden.</td>
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<th>What difference will a National Strategy for MND make?</th>
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<td>• Everyone with MND in this country will have equitable and timely opportunity of access to the range of care and support services, enabling them to achieve the highest quality of life possible and to die with dignity.</td>
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<td>• Increased investment and reduction in bureaucracy will enable the UK to lead the world in MND research so that MND will be beaten. By investing in MND research, Government will also realise significant financial savings both to the public and social care budget, and to wider society.</td>
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<td>• The opportunity to take part in clinical trials is known to be psychologically beneficial to people with MND, irrespective of whether the trial provides them with any improved clinical treatment; this opportunity should be made available to all people with MND who wish to make use of it.</td>
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The MND Association National DNA Bank

The DNA Bank is a project to collect DNA samples from a large number of people with MND, which can then be made available for use in research. There are 20 NHS trusts which act as collection centres for these samples, and pass them to a central storage point. As is standard, the project went to an ethics review six years after it was originally approved, and passed in July 2009; as part of this process, some organisational changes were made to the project, including a new storage location and a clearer process for making the samples available to researchers. Since then, however, it has been unable to take any further samples from the collection centres due to bureaucratic obstacles. Each of the 20 trusts are obliged to issue new approval from their own research and development departments, even though the project has already been approved. There is no standard process for doing this: some trusts give approval readily, while others demand further detail and take a long time to reach their conclusions.

A similar problem applies to the Material Transfer Agreement which must be drawn up to govern the transportation and use of samples: each trust has its own process for approving this agreement, and all 20 are required to do so. At the time of writing, neither process had been completed and the project had lost a third of the year, even though there had been no fundamental changes to its work or methodology.

The ‘BioMOx’ Experience – Dr Martin Turner, Consultant Neurologist, Department of Clinical Neurology, University of Oxford

“The Oxford Study of Biomarkers in Motor Neurone Disease (BioMOx) is a groundbreaking study only possible largely through the joint MRC/MND Association Lady Edith Wolfson Fellowship Scheme established in 2008. It is designed to build a large cohort of patients of all MND sub-types followed carefully throughout their disease course, with six-monthly brain scans, blood and spinal fluid sampling. This is in order to discover ‘biomarkers’ (a ‘disease signature’ unique to MND) that might improve diagnosis and care planning, and lead to more efficient monitoring of future drug trials. Three major issues were identified in the process of setting up this study:

1. Research Ethics Committee (REC) process
“Implicit in the REC pathway seemed to be a lack of recognition of the deep desire to take part in research felt by the majority of MND patients. The application form (up to 50 pages) and approval process appeared adversarial at times, with a misplaced concern that clinicians (who are, after all, involved in day-to-day patient care) must strive above all to avoid any inconvenience to patients, with a hypersensitivity to the study of epidemiological data largely collected as part of routine care. MND patients recognise that they are in a desperate situation, and the MND Association is rightly striving towards the aim of offering all patients the chance to take part in research. Without research using actual patients and their clinical details, our ability to translate new discoveries and treatments from the laboratory into patients will be greatly limited. Recognition of the enormous value of clinical research using patients and their associated epidemiological data, with a switch in emphasis by RECs to active encouragement and celebration of such work, would promote more NHS physicians to engage in research.

2. The value of DeNDRoN
“The Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) has proved invaluable in the identification and recruitment of patients, ensuring regional equity of access to this and other clinical research projects, as well as clinical trials (e.g. LiCALS – a randomised placebo-controlled trial of Lithium carbonate in Amyotrophic Lateral Sclerosis). As a LiCALS trial co-investigator, it has only been through DeNDRoN nursing support that I have been able to continue my BioMOx work without being diverted by the separate needs of MND patients involved in the drug trial. Ensuring a commitment to the long-term funding of DeNDRoN will be vital to continuing success in MND non-therapeutic clinical research as well as drug trials.

3. The need for streamlined processes to share biological samples across international boundaries
“It is virtually impossible at present to transport biological samples (which must be kept frozen) across international boundaries, especially between the UK and USA. Many of the failures to establish and validate robust biomarkers, as well as effective large-scale genetic studies, are being held back by an inability to pool samples in this way. Despite clear labelling, appropriate packaging and documentation in advance, several colleagues have lost valuable samples in the past (donated in good faith by patients) through unreasonable impounding and thawing by customs officials here and abroad. This type of international collaboration has dwindled as a result. A dedicated, secure mechanism to allow sharing of biological samples across international boundaries could make a huge difference to research in MND and other neurodegenerative disorders.”
About the Motor Neurone Disease Association

The Motor Neurone Disease (MND) Association is the only national organisation in England, Wales and Northern Ireland dedicated to the support of people with MND and those who care for them.

Our mission is to fund and promote research to bring about an end to MND. Until then we will do all that we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible, and die with dignity. We will also do all that we can to support the families and carers of people with MND.

Our vision is of a world free of MND.