 **MND Steering Group Minutes**

**7th Feb 2024 10:00 – 12:00**

**MS Teams**

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| **Present** |
| Cillian OBriain (GMNISDN) | Emma Minshull (Stockport CNRS) |
| Tracey Thompson (MND Association) | Bernie Mason (Oldham CNRT) |
| Alicia Hattersley (Bolton PCT) | Liz Holloway (Trafford CSNRT) |
| Cheryl Adamson (Bolton PCT) | Emma Minshull (Stockport CNRS) |
| Vicki Worsley (Trafford CSNRT) | Jennifer Pearce (Bury PCT OT) |
| Sophie Gordon (Central Manchester CSNRT) | Katie Hart (Bolton CNRT) |
| Christina Federico (MND Care Centre) | Andrea McEntee (MND Association) |
| Sarah Rickard (GMNISDN) | Sam Jones (South Manchester CNRT) |
| Selina Makin (Salford CSNRT) | Amanda Fish (GMNISDN) |
| Cathy Armstrong (East Cheshire Community Therapy Team) | Nicola Ashton (North Manchester CNRT) |
| Leanne Harrington (North Manchester CSNRT) | Leanne Harrington (North Manchester CNRT |
| Hetal Sodha (HMR Respiratory Team) | Fatima Sharief (Student at Stockport CNRS) |
| **Apologies** |
| David Derry (NW Ventilation Unit) | Ellie Monteith (Salford CSNRT) |
| Natalie Griffin (HMR Respiratory Team) | Karen Lea (Wigan CSNRT) |
| Melanie Worthington (MND Association) | Samantha Holden-Smith (MND Care Centre) |
| Dr Hisham Hamdalla (MND Care Centre) | Rose Morris (MND Care Centre) |
| Katie Atkinson (MND Care Centre) | Dr John Ealing (MND Care Centre) |
| Jenny Korn (North Manchester CSNRT) | Anna Rutherford (MND Care Centre) |

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| 1. **Introductions and review of previous meeting minutes**
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| The group had representation from the MND Association, GMNISDN, MND Care Centre and GM community teams. New members to the group introduced themselves. Actions from previous meeting were approved. Updates from previous actions:* Patient & Carer recruitment to the group:
	+ AM has brought this to MND Association groups to gain interest – No interest received yet.
	+ Action: Greg (MNDA) to bring to Branch Meeting next week again.
	+ Deb Drinkall (Previous Patient Involvement Coordinator, GMNISDN) also brought to an MND event a few months ago – No interest received yet.
* MND Review Template
	+ Community teams that have an MND Review Template have shared these with CO. These have been shared in the GM MND toolkit on the GMNISDN website: [MND Resources - GMNISDN](https://gmnisdn.org.uk/professionals/mnd-resources/)
* Suctioning meeting
	+ Currently gaining expressions of interest for this meeting. Currently have NW Ventilation Unit, MND Association, South Manchester, Stockport, Trafford, Bury, HMR and North Manchester community teams.
	+ Action: Teams to email CO if wishing to attend this.
* Assessing and supporting cognitive decline
	+ TT has been in contact with Specialist OT at Preston Care Centre who has done some work on this, and they are happy to share with GM.
	+ Action: TT to link CO in with OT to explore opportunities for sharing information.
* Nutrition case studies (MND Association)
	+ MW currently on leave. Action: CO to link in with MW to see if able to get nutrition case studies for sharing with patients to support with difficult discussions relating to nutrition.
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| 1. **MND Project**
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| CO shared updates on the MND care pathway project work since last meeting: See slide 4 (Supporting documentation). Further points raised:* ICB Clinical Effectiveness Group – Great platform to share the MND project work in GM. Positive feedback from the group. Noted the benefits of cost neutral improvements.
* TT & SHS to present this as an exemplar for pathway development work at the Network Conference in March.
* GM MND Toolkit
	+ Already many resources available to professionals through the MND Association website. GM specific resources now available through the network’s website (e.g., GM team’s review templates, GM MND contact directory, approved steering group meeting minutes)
	+ [Motor Neurone Disease Toolkit - GMNISDN](https://gmnisdn.org.uk/professionals/motor-neurone-disease-toolkit/)

CF shared updates on the MND Nutrition project. (See slides 5-8). Further points:* Ongoing development of gastrostomy pathway at Salford.
* Continuing to link in with network and dietetic workforce project work. Some delays in this due to network capacity and sick leave. CO to link in with Farheen (Network Facilitator working on this) when return from leave.
* Training: Dates booked in with East Cheshire, Manchester and Rochdale dietitians. Nutrition also on the MND training day programme.
* Data collected and now currently being analysed. Plan to collect patient stories over coming months to add to this.

TT noted that it would be beneficial to explore opportunities to showcase this work with other MND Care Centres – potential to bring to the MND Care centre and Network day in July. * Action: TT, CO and CF to meet and discuss further.
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| 1. **MND Care Centre & MND Community Teams**
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| CO & CF noted that with development of community teams sometimes patients may be seen by community team before they attend MND MDT clinic. Question raised around how AHP assessment outcomes can be shared between MND Care Centre and community teams to reduce risk of duplication.* CF noted that AHPs document outcomes from MDT clinic sessions on to a letter.
* Community teams noted that receiving AHP letter is inconsistent, and some areas don’t receive this.
* Action: CF to link in with admin team and review processes of sharing this letter with community teams.
* Community teams sharing assessment information with MND Care Centre
	+ NA noted that North Manchester used to send in an MND template with summary of input prior to patient’s clinic day – this has stopped since covid.
	+ CF noted that SLT and Dietitian will reach out to community SLT and Dietitian when they know a patient is due for clinic. May be different for other professions.
	+ Several teams noted that information from assessments is shared with MND Care Centre nurses during MND MDT meeting.

Action: CO & CF to bring discussion points to next MND Care Centre service development meeting to explore internal communication processes and improve information sharing where able. |
| 1. **Speech and Language Therapy Scoping Outcomes**
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| CO shared outcomes from SLT scoping done last year on behalf of Rebecca McErlean (SLT).See slide 10 for details |
| 1. **Training Programme**
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| Cillian shared an update on the MND Training Programme. See slide 11* Registration now open for next training day. Further details and registration can be found here:
* [Motor Neurone Disease Practical Training Event - GMNISDN](https://gmnisdn.org.uk/events/motor-neurone-disease-practical-training-event/)
* Discussed future options for MND training programme:
	+ Potential for training programme to develop into Special Interest Group.
	+ TT noted that the MND Association hold Special Interest Groups open to MND professionals.
	+ Action: CO to link in with MW about this and explore.
	+ Noted benefits of having training day for new starters – maybe less frequently along with SIGs.
	+ Potential to record presentations so that these are accessible afterwards to those that are unable to attend.
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| 1. **Collar Provision in the Community**
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| NA and LH from North Manchester CNRT raised a question around the processes of providing collars to MND patients in the community.* Oldham have reciprocal agreement with orthotics. Team can order collar but will come out of orthotics budget.
* Bolton access orthotics through MND Care Centre MDT clinic.
* Bury, HMR, Central Manchester, East Cheshire refer to orthotics department in local hospital. Orthotics do not do home visits. Will also link in with MND Care Centre for orthotics if needed.
* South Manchester has to refer to GP for referral to orthotics. Also do not do home visits – also link in with MND Care Centre for orthotics if needed.

Update since meeting: MND Association are holding training on posture management and orthotics (MND) in Manchester in November 2024 – [see here for details.](https://mnd.eventsair.com/posture-management-and-effective-use-of-orthotics-for-people-living-with-mnd-19-november-24/ce24cvpw11/Site/Register) |
| 1. **MND Association Grant Application**
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| * MND Care Centre Grant application:
	+ Planning to submit grant for emotional and psychological support scoping to the April panel.
	+ MND Care Centre grants are just for MND Care Centre or MND Networks.
	+ Noted benefits of current project work funded through this grant – the MND Care Centre working collaboratively with the Network and MND Association.
	+ These are not to be confused with the support grants that patients and families can apply for.
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| 1. **Any other business**
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| * TT noted that going forward we will have a separate steering group working alongside this one with smaller membership focusing on contract management.
* LH asked how often other teams are doing their MND reviews.
	+ Oldham – when patient closed, they will have 6 monthly reviews.
	+ CO noted from scoping exercise, most teams will review 6 monthly or review more regularly if needed.
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| 1. **Supporting Documents**
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| **Next meeting: 6th June 2024 10:30 – 12:30, Seminar Room 2, Mayo Building, Salford Royal Hospital** |