



Checklist to Support Meaningful Engagement with People Impacted by MND

This practical checklist is designed to assist professional organisations or groups looking to engage with people with people impacted by MND, during three key phases of engagement: Planning, Delivery and Evaluation.

1. Planning

- Aim to embed lived experience in all stages of your activity, providing opportunities for people to partner with you, instead of only soliciting minor input after work is nearly complete.
- Don't engage to simply "tick a box." Recognise lived experience as a valuable subject matter expertise and be genuinely open to learning from people with lived experience.
- Allow a realistic timeline for engagement, acknowledging that normal processes may take longer for people impacted by MND.
- Be aware of the fundamental principles of consumer engagement and uphold these during any interactions. These principles include: *purposeful, inclusive, respectful, transparent, collaborative*.¹
- Consider the *level of engagement* your activity requires,⁷ as well as which engagement *methods* you might adopt.^{1,3}
- Ensure adequate funding, staff, infrastructure, and other resources to support engagement activities.
- Consider how you will fund reimbursement of any out-of-pocket costs incurred by a person, as well as their accompanying carer (if required).
- If funds are available, incorporate remuneration for people's time and input into the budget. This may be in the form of a gift card, pre-paid Visa/MasterCard, honorarium, or sitting fee. Any negotiations regarding remuneration should be discussed with each person privately, rather than during a group setting.

Include multiple lived experience representatives and consider how your activity can include voices that are often excluded from decision-making due to barriers such as: CALD background, communication impairment, or high levels of physical disability.

Understand that different people may require different approaches. Aim to be flexible and be prepared to meet each individual's needs, using a range of methods.

Build in contingency for people being unwell, or needing to discontinue engagement.

Develop a risk management plan (consider personal, environmental, psychological & privacy).

2. Delivery

Provide a clear and simple explanation of the activity, including your expectations of lived experience representatives.

Provide contact details for people to direct any questions or concerns related to your activity.

Ask people living with MND about their current function and whether any reasonable adjustments are required, to help support their participation. For eg. how do they best communicate in a meeting? Are they able to type into the chat function during a videoconference? Preferred time of day to meet? Are shorter meeting times required to minimise fatigue?

If using videoconferencing, consider the best platform to use (Nb: many people cannot access MS Teams – consider Zoom instead).

Provide as much notice as possible for scheduled meetings. Send a clear agenda, at least one week in advance, allowing time for people to think about the listed items for discussion.

Allow enough time for people to share their stories and insights; be sensitive to adverse experiences and trauma histories.

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.

Be prepared for differences of opinion. Also, you might not hear what you expect or want to hear!

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.

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.

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.

3. Evaluation

Don't leave all of the evaluation until the very end, be sure to check in with people at interim points along the way, using a mix of qualitative and quantitative evaluation methods.

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 of the evaluation output is used for marketing and communication, ensure that the right policies and processes are followed to request and record consent and protect privacy and confidentiality. This includes any capture of individual experiences or testimonials

A special thank you or acknowledgement at the end of an activity goes a long way! For example, a phone call, a thank-you email, invitation to a special event, or acknowledgement of contribution on a report or paper.



References:

1. [Draft National Consumer Engagement Strategy for Health and Wellbeing \(2023\).](#)
2. The Fundamentals of lived experience. Patient Experience Agency. 2023. [The Fundamentals of Lived Experience in Healthcare \(patientexperienceagency.com.au\)](#) . Cited 23.5.2024
3. 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>
4. Consumer and community engagement: A review of the literature (2012). Published by the Centre for Clinical Governance Research, Australian Institute of Health Innovation, Faculty of Medicine, University of NSW and the Agency for Clinical Innovation, NSW.
5. [National Preventive Health Strategy for 2021-2030](#) Australian Government, Department of Health and Aged Care. Cited 23.5.2024
6. [Patient Centred Outcomes Research Institute \(PCORI\): Engagement in Research: Foundational Expectations for Partnerships.](#)
7. [IAP2 Spectrum of Public Participation](#)