

Engagement Checklist:

Partnering with People with Lived Experience of MND

Lived experience of MND encompasses people living with MND, current family carers, former family carers, and asymptomatic carriers of an MND-related gene. These individuals bring valuable insights, varying personal and professional experiences, resilience and creative perspectives to your engagement activity.

This practical checklist is designed to assist professionals when engaging people with lived experience of MND during three phases of engagement: Planning, Delivery and Evaluation.

1. Planning

- ☐ Start early on lived experience engagement—connect with colleagues, teams, or networks, to find and reach out to those with relevant experience.^{1,2}
- ☐ Remember that MND is a progressive, terminal illness, hence it is imperative that professionals approach all aspects of engagement with compassion, empathy and flexibility.
- ☐ Learn about working with people with lived experience of MND, and consider key principles for meaningful engagement^{1,2}, such as: *purposeful, inclusive, respectful, transparent, collaborative*.²
- ☐ Aim to include lived experience in all stages of your activity (where feasible), providing opportunities for people to partner and co-design activities with you^{1,2}, rather than soliciting minor input after work is nearly complete.
- ☐ Don't engage to simply "tick a box." Be genuinely open to learning from people with lived experience.
- ☐ Consider the *level of input* your activity requires^{2,4}, as well as which engagement *methods* you might adopt (note: the method may vary in different stages of your activity).^{3,5,6}
- ☐ Allow a realistic timeline for engagement, acknowledging that people impacted by MND may take longer to process your requests, have varying energy levels, and varying physical abilities.
- ☐ Consider who is best suited for your activity, and how you might meaningfully include diverse voices.² Particularly those who are often underrepresented in decision-making due to systemic barriers related to age, gender, cultural background, communication or cognitive differences, physical disability, socioeconomic status, or limited access to technology.

- ☐ Aim to include representatives with a variety of lived experience. While people living with MND and current carers are often included, don't overlook former carers and asymptomatic gene carriers—they also bring valuable perspectives and insights that can greatly enrich your activity.
- ☐ Incorporate engagement costs into your budget, including staffing, infrastructure, payment for people's time and expertise, and reimbursement of any out-of-pocket expenses (e.g. travel, accommodation).^{7,8} Also, check with your organisation how participation payments or reimbursements might be processed.
- ☐ If you plan to use videoconferencing, consider the most appropriate platform, keeping in mind that participants may have varying levels of digital access and ability. Some may need prior support to join an online meeting, or to use features such as the 'chat' or 'raise hand' function. Note: MND Australia prefers Zoom for online engagements, as MS Teams can be difficult to access if the person doesn't have MS Office.
- ☐ Develop a plan to mitigate personal, environmental, psychological and privacy risks.
- ☐ To assist with recruiting people for your activity, prepare a short and simple explanation, including relevant background information, eligibility, role, time commitment, and whether paid participation will be offered.

2. Delivery

- ☐ Keep people's personal details safe and only share them with staff who need them for the engagement activity. When sending group emails, use BCC to protect everyone's privacy, as some people may not want others to see their email address.
- ☐ Aim for rapid onboarding - reach out to introduce yourself, your role and any other professionals involved in the activity, asap. Provide contact details for people to direct any questions, feedback or complaints.
- ☐ Ask people living with MND if they require adjustments to support participation? For eg. preferred time of day to meet? Strategies to best support communication? Ability to access and participate in online meetings?
- ☐ Give plenty of notice for meetings. Share a clear agenda at least one week in advance, allowing time for preparation. If you would like specific individuals to speak to certain items, clearly indicate this on the agenda, along with what you're asking them to contribute.
- ☐ Ensure the start time for any national meetings is clearly communicated for people living in different states (particularly during daylight savings).
- ☐ Aim to keep meetings to a maximum of 90 minutes. Please be mindful that some people may only be comfortable participating for 30–60 minutes, depending on their energy levels and needs.

- ☐ Keep written communication clear, simple and as short as possible. Avoid jargon, abbreviations and long, overwhelming emails.
- ☐ If asking people with lived experience to review a document, be mindful that some may not be familiar with 'track-changes'. Offer alternative ways to provide feedback such as: reviewing it together online or over the phone, or providing feedback in dot points via email.
- ☐ If group work is involved, offer a one-on-one meeting before and/or after to prepare and debrief, and ensure those with lived experience are warmly introduced at the first session.
- ☐ You may wish to open formal meetings with an acknowledgement of the lived experience community and those participating in your activity.
- ☐ Don't expect people with lived experience to spontaneously talk to issues that have not been listed on an agenda, or on which they have had no prior experience or knowledge.
- ☐ Establish meeting rules for a psychologically safe environment, encouraging open, honest and respectful discussions, amongst people with live experience and professionals.
- ☐ Create a calm, distraction-free environment. Listen with patience and empathy to show you are fully present. This is especially important when supporting individuals who may have difficulty communicating.
- ☐ Allow adequate time for people to share their stories and insights; being sensitive to adverse experiences and trauma histories.
- ☐ Be prepared for differences of opinion, as well as situations where you may not hear what you want, or expect, to hear!
- ☐ Consider how decisions will be made and communicated throughout your activity. Strive to act on suggested recommendations and provide transparency when that is not possible.
- ☐ Recognise potential power imbalances between people with lived experience and other professionals in the group; and be prepared to take action to ensure equal opportunity for all to provide input.
- ☐ Remember that the function and needs of people living with MND may change over time, so you may need to check-in with people about this at regular intervals.
- ☐ If someone becomes unwell, or sadly passes away, plan for compassionate closure. Aim to end a relationship with empathy, respect, and care. If appropriate, liaise with the person's carer to acknowledge the person's input to date and discuss how that might be acknowledged.

3. Evaluation

- ☐ Don't leave all of the evaluation until the end, be sure to check in with people at interim points along the way, using a mix of qualitative and quantitative evaluation methods.
- ☐ A special recognition or acknowledgement at the end of an activity goes a long way! For example, a phone call, a thank-you email, invitation to an event, or acknowledgement of contribution on a report or paper.
- ☐ Ensure any participation payments or reimbursements are processed.
- ☐ Develop a clear plan to directly share any feedback, outcomes, or results, with the people who assisted you (Nb: this feedback loop is very important for people with lived experience).
- ☐ If any photos or evaluation outputs are used for marketing and communication, ensure that the right policies and processes are followed to record consent and protect privacy and confidentiality. This includes any capture of individual experiences or testimonials.

References:

1. [Patient Centred Outcomes Research Institute \(PCORI\): Engagement in Research: Foundational Expectations for Partnerships](#). Cited 28.8.2025
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4. [IAP2 Spectrum of Public Participation](#). Downloaded on 8.7.2025.
5. [Patient Experience Agency: The Fundamentals of Lived Experience. 2023](#). Cited 28.8.2025
6. Wiles LK, Kay D, Luker JA, Worley A, Austin J, Ball A, et al. (2022) Consumer engagement in health care policy, research and services: A systematic review and meta-analysis of methods and effects. PLoS ONE 17(1): e0261808. <https://doi.org/10.1371/journal.pone.0261808>
7. Patient Centred Outcomes Research Institute – [Budgeting for Engagement Activities](#). Downloaded on 7.7.2025: <https://www.pcori.org/resources/budgeting-engagement-activities>
8. [Guide to Paid Participation for People with Lived Experience of MND](#). Cited on 5.11.2025

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