

Neuromuscular Disease Workshop

NNAG event write up

February 2018



Document control

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The Strategy Unit, hosted by Midlands and Lancashire CSU, has been employed by the Neurological Alliance to provide programme management for the National Neuro Advisory Group. This document has been produced as part of this package of work. Please direct any queries to Lucy Hawkins, Senior Consultant, lucy.hawkins4@nhs.net.

1. Event description

The National Neuro Advisory Group (NNAG) exists to seek alignment between programmes in NHS England, the Department of Health's Arm's Length Bodies and system partners, such as charities relevant to people with neurological conditions, and to guide the strategic development of work to improve outcomes for people living with neurological conditions. One of the aims of NNAG is to bring together all the different professionals that need to work together to achieve improvement in neurology services including clinicians, patients, commissioners and academics.

As part of the NNAG's wider scheme of work a number of condition specific groups have been identified to lead the development of pathways to complement the revised neurosciences specification.

These groups have been identified by conditions that share similar challenges in ensuring access and equity of care, as well as where pathways between services could be improved. The groups are as follows:

- Neuromuscular
- Headache and Migraine
- Epilepsy
- Neurorehabilitation
- Parkinson's, Dementia and Psychiatry

A number of workshops have been established by these groups in order to facilitate the improvement of services nationally through the sharing of good practice and identification of areas where more work is needed. Different models of care will work in different parts of the country but equity in the standard of care is the goal.

This report concerns itself with the first of these workshops that focused on neuromuscular disease and was held on the 23rd of February 2018. It summarises each of the presentations, including the challenges identified and solutions already in place, as well as identifying the key actions to be taken forward from discussions

2. Neuromuscular Disorders

Neuromuscular disorders are diseases that affect the muscles and their direct nervous system control, i.e. the peripheral nervous system (motor and sensory nerves) and the neuromuscular junction.

Approximately 1 in 1,000 people are affected by neuromuscular disorders. They can be caused by autoimmune disorders, genetic/hereditary disorders and exposure to environmental chemicals and poisoning. Symptoms of neuromuscular disorders include weakness and loss of sensation, wasting in the arms and legs, and due to the impact on the sensory nervous system, a lack of feeling or pain sensations.

A wide range of conditions fall under the category of neuromuscular disorders including;

- Motor neurone disease
- Motor / sensory neuropathies
- Myasthenia Gravis
- Muscle dystrophies / myopathies
- Mitochondrial diseases / metabolic diseases

Some neuromuscular disorders will present very acutely e.g. Guillain Barre and Myasthenia. Some are rapidly progressive e.g. Motor Neurone Disease. Others are chronic e.g. the dystrophies and Charcot Marie Tooth disease and others are acute on chronic e.g. immunosuppression and complications of long term chronic conditions.

Despite the differences in presentation many have problems and management issues in common. As neuromuscular disorders are complex, multisystem disorders that lead to physical and intellectual disability, many people need to be involved in the care of these patients, including different types of doctors, nurse specialists, therapists, palliative care, geneticists, care workers and family support.

3. Summary of presentations

Please read the following summaries in conjunction with the corresponding slide pack.

3.1 Neuromuscular conditions and access to levels of care

Professor Mary Reilly

The Association of British Neurologists (ABN) Acute Neurology Survey reviewed the Neurology provision in hospitals across the UK, the criteria for hospitals selected was those with more than 250 beds and had an accident and emergency department dealing with acute unselected take. The results of the survey¹ highlighted that:

- There are approximately 500 WTE Neurologists in the UK
- 1 in 5 UK hospitals have access to a Neurologist on 3 or fewer days per week
- 6 hospitals in the UK have no face to face Neurology access at all

In summary there are too few neurologists to meet the needs of patients nationally. Workforce planning is underway to increase medical student intake in 2018, but it will be 12-14 years before they are specialist consultants. The vote for Brexit may also have an impact on recruitment of EU doctors. This could mean that there will be no net change in the neurology workforce in current to medium-term future.

3.2 Unplanned admission audits and one-stop shop model of care

Dr Ros Quinlivan

Patients with neuromuscular disorders often have difficulties in accessing services because of severe health needs. This leads to poor attendance in clinics and patients who are socially isolated.

Added to this, there is no clear point of access for emergency advice and often poor access to acute care in DGH's as a result of inexperienced staff and insufficient staffing levels, leading to poor communication between specialists and fragmented care for patients. As a result, there is a general dissatisfaction from this patient group with access to hospital services.

Two audits have been conducted on unplanned admissions where a neuromuscular diagnosis has been coded, in order to determine the proportion of preventable admissions as well as the proportion of neuromuscular patients known to a specialist. The first audit was carried out in 2012 and a re-audit was undertaken in 2017 using the same methodology.

12 UK trusts were assessed in 2012 and 9 of the 12 participated in the 2017 re-audit.

¹ <https://www.theabn.org/news/abn-acute-neurology-report.html>

Key headlines from 2012 were:

- 64.8% of patients admitted had a pre-existing neuromuscular condition
- 63% of unplanned admissions for patients with a known neuromuscular disorder were considered avoidable
- Only 25% of patients with a known neuromuscular condition were known to a specialist
- 18.5% had delayed discharges

The re-audit illustrated that there were fewer unplanned admissions per trust in 2017 compared to 2012. There was an increase in the number of patients known to a specialist centre and 5 times as many patients were now admitted under neuroscience. Preventable admissions for people known to have a neuromuscular disease halved and readmission rates had halved. However, the proportion of patients with delayed discharges had increased and there had been a reduction in the number of patients with emergency care plans.

In response to the access and avoidable admissions issues identified in 2012, a London and South East Neuromuscular Network was developed which has undertaken service and patient mapping, a patient information day, an upskilling event for local professionals and developed an ambulance flagging system in London.

In addition to this the University College London Hospitals (UCLH) Neuromuscular Complex Care Centre (NMCCC) a small elective ward which aims to provide holistic, streamlined, high quality, cost effective care opened in 2014. Its environment is physically adapted for patients with neuromuscular disabilities. The model puts the patient at the centre with specialists coming to the patient, especially benefitting patients who fatigue easily and have trouble travelling.

The ward working has improved communication between specialists, facilitating coordination of care and improved access to therapists and specialists for patients. Admissions have increased gradually since opening and in 2017 a second business case was approved to introduce 24/7 working.

The ward provides a central point of access for advice and support from the NMCCC team for patients in the community, and staff will provide advice on management to local teams and hospitals. A prospective audit of patient reported outcomes reported a 42% reduction in unplanned admissions for patients who had been assessed on NMCCC more than once.

Discussions after the presentation highlighted that for the NMCCC model to be adapted and scaled a service mapping to identify current and potential centres is required; this could tie in with the current mapping of need for Thrombectomy services in specialist centres.

As it is assumed that financial sustainability of the model results from a reduction in transport costs and unplanned admissions, a business case proving quality and cost savings is also required. MDUK have offered to support the scale and spread of this model.

3.3 Commissioning for NIV and Cough Assist

Dr Ronan Astin (presented by Ros Quinlivan)

Non-invasive ventilation (NIV) service provision in neuromuscular disease is increasing, most markedly in Motor Neurone Disease (MND) and Duchenne Muscular Dystrophy (DMD) for which there is the largest evidence base for benefit. However, NIV provision in this group is complex.

In conjunction with this, the demand for home NIV is also increasing. The 2005 Eurovent study demonstrated that just over 50% of home ventilated patients in the UK have a neuromuscular condition. However, later review suggests that this was underestimated.

With a poor understanding of the number of home devices in use or the numbers of patients being treated it is impossible to guarantee that provision of home NIV is equitable in terms of access and of the same standard.

In order to try and address these issues a complex home ventilation registry is being set up in order to identify how many patients are on home ventilation, where they are receiving treatment and what their needs are. From April all units providing home NIV to complex patients will be invited to join an online registry. It is expected that this will improve data and outcome capture for patients on NIV and provide an opportunity to map service provision and service gaps.

Discussions suggested that in the future a specialised service commission of home ventilation could further ensure equity of access and standards of care for relevant patients with neuromuscular disease.

3.4 Parity of access across England, service specification and networks

Dr Andria Merrison

In the South West a backdrop of poor performance and high mortality rates led to the development of a network providing specialist multidisciplinary care for people living with neuromuscular conditions in order to try and address these issues. The network enables the provision of specialist care closer to home with little resource. It enables flexibility and the crossing of health and social care boundaries, and aligns with the model of placed based care encouraged in the Five Year Forward View.

The outcomes of the network have been increased survival rates, lower hospital admission rates and increased patient and professional satisfaction.

The key ingredients of a successful network were identified as:

- The right partners – a patient led and designed service

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- A clear set of objectives that are agreed between partners
 - The right funding blocks
 - A system of governance
 - An agreed approach to conflicts
 - A sustainable financial plan moving forward
 - Being clear about what you can and can't do
 - Clear communication to facilitate network and collaborative working
 - A flat hierarchy to engage a range of different people in different circumstances across the network

The disadvantage of networks is that they are fragile. They are dependent on shared views between teams. Changes in personnel or opinions can shut down elements of a service and money is always a tricky topic. Therefore, sustaining a network is a challenge.

Networks may not be the solution everywhere, but do provide an opportunity to address inequalities in access and provision across a region.

3.5 The role of the Clinical Nurse Specialist (CNS)

Lisa Joyce

Clinical Nurse Specialists are considered invaluable in supporting the care of patients with neuromuscular conditions, particularly myasthenia gravis. A Clinical Nurse Specialist post was introduced in Southampton in 2010 funded by MyAware, (who have also funded several similar posts across the country). Since 2010 the team has grown and now has a caseload of 350 patients across the region.

The role of the CNS is to provide a service that is patient centred, recognising their different needs and providing them with advice and support in managing their condition. They promote self-management and provide an early response when patients or their carers identify signs of deterioration. The CNS also acts as a care coordinator to maintain continuity of care, offering outpatient appointments and telephone follow up.

Outcomes following the introduction of these posts have been: positive patient satisfaction survey results; a reduction in the number of Consultant Neurologist follow up appointments; a reduction in the number of GP appointments; as well as a reduction in A&E attendances and unplanned hospital admissions.

Case studies demonstrate savings can be achieved by: moving treatments out of hospital where possible; early intervention which result in ITU admissions avoided; telephone consultations which reduce GP / Consultant appointments.

In the discussion it was recommended that the demonstrable benefits support the need to increase the numbers of CNSs nationally. This would require the RCN to recognise the value of these roles and work with trusts to facilitate the training and development of staff to undertake them.

3.6 Nutrition and Feeding support

Dr Nik Sharma

Motor Neurone Disease is a rapidly progressive disease that affects the arms, legs, bulbar region and diaphragm. Nearly all patients will benefit from nutritional support. However, there is a narrow window of opportunity to insert feeding tubes due to respiratory decline.

A diagnosis of MND will have a significant impact for patients and they will have a number of big life decisions to be making. Therefore, feeding tubes and non-invasive ventilation are low on the priority list and it is important for clinicians to be aware of this.

NICE guidelines state that feeding tubes should be discussed at regular intervals. The challenge with MND patients is that it is difficult to define regular intervals as the disease progresses so rapidly.

Discussions around feeding support start early in the patient pathway and the UCLH model presented demonstrated a high number of contact points in the early diagnosis stages. However, it is also important to give patients time to consider the information provided and make a decision regarding feeding support.

The accessibility of information on the internet via smart phones can also have a large impact on patient perception and the decision-making process for nutritional support. There is a need to ensure that the information available on the internet is correct; there is increased clinician understanding of patient perception; and patients are given time to make their decision.

3.7 CRG and Specialised Commissioning Update

Jacquie Kemp

The Neuroscience CRG includes Neuropsychiatry, Neurosurgery, Neurophysiology, Neuroradiology, and Neurology, working across groups to recommend priorities and service improvements for specialised services to NHS England.

The CRG is currently writing a service specification for neuroscience specialised services, as part of this they can produce recommendations and demonstrate value to CCGs but it is important to note that specialised commissioning cannot mandate the services CCGs deliver.

Current CRG projects include:

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- The National roll out of Thrombectomy for stroke
 - A Policy proposition to commission Rituximab
 - Development of a Neuro-immunology sub group (joint with the Immunology CRG)
 - Writing service specifications for Neuroradiology, Neurosurgery and Neurology

The discussion noted the difficulties in identifying the proportion of neurology activity within specialised services versus non-specialised due to coding issues. It was suggested that the way forward for Neurology would be for joint commissioning via a STP route rather than just commissioning via specialised services. This would have an added benefit of providing a long term and holistic focus.

In addition to the above work NHS England are also undertaking a national review of registries including writing a service specification and standards for the information they hold, this will help to further realise the benefits of registries as a tool for analysing services in Neurology and other specialties.

3.8 Access to intravenous immunoglobulin (IVIg)

Dr Yusuf Rajabally

Despite Department of Health Guidelines and a national immunoglobulin database there remain several issues in relation to access to IVIg treatment. These can be summarised as:

- Differences in access
- Discrepancies in approval
- Varying functioning of approval panels
- Variable post usage queries
- Differences in long term monitoring

There are a number of case studies highlighting the causes of these challenges. These fall broadly into the following categories: diagnostic challenges, which can lead to the prescription and dispensing of IVIg without robust diagnosis. Bureaucratic challenges, which can lead to funding for treatment being stopped or not granted in the first place despite patient need, and monitoring challenges where there is a lack of consistent review, lack of medical monitoring of early response to the treatment and outcome measure reporting, resulting in frequent inappropriate continuation of treatment.

Nationally there are highly variable levels of policing of indications for IVIg and diagnosis checking prior to prescribing, this is due to a lack of expertise of prescribers and panel members. Possible solutions could be;

- An enhanced role of neuromuscular units
- Diagnostic and therapeutic efficacy validation in NM centres for all patients

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- Enhanced clinical monitoring through increased education and awareness within trusts
 - Requesting evidence of outcomes in order to continue treatment at doses used (outcomes should be compared against pre-established functional scales and minimal cut offs for response).

It is expected that the formation of a new Neuro-Immunotherapy group as a sub group of the CRGs will help to address these issues by looking at the process around access to IVIg.

3.9 Access to Rituximab

Dr David Hilton-Jones

Myasthenia Gravis is an acquired auto-immune disease with a prevalence of 1:10,000. Myasthenia is treatable in nearly all patients but with some problems. 20% of patients present with ocular muscle weakness and 80% with generalised muscle weakness.

The standard treatment for myasthenia is to give pyridostigmine which strengthens muscles, and steroids in combination with immunosuppressant drugs to minimise the side effects. Over 90% of patients have a positive response to these treatments.

The remaining 10% who do not respond well may have the following treatments:

- Rituximab
- Cyclophosphamide
- Stem cell transplants
- Chronic IVIg or plasma exchange

Rituximab is easy to give it is safe and well tolerated by patients and relatively cheap, £5k per treatment. However, it is not licenced or funded for use with myasthenia as the formal evidence base is lacking.

Currently in order to prescribe Rituximab an Individual Funding Request (IFR) is needed for each patient, however due to increasing numbers of IFR requests being submitted IFR panels are saying that this no longer qualifies as an IFR. Therefore, there is currently work underway with NHSE to approve funding Rituximab in specialist centres for patients with Myasthenia Gravis who have failed to respond to conventional treatment. A paper has been submitted to NHSE and a working group proposed. This was supported at clinical panel as the evidence was compelling and NHSE are drafting an urgent policy statement.

It was also recommended that the evidence base for rituximab use in Myasthenia Gravis be improved through a prospective study with detailed collation of cases and agreed outcome measures to prove efficacy.

3.10 Emerging drugs for DMD and SMA

Dr Chiara Marini Bettolo

Duchenne Muscular Dystrophy (DMD) is an X-linked muscular dystrophy which is caused by mutations in the dystrophin gene. Its prevalence is 19.5 cases per 100,000 and the incidence is 1:5000 live male births.

Spinal Muscular Atrophy (SMA) is a rare autosomal recessive motor neuron disease caused by insufficient levels of survival motor neuron (SMN) protein. It causes progressive muscular atrophy and weakness in the limbs but also bulbar and respiratory muscles. It affects approximately 1 in 10,000 births.

Both diseases are rare but severely disabling and life limiting neuromuscular conditions. There has been increasing numbers of clinical trials and novel treatments developed for these conditions in recent years, which is a positive step for people with genetic conditions, but challenges and delays in accessing the treatment remains.

There are short term challenges around these new treatments in terms of caseload and capacity, complexity of delivery, expertise, and cost, equity to accessing treatment and appraisal routes for the treatments.

Longer term challenges are the unknown long-term impacts of the new treatments. An increased life expectancy in this population is being observed which has implications for adult services.

Moving forward consideration needs to be given to the appraisal system in the UK for these new treatments, the capacity implications including staffing, infrastructure and services to support the treatment in both paediatric and adult services, and the cost implications of both the drugs and administration process.

In order to review the processes around emergent drugs for these patients it has been suggested that a virtual group spanning the Paediatric and Neuroscience CRG's could be established.

3.11 Providing the evidence for treatment, Cochrane neuromuscular disease group

Dr Mike Lunn

Cochrane is a collection of databases which began in 1972 by providing a critical summary of randomised control trials. It is now considered to be the start of evidence based medicine. Cochrane reviewers are an international and independent network of more than 28,000 people from over 100 countries. They undertake systematic reviews of evidence around treatments and in doing so provide quality assurance. Systematic reviews are important to ensure quality of practice, minimise bias and provide a useful tool to determine when to stop running clinical trials.

The Cochrane library is free at the point of use to anyone with internet access and there have been over 5000 Cochrane reviews so far. The latest estimate is that at least 10,000 Cochrane reviews are needed to cover all healthcare interventions that have already been investigated in controlled trials. These reviews will need to be updated at a rate of 5,000 per year.

Cochrane Neuromuscular has published 138 reviews, 33 protocols and has over 450 active authors. There are 8 new reviews and 10 substantive updates planned for 2018, fulfilling the role of summarising and publishing evidence for neuromuscular disease.

3.12 Care plans – Additional discussion

Emergency care plans were highlighted as an area of reduced performance in the unplanned admission audits undertaken. However, it was not clear from the presentation whether all patients were asked if they had an emergency care plan or only those who needed one.

A clear definition of whom needs an emergency care plan, what it looks like and what format it takes is needed. MDUK have already developed a template that is in use at the NMCCC, this could be adapted for national use. There was also discussion around raising awareness of neuromuscular conditions in A&E to ensure that emergency care plans are followed once in place.

This falls into a wider discussion around care planning for patients with Neurological conditions. The Neurological Alliance survey highlighted that only 10% of patients had a care plan and 85% had not been offered one.

It was agreed that a piece of work should be done in order to define what constitutes care planning and review how it can be embedded into practice.

4. Actions

There were a number of actions, with general consensus, that were recommended through discussions at the event. Where a specific individual or group has been identified to take these forward, this has been detailed below, the remainder are as yet unassigned.

Table 1: Action summary

Action	By whom
Neuromuscular Complex Care Centres – developing the quality and financial case.	MDUK / local champion
IVIg process review	Neuro-Immunotherapy CRG sub group
Transition from Paediatric to adult services	Joint CRG virtual group
Process around gene therapy and commissioning of emergent drugs (Paediatrics)	Joint CRG virtual group
Patient communication and ensuring that appropriate information is accessible	TBC
Care planning – defining who needs one and what it should look like	MS Society / ABN
Embedding the use of registries and databases in Neurological care	TBC
Paper on the quality and financial benefits of CNS' to take to NMC	TBC

5. Appendices

Appendix 1 –Event agenda



National Neurology Advisory Group (NNAG) Neuromuscular Disease Workshop

23rd February 2017 from 9:50am - 4:30pm

Lecture Theatre, Institute of Neurology, 33 Queen Square, WC1N 3BG

Aim: To identify challenges and solutions to providing equitable and excellent care across England

This event is being funded by Muscular Dystrophy UK

To register for this workshop please email Lucy Hawkins (NHS Midland and Lancashire Commissioning Support Unit) at lucy.hawkins4@nhs.net

Chair (morning session): Professor Adrian Williams, Consultant Neurologist, University Hospitals Birmingham NHS Foundation Trust, and Chair, Clinical Reference Group for Neurosciences

1. 9:50am – 10:00am Welcome - Professor Adrian Williams
2. 10:00am – 10:20am Neuromuscular conditions and access to levels of care - Professor Mary Reilly, Professor of Clinical Neurology, University College London, and President, Association of British Neurologists
3. 10:20am – 10:40am Unplanned admission audits and One-stop shop model of care - Dr Ros Quinlivan, Consultant Neurologist, National Hospital for Neurology and Neurosurgery
4. 10:40am – 11:00am Commissioning for NIV and cough assist - Dr Ronan Astin, Consultant Neurologist, University College London Hospitals NHS Foundation Trust
5. 11:00am – 11:20am CRG and Specialised Commissioning update - Professor Adrian Williams and Jacquie Kemp, National Programme of Care Senior Manager, NHS England

11:20am – 11:40am Tea and Coffee break

6. 11:40am – 12:00pm Parity of access across England and service specification, networks - Dr Andria Merrison, Neuromuscular Neurology Consultant, North Bristol NHS Trust, and Chair, Neuromuscular South West Operational Delivery Network
7. 12:00pm – 12:15pm Q and A

Chair (lunchtime session): Robert Meadowcroft, Chief Executive, Muscular Dystrophy UK

8. 12:15pm – 12:35pm The role of palliative care - Dr Idris Baker, Consultant in Palliative Medicine and Joint Clinical Lead for Oncology, Abertawe Bro Morgannwg University Health Board
9. 12:35pm – 12:55pm The role of the Clinical Nurse Specialist (CNS) - Ruth Ingledew, Chief Executive, Myaware
10. 12:55pm – 1:15pm Nutrition and feeding support - Dr Nik Sharma, Consultant Neurologist, National Hospital for Neurology and Neurosurgery
11. 1:15pm – 1:30pm Q and A

1:30pm – 2:10pm Lunch

Chair (afternoon session): Alex Massey, Policy Manager, MND Association

12. 2:10pm – 2:30pm Access to intravenous immunoglobulin (IVIg) - Dr Yusuf Rajabally, Consultant Neurologist, Neuromuscular Disease and Peripheral Neuropathy, University Hospitals Birmingham
13. 2:30pm – 2:50pm Access to Rituximab - Dr David Hilton-Jones, Consultant Neurologist, Oxford University Hospitals NHS Foundation Trust
14. 2:50pm – 3:10pm Future challenges: Emerging Drugs for DMD and SMA – Dr Chiara Marini Bettolo, Consultant Neurologist Newcastle upon Tyne Hospitals NHS Foundation Trust, and Clinical Care Lead, John Walton Muscular Dystrophy Research Centre
15. 3:10pm – 3:25pm Q and A

3:25pm – 3:45pm Tea and Coffee break

Chair (final session): Ruth Ingledew, Chief Executive, Myaware

16. 3:45pm – 4:05pm Providing the evidence for treatment Cochrane neuromuscular disease group - Dr Mike Lunn, Consultant Neurologist, Clinical Lead in Neuroimmunology and Honorary Senior Lecturer, National Hospital for Neurology and Neurosurgery
17. 4:05pm – 4:20pm Q and A
18. 4:20pm – 4:30pm Closing remarks and Next steps - Professor Adrian Williams

Appendix 2 – Event attendees

Name	Organisation
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Adrian Williams	University Hospital's Birmingham
Ajit Thomas	University Hospital North Midlands
Alex Massey	MND Association
Andria Merrison	North Bristol NHS Trust and Chair of Neuromuscular South West Operational Delivery Network
Caroline Appel	Central and North West London NHS Foundation Trust
Caroline Morrice	Gain Charity
Carolyn Young	NHS England
Chiara Marini Bettolo	John Walton Muscular Dystrophy Research Centre
Claudia Canova	Royal Free London NHS FT
David Hilton-Jones	Oxford University Hospitals NHS Foundation Trust
Diana Ribeiro	Action Duchenne
Emma Hollingsworth	NHS East and North Hertfordshire CCG
Emma Matthews	UCL
Fredi Cavander-Attwood	MS Society
Gita Ramdharry	St George's University of London
Helen Chase	University Hospital's Birmingham
Jacque Kemp	NHS England
Jane Freebody	Oxford University Hospitals NHS Foundation Trust
Jen Barron	Central and North West London NHS Foundation Trust
Jo Reffin	Kings College Hospital
Joe Korner	The Neurological Alliance
John Bourke	Newcastle-Upon-Tyne Hospitals NHSFT
Katharine Young	NHS England
Laura Wrangles	Hertfordshire Neurological Service
Leslie Richards	Barts Healthcare NHS Trust
Lisa Joyce	University Hospital Southampton
Lucy Hawkins	The Strategy Unit
Mary Reilly	UCL / President, Association of British Neurologists
Mike Lunn	National Hospital for Neurology and Neurosurgery
Neeru Malhotra	Muscular Dystrophy UK
Nick Goldup	MND Association
Nik Sharma	National Hospital for Neurology and Neurosurgery
Rahul Mukherjee	Heart of England NHSFT
Richard W Orrell	Institute of Neurology
Robert Hadden	Kings College Hospital
Robert Hadden	Kings College Hospital
Robert Meadowcroft	Muscular Dystrophy UK
Ronan Astin	National Hospital for Neurology and Neurosurgery
Ros Quinlivan	National Hospital for Neurology and Neurosurgery
Ruth Clark	The Transformation Unit
Ruth Ingledeu	MyAware
Tracy Howe	ULH Neuro-Rehabilitation community outreach team
Yusuf Rajabally	University Hospital's Birmingham

Appendix 3 – Presentations

Please see attached presentation documents



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