AUSTRALIAN MND GUIDELINE

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ISSUE 3: OCTOBER 2025

Australian Motor Neurone Disease (MND) Guideline Newsletter

A message from the Director

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

We are excited to share our progress with developing the questions for the first iteration of the guideline as we transition into the Development Phase, where we will undertake large scale evidence synthesis work to inform our Evidence to Decision frameworks and recommendations. We share our progress on piloting our processes on two guideline questions, forming an International Advisory Network for ALS/MND Care Guidelines, and provide further updates on other guideline projects.

In addition, we share some of the unique stories and insights that drive our community through member spotlights.

As always, we are grateful for your efforts in this work.

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

What's happening with the Guideline questions?

Previously, the Guideline Panel voted on three initial scope areas for the first iteration of the Guideline, including:

Recognition, Referral and Diagnosis

Clinical Assessment and Care Management

Models of Care

The Guideline Panel has been busy reviewing all the data gathered from our community as well as the evidence mapping exercises and have approved a set of draft questions for the first iteration of the Australian MND Guideline. This has been a mammoth task and involved multiple prioritisation activities and a lot of discussion and refinement.

The questions have been sent out to all groups and committees associated with the guideline for an opportunity to provide critical feedback. All feedback will be collated and reviewed by the Panel to consider.

We expect there will be some changes made and once questions are confirmed, we will publish the full list of questions on the website (including those planned for future updates) and get stuck into the evidence synthesis work.

What have we been working on?

The Australian MND Guideline project is transitioning into the Development Phase which means we will be undertaking lots and lots of evidence syntheses and using the results to develop Evidence to Decision frameworks to inform guideline recommendations that the Panel will vote on.

Here's what's been happening:

We have been piloting our evidence synthesis process on two questions the Panel have approved to ensure our approach is both rigorous and efficient. The questions are:

> "Should pharmacological interventions be used as disease modifying therapies for people with MND/ALS?"
> "Should standardized diagnostic criteria (e.g., El Escorial, Awaji, Gold Coast) be used to confirm a diagnosis of MND?"

We will have our first Evidence to Decision framework to share at our next Panel, advisory group, and committee meetings so we can run through the whole process with the community and create our very first recommendation.

Part of the pilot process has included drafting **'Health Outcome Descriptors (HODs)'** for the questions that will focus on medications to modify disease. HODs help us choose and rate which outcomes are important as this will be different across topics. We asked our community to rate the utility and importance of a set of outcomes (a big thankyou to you all) and the Guideline Panel are now looking over the feedback to confirm the outcomes for this topic.

If you'd like to learn more about why we rate the importance of outcomes in guidelines, please see Zac's short YouTube video here.

The first version of our **Evidence and Gap Map (EGM)** which helps us visually map all the evidence on care interventions for people living with MND has been completed. We are currently looking at how we best organise the data (since there is a lot of it) and we will share with you all soon. We hope this might be a useful resource for the wider MND community in their research and future planning and the map will be turned into a living map, meaning it will be regularly updated throughout the project.

It's important we share all the research we undertake with the community to increase the MND evidence base. Our **Scoping Review of Previous MND Guidelines** has just been accepted into the Journal Neurodegenerative Disease Management and is in the final stages of being proofed.
Our **Protocol for the Guideline** has also been accepted into Clinical and Public Health Guidelines. We hope to share similar news as other research is completed and published.

Our Lived Experience Advisory Group have been busy working on developing a set of **Values and Principles** for the guideline. These are important because they provide the ethical and conceptual foundation that guides decision-making, ensures consistency and reflects the priorities and needs of our community. Once drafted they will be sent to our Panel for approval and then shared on our website.

Through our engagement processes to develop the guideline, we identified various international groups/colleagues that are undertaking work related to the guideline effort and thought it might be a good idea to try to connect us all together. We have established an **International Advisory Network for ALS/MND Care Guidelines** to strengthen and align global efforts in MND care through international collaboration. Invitations have been sent out, and we will be holding the first meeting near the end of the year.

MND Guideline Website

Guideline Panel Co-Deputy Chairs

We are pleased to introduce and congratulate our newly appointed Australian MND Guideline Panel Co-Deputy Chairs. Deputy Chairs will

support the Chairs in all responsibilities, and step in to lead Panel meetings when the Chairs are unavailable.

Jacqui Taylor

David Berlowitz

Member spotlight

In each issue of our newsletter, we look forward to highlighting the profiles of members of the MND Guideline community. Thank you to those who have submitted their profile for inclusion. If you would like to do so, we would love to hear from you! Simply email your responses to the questions provided and we will publish your profile in a future issue of the newsletter. In the meantime, please take a moment to enjoy learning more about members, Alicia, Barry, and Hannah below.

Member spotlight: Alicia Edwards

Co-Chair, Clinical and Content Advisory Group

What motivated you to be part of this guideline development process?

Even though I've only been involved in the MND space for about a year and a half, it's been more than enough time to see just how devastating and complex this disease is — not just for the person diagnosed, but for their entire support network. To borrow the powerful shared message from the state MND Associations: until there's a cure, there's care. That idea resonates deeply with me, and it's at the heart of why I wanted to be part of this guideline development.

As a physiotherapist and currently the Director of Care Services at MND Queensland, I feel a strong sense of responsibility to help shape care that is equitable, evidence-informed, and genuinely person-centred. This guideline represents a critical opportunity to raise the standard of care across Australia, and I'm proud to contribute to something that I hope will make a real and lasting difference.

What perspective or experience do you bring to the group?

I bring a blend of clinical insight and strategic leadership, grounded in my experience as a physiotherapist and supported by my background in change management. I am particularly focused on how we can translate guidelines into real-world practice, ensuring we are not just creating documents, but actually driving meaningful improvements in the way care is delivered and experienced.

In my role at MND Queensland, I have visibility across a broad range of service delivery challenges and opportunities. I am passionate about connecting the dots between evidence, systems, and people, and I hope that perspective adds real value to the group's work.

What's one thing you've learned or found interesting so far during the guideline development?

One of the things I've found most meaningful is how much value has been placed on lived experience and practical knowledge. As someone who deeply believes that good care is about more than what's published in a journal, it's been refreshing to see how real-world perspectives are going to be captured and embedded throughout the process.

It's reminded me that evidence takes many forms. Yes, clinical research matters, but so do the insights that come from working alongside people with MND, supporting carers through complex decisions, and navigating the realities of service delivery. Seeing that blend reflected in the development of the guideline has been incredibly powerful and encouraging.

What do you hope this guideline will achieve for people living with MND, their carers, or health professionals?

I hope this guideline becomes a trusted and practical resource that supports more consistent, coordinated, and person-centred care across Australia.

People living with MND deserve access to high-quality support no matter where they live, and health professionals deserve to feel confident and well-equipped in how they provide that care.

I also hope the guideline reinforces the importance of genuine multidisciplinary teamwork. Each profession brings unique and essential expertise, and no one discipline can do it all. When we work together, within our scope and in partnership with each other and with families, that's when we see the best outcomes. I'd love to see this guideline empower collaboration as much as it empowers clinical decision-making.

What's one thing people might be surprised to learn about you?

I've fallen completely in love with Norway — I've been lucky enough to visit twice, and now I'm quietly working on a plan to stay there for longer than just a holiday. In preparation, I've been learning Norwegian in my spare time... which has been equal parts fun and humbling! Apologies in advance if I randomly start dropping in Norwegian words during meetings — it's not intentional, just enthusiastic! Tusen Takk!

Alicia Edwards, Co-Chair, Clinical and Content Advisory Group

Member spotlight: Barry Werth

Co-Deputy Chair, Lived Experience Advisory Group

What motivated you to be part of this guideline development process?

My motivation is to contribute to the improvement in care of Australians with MND.

What perspective or experience do you bring to the group?

I have experience as a past carer of my wife who was diagnosed and passed away in 2013. I am actively involved in the MND community and also serve as co-chair of the Lived Experience Research Advisory Panel of MND Australia. I am a pharmacist and I would like to see pharmacists more involved in care, particularly as participants in multidisciplinary teams. My PhD concerned the epidemiology of constipation and pharmacoepidemiology of its prevention and treatment. In particular, I would like to contribute to care guidelines relating to the management of constipation which is very prevalent in MND.

What's one thing you've learned or found interesting so far during the guideline development?

I have had limited time so far in the guideline development but I can see that there are some highly motivated and intelligent people involved hence there should be a very good outcome.

What do you hope this guideline will achieve for people living with MND, their carers, or health professionals?

I expect that the guideline should improve the diagnosis and care of Australians with MND, to improve their quality of life, assist carers and health professionals in the management of symptoms and increase awareness of MND with health professionals.

What's one thing people might be surprised to learn about you?

There is another Barry Werth in the world who happens to be a successful author of non-fiction books in the USA. I tend to use my Dr title and middle initial so that I am not confused with him.

Barry Werth, Co-Deputy Chair, Lived Experience Advisory Group

Member spotlight: Hannah Timmins

Co-Deputy Chair, Research and Policymaker Advisory Group

What motivated you to be part of this guideline development process?

What motivated me most was the potential to bridge the gap between cutting-edge research and real-world clinical practice, ensuring that the lived experiences of patients and families are reflected in care recommendations. The collaborative and multidisciplinary nature of the group—bringing together researchers, clinicians, policymakers, and community voices—was another key factor in my decision to become involved. Being part of this guideline development process offered a unique opportunity to directly contribute to shaping evidence-based, nationally consistent standards of care.

What perspective or experience do you bring to the group?

I bring a practical and implementation-focused perspective shaped by over a decade of experience in neuroscience research, with a particular focus on MND. In my role as Clinical Research Manager and Principal Research Scientist at NeuRA, I've being involved with multidisciplinary research programs and clinical trials that span scientific discovery through to real-world application.

My work has involved close engagement with clinicians, people with lived experience, and policymakers, which has deepened my understanding of both the complexities of care and the need for clear, actionable guidance. Above all, I'm committed to ensuring that our work reflects both the best available evidence and the lived realities of those affected by MND.

What's one thing you've learned or found interesting so far during the guideline development?

One of the most interesting and valuable aspects of the guideline development process has been witnessing the integration of diverse perspectives—from clinicians, researchers, policymakers, and people with lived experience of MND. The collaborative nature of this work has reinforced how essential it is to balance scientific evidence with the practical realities of care delivery and the personal experiences of those affected.

I've also found it particularly insightful to explore how variation in current clinical practice can be addressed through a unified, evidence-based approach. It's highlighted the importance of clarity, feasibility, and stakeholder engagement in ensuring that the final guidelines will be both implementable and meaningful across different settings.

What do you hope this guideline will achieve for people living with MND, their carers, or health professionals?

I hope this guideline will provide a nationally consistent, evidence-based framework that supports timely, person-centred care for people living with MND. Too often, the experience of care varies significantly depending on geography, clinician familiarity, or access to services. This guideline is an opportunity to reduce that variability and ensure that all individuals—regardless of where they live—receive care that is informed by best practice and guided by their needs and values.

For carers, I hope it will offer clearer pathways for support and recognition of the critical role they play. For health professionals, I hope it will serve as a practical resource that improves confidence in clinical decision-making, encourages multidisciplinary collaboration, and supports earlier, more coordinated intervention.

Ultimately, I hope the guideline contributes to improving quality of life and care outcomes for people living with MND and their families.

What's one thing people might be surprised to learn about you?

I won the 1998 national McDonald's colouring competition—my artistic peak, which is why I now work in science!

Hannah Timmins, Co-Deputy Chair, Research and Policymaker Advisory Group.

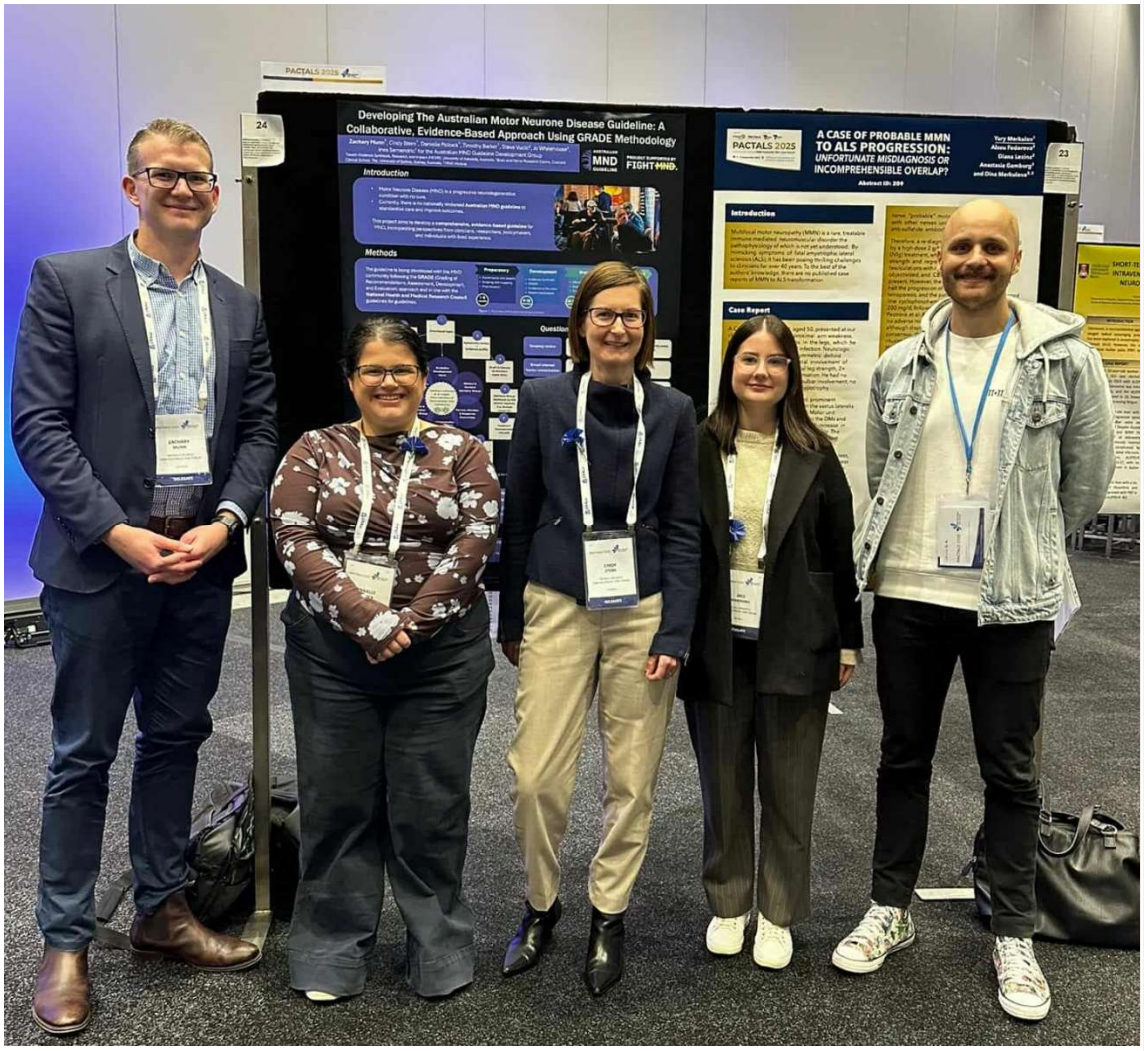
PACTALS Congress 2025

Several members of the HESRI team headed to the Melbourne Convention and Exhibition Centre for the Pan-Asian Consortium for Treatment and Research in ALS (PACTALS) and the 12th MND Australia Care Forum from 7-9 September 2025.

Professor Zac Munn spoke at the MNDA Care Forum on "Developing the Australian Motor Neurone Disease Guideline: A Collaborative, Evidence-

Based Approach using GRADE Methodology". A poster was also presented for PACTALS.

It was great to see many of our members present talks and posters on their areas of expertise. Thank you to those who stayed around for informal drinks on Monday night. We had a fantastic time catching up!



GIN 2025

Several members of the HESRI team headed to the Geneva Exhibition and Trade Centre (PALEXPO) in Switzerland for the Guidelines International Network (GIN) Conference from 16-19 September 2025.

Zac presented on "Applying cutting-edge methods in the develop of the Australian Motor Neurone Disease (MND) Guideline: Innovations, Challenges and Lessons Learned".

Cindy presented on “Representation of culturally and geographically diverse populations in guidelines – do we have a problem?”.

Tim presented on “Methodological approaches to systematic reviews of values and preferences - learnings from the Australian MND Guideline”.

Danielle presented on “Can evidence and gap maps improve guideline efficiency?”.

The team’s presentations received a lot of interest and positive feedback.

Opportunity to help co-design solutions to improve non-invasive ventilation provision in Australia

Do you live in Australia, have MND, care for someone with MND, or are a healthcare professional working with people with MND?

We invite you to get involved in a research project, Motor Neurone Disease Co-Design Project. Dr Marnie Graco and the team at the Institute for Breathing and Sleep at Austin Health are conducting a co-design study to help design solutions to improve breathing support/non-invasive ventilation provision in Australia.

Please contact Dr Marnie Graco and the research team to find out more. Click here to send an email.

Publications and presentations

HESRI Senior Research Fellow, Dr Timothy Barker, has published “The Values and Preferences of People Living With Motor Neurone Disease (MND): A Systematic Review Protocol” in the Clinical and Public Health Guidelines journal. Read more here.

Professor Zac Munn presented “Developing Australia’s First Evidence-Based Guideline for Motor Neurone Disease (MND)” to the Dysphagia and Adult Rehabilitation Interest Group (DARIG).

In the news

MND Australia have become the official custodians of the MiNDAUS Registry – Australia’s Motor Neurone Disease registry. Find out more here.

We are pleased to announce that HESRI Senior Research Fellow Dr Danielle Pollock has been awarded the GIN 2025 Najoua Mlika-Cabanne Innovation Award. This award acknowledges an individual’s contributions to

innovation in the methodology, development, and/or implementation of clinical practice guidelines. Learn more about Danielle's contributions here.

Training Opportunities

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!

Watch this space for further opportunities to learn about GRADE in the context of the MND Guideline later this year. We are currently developing resources for our Lived Experience Advisory Group to learn more about the evidence synthesis and guideline development process.

Community news

MND SA Totally Tubular Quiz Night

On Friday 22 August a team from HESRI attended the MND SA Totally Tubular Quiz Night - 80s Prom Edition. We had a fabulous time and it was great to see some of our Adelaide-based members there, all dressed up!

The Big Ride 2026

In 2025, a fleet of jet skis (including our Lived Experience Advisory Group Member, Anthea Henman!), covered more than 2000 kilometres, from Albury NSW to Goolwa SA, to raise awareness and funds for people diagnosed with MND. They raised $28,000 funding the lease and initial running costs of a new accessibility vehicle for MNDSA. This vehicle is available for clients to use for day trips, holidays, and everyday outings.

The Big Ride returns in 2026 (Friday 10th - Saturday 18th April) with an even bigger goal to keep this vehicle on the road for years to come. Find out more here.

Guideline Panel Update: Thank you, David

We extend our sincere thanks to David Ali, who is stepping down from his position on the Guideline Panel. We're pleased that he will continue to support the guideline in an informal capacity, and we look forward to his ongoing involvement in this important work.

Getting involved

There are many ways to be involved in the MND Guideline Project, including participating in one of our advisory groups, contributing to the systematic reviews that will inform the MND Guideline, or simply sharing your experiences and feedback. For more information, please explore the opportunities at How to get involved or reach out to us by email.

If anyone is interested in being involved in any of the evidence synthesis work, there will be opportunities to do so. We will send out an email/survey shortly.

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

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