

All Party Parliamentary Group for Muscular Dystrophy UK
Meeting Minutes
Tuesday 24th May 2022, 13:00 – 14:30
Room C, 1 Parliament Street, Westminster, London & Zoom ('Hybrid meeting')

Attendees:

Mary Glindon MP	Chair of APPG, and MP for North Tyneside
Liz Twist MP	Vice Chair of APPG, and MP for Blaydon
Baroness Celia Thomas of Winchester	Vice Chair of APPG
Professor Ros Quinlivan	Consultant Neurologist and Honorary Senior Lecturer Sheffield Teaching Hospitals NHS Foundation Trust
Dr Niranjanan Nirmalanathan	Consultant Neurologist at St George's University Hospitals NHS Foundation Trust and ICS Lead
Elizabeth Wraige	Consultant, Guys and St Thomas NHS Foundation Trust
Cathy Prescott	Neuromuscular Specialist Nurse, Walton Centre
Rebecca Flesher	Occupational Therapist, Walton Centre
Keith Spratt	NHS North Central London CCG
Dr Stefan Brady	Specialist Neuromuscular Consultant, Oxford University Hospital Trust
Louisa Kent	Oxford University Hospital Trust
Christian De Goede	Paediatric Neurologist, Lancashire Teaching Hospitals NHS Foundation Trust
Professor Tracey Willis	Consultant Paediatric Neurologist, Robert Jones and Agnes Hunt hospital
Emma Manchester	Neurological Physiotherapist, Bradford Teaching Hospitals
Dr Min Ong	Neuromuscular Lead, Sheffield Children's Hospital
Channa	Consultant Neurologist and Honorary Senior Lecturer Sheffield Teaching Hospitals NHS Foundation Trust
George Baker	Patient representative
Sulaiman R. Khan	Patient representative
Ray Christian	Patient representative
Richard Haselgrove	Patient representative
Peter Ashley	Patient representative
Steve Ledbrook	Patient representative
Bryan Gould	Patient representative
Andrew Robertson	Patient representative
Phillipa Farrant	Development Officer, Duchenne Family Support Group
Tanvy Vyas	Patient representative
Lloyd Tingley	WA Communications
Sophie Peet	Policy Analyst, Genetic Alliance UK
Rob Burley	Director of Care, Communications and Support, Muscular Dystrophy UK
Michaela Regan	Head of Policy and Campaigns, Muscular Dystrophy UK
Matthew Rose	Policy Manager, Muscular Dystrophy UK
Imogen Kearns	Editorial Assistant, Muscular Dystrophy UK

1. Welcome and introductions

- Mary Glendon MP, Chair of the APPG, welcomed attendees to the meeting and set out upcoming changes in the NHS with the introduction of [Integrated Care Systems](#).
- She highlighted how [specialised commissioning](#) will move to ICSs instead of happening at a national level, to provide a more local approach - and that these changes to commissioning may provide opportunities for ICSs to tackle existing barriers to neuromuscular care.
- Rob Burley, Director of Care, Communications, and Support at Muscular Dystrophy also welcomed and thanked attendees. He highlighted the nature of muscle-wasting conditions in terms of their complexity - meaning that people with muscle-wasting conditions require access to multi-disciplinary teams of professionals and services.
- He also spoke about the variability across neuromuscular services and that there is not always a clear commissioning route for neuromuscular services.
- NHS service specifications, consistent commissioning pathways for neuromuscular services, and equal access to specialist and multi-disciplinary staff were the three things set out as ways to address this variability – with collaboration with ICSs on these points needed in order to make the most of NHS reform.

2. Neuromuscular networks supporting ICSs

- Professor Ros Quinlivan introduced [Neuromuscular Networks](#) and talked through what they are for - explaining that they are groups of professionals and patient representatives from across the whole spectrum of neuromuscular disease that come together to discuss local services, developments, and issues.
- Professor Quinlivan highlighted that people coming together from across different geographical and service boundaries means networks can strive towards representing and advocating for everyone in that region.
- She talked through some of the work of the networks – such as deciding on priorities that will benefit patients, identifying gaps in service provision, liaising with local services, and working on relevant service specifications. She also said how they are a place for networking and education to take place, with events for patients and carers.
- With regards to ICSs, Professor Quinlivan recommended that there is opportunity to similarly provide stakeholder events to discuss patient pathways.

3. ICSs improving neuromuscular care

- Dr Nirmalanathan spoke next, particularly around the way that ICSs could improve neuromuscular care. He talked about what systemic change will entail, explaining how ICSs are intended to bring more collaboration between all parties in the health and care system - given that there is a legal duty around collaboration.
- Specifically on neurology, Dr Nirmalanathan said that he expects these services will be delegated to ICSs to oversee, except from a very small number of services, and that although national services and centres will remain, most services will be delegated to be managed at a regional level.
- Speaking on how that arrangement fits with neuromuscular conditions, Dr Nirmalanathan highlighted the need for a multi professional and disciplinary team for neuromuscular patients, and the opportunity of integrated care being delivered in a person centred way with a population focused approach to funding.
- Finally, he mentioned some of his experience with The South West London Health and Care Partnership Integrated Care System (ICS), and the neuro-specific initiatives set up there such

as funded neuroscience networks; funded patient engagement groups; and the development and funding of neuromuscular specific roles to meet population needs.

4. Discussion and questions

Navigating structures and seeing a practical pathway of how things will work

- There were several questions from attendees around bringing theory about NHS reform to life, with requests for tangible and workable maps. From a patient point of view, this would be helpful so that someone can understand the structure caring for them, and from a professional's perspective, so that they know how anything existing may change.
- Dr Nirmalanathan agreed this would be useful and Professor Quinlivan said that on a day-to-day basis, there won't be much initial change (clinics will carry on as normal but the question will be how the new system can provide additional support).
- It was suggested that MDUK could organise an event on how ICSs work. Professor Quinlivan noted that through the neuromuscular network in London there are already attempts underway to bring clinicians, patients, and ICSs together for this aim. It was advised that other regions could do something similar.

Engagement with patients, people who use services and their circles of support

- There was some anxiety and worry expressed around the possibility of reform meaning people who are already engaged in shaping services will be cut off when change happens. For example, where some people feel involved in service-design through a CCG, that will no longer exist.
- Dr Nirmalanathan explained that there is a requirement for ICSs to have patient engagement and they have a duty to carry out engagement like that being described.
- There was agreement that there is a role for the existing neuromuscular networks to play.
- There was a question about accountability and regulation for ICSs in this area to which it was answered that the Care Quality Commission will be regulating ICSs.

Social care

- Some attendees indicated that the introduction of Integrated Care Systems present an opportunity for the NHS to be joined up with social care services.
- Dr Nirmalanathan highlighted that [Integrated Care Boards](#) don't include social care but there is a [Partnership](#) as well as the ICBs that brings social care in.
- Professor Quinlivan said that the Neuromuscular networks are important in relation to social care because for each region they can advocate for social care involvement.
- Many attendees felt that a good MDT for someone with a neuromuscular condition should include social care representatives. It was also felt that within a local area, good provision for social care will help to reduce health inequalities. It was noted there is some useful information on this in a recent [Public Policy Projects report](#).

Holistic care for patients

- There was a question around accessing holistic care provision via Integrated Care Services, to which Dr Nirmalanathan answered that care advisors are important. Rob Burley from MDUK supported the idea that the role of the care advisor putting people at the centre should be recognised across the whole system.

Service specification

- Dr Nirmalanathan proposed that as ICSs are new, it would be helpful to set up a minimum specification for what they should be providing in their area for people with a neuromuscular condition.
- Professor Quinlivan said that there was work done by MDUK and others to establish a service specification through speciality groups and that it could be shared with ICSs.

Next steps

- There was agreement that MDUK should continue to work with other charities and organisations that fall under the wider umbrella of rare diseases whilst moving forward in engaging with ICSs
- Attendees would appreciate some guidance on the working of ICSs and the contacts for ICS leads in their region.
- It was felt it would be valuable to revisit this topic at future APPG meetings.
- It was proposed that it may be worth contacting the relevant government Minister or the Department of Health and Social Care to outline the importance of ICSs working with the community.
- MDUK will continue to monitor ICS developments across England and identify further opportunities to engage.

5. Actions

No.	Action	Owner	DD
1	Keep ICS reform and engagement on agenda for next APPG meeting.	MDUK	June 2022
2	Service specification to be developed/shared with ICSs through networks	RQ/MDUK	Ongoing
3	Patient representative groups to continue working together to monitor changes to specialised commissioning with the incoming ICSs	MDUK	Ongoing
4	Send attendees guide on how ICS work and list of different regional contacts	MDUK	June 2022
5	Neuromuscular networks to consider holding events with relevant ICSs	MDUK	Ongoing