

**MND Steering Group**

**Minutes**

**10:00-12:00 20th November 2024**

**Mayo Building, Salford Royal Hospital and Via MS Teams**

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| **Present** | |
| Cillian OBriain (GMNISDN) | Nicola Ashton (North Manchester CSNRT) |
| Sarah Rickard (GMNISDN) | Nicola Boyle (North Manchester CSNRT) |
| Christine Hyde (GMNISDN & Stockport CNRS) | Ali Cherriman (North Manchester CSNRT) |
| Christina Federico (MND Care Centre) | Karen Lea (Wigan CSNRT) |
| Sam Holden-Smith (MND Care Centre) | Leanne Lowdon (Wigan CSNRT) |
| Haley Williams (MND Care Centre) | Sarah Elizabeth Morris (Central Manchester CSNRT) |
| Dr John Ealing (MND Care Centre) | Sophie Gordon (Central Manchester CSNRT) |
| Dr Hisham Hamdalla (MND Care Centre) | Juliet Smith (HMR Respiratory Team) |
| Anna Rutherford (MND Care Centre) | Lynn Swift (HMR Respiratory Team) |
| Selina Makin (Salford Neuropsychology) | Vicki Worsley (Trafford CSNRT) |
| Tracey Thompson (MND Association) | Liz Holloway (Trafford CSNRT) |
| Melanie Worthington (MND Association) | Cheryl Adamson (Bolton Palliative Care Team) |
| Andrea McEntee (MND Association) | Diane Moore (Oldham CNRT) |
| Debbie Freeman (NWVU) | Emma Minshull (Stockport CNRS) |
| **Apologies** | |
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# Welcome, apologies and conflicts of interest

CO welcomed attendees to the meeting and done a round of introductions.

# Matters arising

Minutes from the previous meeting (June 2024) were reviewed and approved.

* Discussed PPI and explored opportunities on getting patient and carer voices heard as part of the project. Noted that there are various ways of ensuring successful PPI and that it may look different in this project compared to others given the progressive nature of the condition. Agreed that it would be beneficial for teams to reach out to their MND caseload with opportunities to engage with the project.
* Project work ongoing at Preston (Cognitive decline) and West Yorkshire (Pathway Development).   
  Action: TT to share contact details with CO and link in to get information for sharing with the group.
* Community Review Checklist now available on the MND Toolkit [here](https://gmnisdn.org.uk/professionals/mnd-resources/). North Manchester also accesses a community review checklist on EMIS Titled: *CNRT Therapy Motor Neuro Disease Review V2*

# Project Feedback

CO & CF delivered presentations on the MND Care Pathway Project and the Nutrition Project, focusing on progress, key findings, and future plans (refer to attached slides​ below).

Highlights from each project included:

* MND Care Pathway Project:
  + Improved networking opportunities and communication channels.
  + Successful delivery of MND training days with positive feedback from clinicians.
  + Creation of a toolkit for GM resources including a contact directory for GM teams.
* Nutrition Project:
  + Data audits revealed key findings, such as high rates of weight loss in newly diagnosed patients and challenges in gastrostomy pathway efficiency.
  + Training sessions improved confidence among dietitians and broader MDT members.
  + Noted ties in with network nutrition pathway development for stroke and neuro patients in GM. Action: Network to meet and explore opportunities to progress this project.

Patients’ outcomes can vary depending on timeliness of referral to MND Care Centre – noted patients presenting late, delayed primary care referrals due to lack of awareness and long neurology waitlists can impact this. As a result, increased referrals from private healthcare organisations – increasing health inequality.

Action: MND Care Centre to explore opportunities to audit previous referrals into clinic to highlight issue.

# Measuring Impact

The group discussed how we can measure project and pathway development impact.

* MND Training Evaluation Forms completed
* Clinician feedback on project impact would be beneficial.
* Discussed opportunity for MND Care Centre and community team to complete MND Association Transforming Care Audit collaboratively next year to capture full pathway.

Action: Add to the agenda for discussion at next meeting to explore for next year.

# Emotional Support Pathway Development Project

A new two-year project funded by the MND Association has been initiated, focusing on emotional and psychological support for people affected by MND and their families. See presentation slides below for details.

* Discussed Acceptance and Commitment Therapy (ACT). Most teams have staff that are trained in using this. Staff that are trained can cascade training to rest of MDT. Noted another training cohort with a focus on MND would be beneficial.

Action: Network, MND Care Centre and MND Association to explore opportunities to fund this as part of this project.

# Sharing Information

Group discussion on sharing outcomes from assessments between MND Care Centre and MND Community Teams.

* Community teams liaise closely with MND Specialist nurses through MND MDT meetings.
* Community teams receive consultant letters.
* Information from MND MDT clinics including AHP assessment outcomes are sent out to community teams however, some community teams noted that these are not reaching them.

Action: MND Care Centre Team to review contact lists and cross reference with MND Contact Directory on website [here](https://gmnisdn.org.uk/professionals/mnd-resources/) to ensure contact details are up to date.

# Oral Suctioning

HW shared some recent challenges for patients accessing oral suctioning equipment.

CH shared information from a scoping exercise done looking at processes involved in the delivery of this interventions. Three key areas identified:

* Equipment provision and maintenance in particular funding responsibilities
* Training for patient and family
* Staff competency and training

Network has an upcoming meeting with the ICB to share current challenges.

Action: Network to feedback outcome at next meeting.

# Any other business

SHS shared information about an event: Moving on up! The importance of research in the fight against MND. See presentation slides for details.

# Next meeting

May 2025 (Date to be confirmed)

# Presentation slides

 