AUSTRALIAN MND GUIDELINE

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ISSUE 4: DECEMBER 2025

Australian Motor Neurone Disease (MND) Guideline Newsletter

A message from the Director

Welcome to the December newsletter of the Australian MND Guideline - the final newsletter for 2025. This update shares our progress towards Australia's first evidence-based guideline to improve the care and quality of life for people living with MND.

With the December holidays approaching, we firstly wanted to thank everyone for their tremendous contributions throughout the year and your continued collaboration.

This year we have met and engaged with a network of over 200 people all committed to improving the lives of people with MND!

With your support we have been able to reach some fantastic milestones this year including forming and finalising our governance structure, the first iteration of the topics and questions for the Guideline, completing the first version of the Evidence and Gap Map and hosting our kick-off event earlier this year with over 150 participants.

We have kept this update brief, as we know this is a particularly busy time in the lead-up to the holidays. On that note, we wish you all a safe and enjoyable holiday period and look forward to working with you all in the new year.

Professor Zachary Munn
Director, Health Evidence Synthesis,
Recommendations and Impact (HESRI)

We have Guideline questions!

A few weeks ago we emailed you the list of topics and questions the Guideline Panel have approved for the first iteration of the Guideline. These are now also available on the MND Guideline website. In total, there are 52 questions across 12 topics. Feedback from our recent advisory group meetings indicated that the community wanted to know which areas we will be working on as we progress through the questions.

While we initially started on pharmacological interventions to modify disease for our pilot question (which we will finish), we are now additionally focusing on two areas -

Respiratory Support and Diagnosis, Recognition and Referral. We will keep you all updated about the progress as we move through each topic. We will also be posting all the other questions that we will not be covering in the first iteration on the website as well.

What should you expect as an Advisory Group member in the new year?

As we begin scaling up our evidence synthesis work to answer the guideline questions and develop our evidence to decision tables that underpin recommendations, you will start to see an increasing number of survey invitations hit your inboxes. Surveys will usually be conducted for three main reasons: **1) to rate the importance and utility of outcomes for a particular topic/question, 2) to get your feedback on evidence to decision tables for each question and 3) to get your feedback on draft recommendations.** Each survey will be open for at least 10 days and after it closes we then collate the data (by Advisory Group) and present it to the Panel for their consideration.

Please note that we don't expect you to participate in every survey as this would be an enormous amount of work (but you can if you want). Please feel free to participate where you feel most comfortable. We will discuss the process at our Advisory Group meetings moving forward and unpack any questions and comments you have. A reminder that for our Lived Experience Advisory Group Members, further support is available. Danielle (danielle.pollock@adelaide.edu.au) has sent through some additional resources and she will be hosting further pop-in sessions if needed. We have also sent out a separate survey for those interested in contributing to the evidence synthesis work to gauge interest.

Community News

A big congratulations to the Chair of our LEAG, Peter Chambers for the release of his short film ***I Choose Happiness***, which recently won the 2025 Focus on Ability Short Film Festival Most Votes award! Check out the film on Peter's website.

Training and Resources

In August, Professor Zac Munn and the HESRI team held an educational session on Evidence to Decision (EtD) frameworks. This 2-hour session introduces the purpose and structure of GRADE EtDs, explains how they are developed and how to interpret them. See the recorded session here!
Please find a link here to the Advances in GRADE and the use of decision thresholds (HESRI Special Topics in Evidence Synthesis) presented by Professor Zac Munn.

Publications and presentations

Stern C, Semendric I, Shrestha N, Beasley-Hall J, Hasanoff S, Barker T, Pollock D, Schubert C, Giles L, Vucic S, Merlin T, Munn Z. Guidelines addressing Motor Neurone Disease (MND): a scoping review. Neurodegener Dis Manag. 2025 Nov 3:1-16. doi:10.1080/17582024.2025.2573608.

Stern, C, Pollock, D, Barker, T, Holland, G.M, Hasanoff, S, Shrestha, N, Semendric, I, Bulto, LN, Sharma, S, Fragkoudi, A, Facchin-Young, S.C, Day-Sharman, A.M, Stollery, L, Beasley-Hall, J, Schubert, C, Giles, L, Merlin, T, Vucic, S, Whitehouse, J, Munn, Z. Protocol for the development of the Australian Motor Neurone Disease (MND) Guideline. Clinical and Public Health Guidelines. 2026 Vol 3; issue 1:e70055. doi:10.1002/gin2.70055.

Staying connected

We'll be emailing newsletter updates every 6–8 weeks. Please visit the MND Guideline website often for more information and updates and if you have questions, ideas, or want to get in touch, please email anytime.

Thank you for your support and interest in this critical work.

The HESRI Team
Australian MND Guideline Project

MND Guideline Website

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