

Guide to Paid Participation for People with Lived Experience of MND

Introduction

Background and purpose

This document provides guidance on recognising, reimbursing, and paying people with lived experience of motor neurone disease (MND), who participate in *engagement activities* (see definitions below). It aims to support consistent, equitable, and respectful practices across the Australian MND community.

People with lived experience of MND bring invaluable insights, knowledge, and expertise; not only about the disease and its impact, but also about navigating health, disability, and aged care systems, gained through their direct, personal experience. The voices of those with lived experience are essential for shaping decisions and actions that are inclusive, responsive, and meaningful for people impacted by MND.

When individuals choose to share their lived experience through a wide variety of engagement activities, best practice supports that they be recognised and fairly paid for their time and expertise; an approach that is endorsed by the Consumers Health Forum of Australia¹ and the NHMRC².

How was this document developed?

MND Australia developed this document in close collaboration with the broader MND community through a two-phase process:

Phase 1 involved drafting by a working group comprising representatives from the [National MND Lived Experience Network](#) (LEN), MND Australia, State MND Associations, and care research.

Phase 2 included wider consultation with key stakeholders and end users. Feedback was sought from the LEN Approval Panel, MND Research Collective, State MND Associations, and MND Australia (staff and Lived Experience Ambassadors).

Definitions

Term	Definition
Carer	A family member or friend, who currently cares for, or previously cared for, a family member living with MND.
Engagement activities	The intentional and respectful involvement of people with lived experience and communities in the planning, design, delivery, and evaluation of MND care, research, or advocacy activities. It is grounded in principles of inclusion, equity, and collaboration, recognising the unique insights and expertise of those directly impacted. Engagement activities generally have a defined purpose and timeframe.
People with lived experience	Encompasses: people living with MND, current and former carers (unpaid/ informal), and asymptomatic carriers of an MND-related gene.

Paid participation	Refers to the practice of providing financial payment to individuals with lived experience, in recognition of their time, expertise and contributions to engagement activities, either via a monetary payment or gift card. (nb: may also be referred to as 'remuneration' or 'compensation')
Recognition	Non-financial acknowledgement of the valuable contribution made by a person with lived experience during their engagement. For example, providing a formal thank you letter.
Reimbursement	Repayment for out-of-pocket expenses a person incurred as part of their participation in an engagement activity. For example, travel or meal costs.

Scope

This guidance document is relevant for professionals or organisations who connect with people with lived experience of MND, for engagement activities. This might include for example: not-for-profit organisations, researchers, health professionals, media/PR agencies or the pharmaceutical industry. It is also highly relevant to people with lived experience, to assist their decision-making for participation.

The guidance in this document aims to support consistent, equitable, and respectful practices while allowing the flexibility needed to reflect the diverse nature of engagement activities and varying budget capacities. The suggestions provided are not prescriptive. You are encouraged to remain flexible and adopt approaches that are appropriate to your organisation and to the context of the engagement.

Organisations may choose to reference this document when developing internal practice guidelines, policies and procedures, to clearly define how their organisation will process reimbursement and paid participation payments.

Guide

Engaging people with lived experience

People with lived experience can share their expertise through engagement activities such as:

- joining working groups, panels, or committees
- participating in interviews or focus groups
- co-designing policies, projects, or programs
- contributing to the development of information resources
- supporting media releases
- being involved in the planning, execution, translation and/or dissemination of research
- acting as a participant in a research study (if eligible)

Recognition

All people with lived experience should be recognised for their contributions to an engagement activity, regardless of whether payment is provided. A special recognition or acknowledgement at the end of an activity goes a long way. For example:

- a phone call or a thank-you email
- sharing results or outcomes of the activity
- invitation to a special event
- acknowledgement of contribution on a document
- co-author listing on a publication (note: please obtain consent prior).

Reimbursement

People with lived experience, should be reimbursed for reasonable out-of-pocket costs, such as travel, fuel, parking, accommodation, meals, or childcare. If interstate travel, or overnight accommodation is required, itineraries should ensure:

- travel is within business hours
- the accommodation is suitable for the person's physical needs (e.g. wheelchair-accessible bathroom, lift access)
- all transportation maximises safe transfers and comfort

Consideration must also be given to any out-of-pocket costs for accompanying carer/s who are required to support that individual's participation in the engagement activity. This might include a family member, friend, or paid carer.

Reimbursement is generally not provided for home office expenses, such as internet costs and printing; parking fines, or other traffic infringements.

Claims for the use of private cars should be calculated using the Australian Taxation Office's 'Motor vehicle expense calculation' policy as a sole trader in [cents per kilometre](#).

Note that delays in reimbursement payments can be a barrier to participation and lead to additional stress, hence where possible, aim to cover costs in advance, or clearly explain reimbursement timelines, prior to a person agreeing to participate.

Paid Participation

What is it?

Paid participation is the practice of providing financial payment to individuals with lived experience for their involvement in engagement activities, which have a defined purpose and timeframe.

Benefits and potential drawbacks

This approach fosters inclusivity and respect by recognising and valuing the person's time, expertise, and the potential emotional, social, or physical burdens associated with their contributions. This is particularly relevant for individuals impacted by MND.

Paid participation also promotes equity (especially when professionals are being paid for similar involvement). It can also help to reduce potential barriers, thereby attracting a more diverse group of contributors and a wider range of perspectives.

While paid participation offers important benefits, it requires careful consideration of its ethical², practical, and financial implications. Key considerations include:

- *Cost implications:* Budget constraints may limit the number or scope of engagement activities an organisation can offer.

- *Risk of bias*: Participants may feel a sense of obligation or loyalty to the organisation that is providing payment, which may inadvertently influence their input.
- *Impact on volunteerism*: As paid participation becomes more common, there may be a decline in people offering time and services to help others or contribute to a cause without receiving payment.
- *Motivation*: While most individuals with lived experience are driven by a sincere desire to contribute and help others, for some, financial incentives may also play a significant role. In certain cases, these incentives might become a key motivator, alongside, or even in place of, personal interest or altruism.

Eligibility

The following individuals are considered **eligible** for participation payments:

- People living with MND
- Family members or friends who currently care for a family member living with MND
- Family members or friends who previously cared for a family member living with MND
- Asymptomatic genetic carriers of an MND-related gene

Participation payments may be deemed **unsuitable** for:

- governance roles (e.g. Board members)
- routine or ongoing organisational tasks
- fundraising volunteers
- open forums, webinars, conferences
- ad-hoc discussions
- individuals who:
 - hold formal representative roles within the health sector (such as Ambassadors)
 - represent another organisation, group or council and are funded as part of their recognised duties to participate in MND-related engagement activities.
 - are a professional consultant, contracted to participate in MND-related engagement activities.

Planning and budgeting

Not all activities will have funding to provide participation payments, so it's important to assess each situation individually, while applying a consistent and fair decision-making process. *People with lived experience appreciate invitations to contribute and value the opportunity to consider each engagement, regardless of whether payment is available.* Therefore, even if funding is not available for a specific activity, extend the invitation—but be transparent upfront about the lack of payment.

When planning an engagement activity, your plan should specify funding sources, payment processes and timing of payment, for people with lived experience. Include all engagement costs in the budget, such as participation payments, reimbursements, staffing, event expenses, and materials.^{3,4}

As part of your recruitment process, clearly explain the activity's purpose, tasks, time commitment, and payment rate, to help people decide if they wish to participate. For further details on planning, delivering and evaluating an engagement activity, see MND Australia's: ['Checklist to support meaningful engagement with people impacted by MND'](#).⁵

On commencement of your engagement activity, ensure you keep a record of participation to support payment, reimbursement and recognition.

Payment Considerations

In Australia, payment options vary widely. Consideration of a fair and reasonable payment rate is an essential step before commencing any engagement activity. According to guidance from the National Health and Medical Research Council (NHMRC), payment rates should be *adequate, proportionate, fair, and not excessive*.⁶

Before determining a suitable payment rate, consider the factors listed in **Table 1**.

Table 1: Considerations when determining a suitable payment rate.⁷

❖	Required level of input and decision-making (for e.g. a lead/ chair role will likely require a higher rate of payment than a consult role – see Table 2 for details)
❖	Responsibilities and time commitment (including travel, preparation, attendance and follow-up)
❖	Available funding
❖	Organisational size, structure and core functions
❖	Nature and sensitivity of the engagement activity
❖	Barriers to participation, such as social, emotional, financial, or physical challenges
❖	Equity with others performing similar roles
❖	Individual skills, expertise, and lived experience
❖	Potential personal benefits, gains or other anticipated forms of recognition

Payment Methods

Table 2 outlines possible payment methods. Before deciding on an approach, consult your finance or payroll team to ensure it fits with your organisation's systems and considers any tax implications for both the individual and the organisation.

Table 2: Payment methods

Method:	Information:
Gift card or pre-paid credit card	These can be a quick and easy option to organise, but they may limit the person's choice in how they use the money. Some people may also have trouble using them, especially if it's a digital gift card. If using a gift card, talk with the person first to make sure it suits their needs. Explain how it will be sent and how they will access it.
Hourly rate*	See Table 3 below for guide to hourly rates.
Honorarium*	A predetermined monetary reward for voluntary involvement, usually paid via a once-off payment. It is intended as a token of appreciation for the person's contributions. The amount may not reflect the full value of a person's time and effort. ⁸
Allowance* (or sitting fee)	A definite, predetermined monetary amount for voluntary involvement, to cover estimated time and effort. ⁹ This may be a once-off or recurring payment.
Employment contract	For formal, long-term roles or significant project involvement, individuals may be added to the organisation's payroll and human resources systems. This process should include consideration of superannuation, insurance, and other relevant employment requirements.

Non-financial

For example: free access to an event, or professional development training.

If you're making a direct deposit payment over \$75 (ex GST) to someone who doesn't have an ABN, an **ATO Statement by a Supplier form (NAT 3346)¹⁰ should be completed, to state why the person is not quoting an ABN. This will avoid withholding 47% tax from the payment.¹⁰*

Guide to Hourly Rates

To support discussions and decision-making, Table 2 outlines the suggested range for hourly rate payments, considering the person's level of input and the involvement in decision-making.¹¹ The suggested rates should serve as a guide only. Rates have been informed by recommendations from the *Consumer Health Forum of Australia*¹ and the *Commonwealth Remuneration Tribunal - for part-time office holders*¹²; together with current practices across numerous organisations within the Australian health sector.¹³⁻¹⁹

Table 3: Guide to hourly rates

Level of input	Possible roles and activities*	Time	Rate (guide-only)
Lead/ Empower: Contributes to final decision-making at a strategic, governance, or management level.	Role: Chair or co-chair of a committee/ panel; participates in strategic planning; manages other people with lived experience; co-primary investigator via: steering committee, advisory panel, primary stakeholder group	Per hour	\$60 - \$126
		Day rate**	\$300 - \$631
Partner / Collaborate: Partner with professionals to co-design all aspects of the decision-making, including development of options and preferred solutions.	Role: Co-design a new project, program, resource, policy, or grant application; associate investigator via: project management team, committee, advisory group	Per hour	\$50 - \$95
		Day rate**	\$250 - \$476
Involve: Work directly with professionals throughout the process, to ensure lived experience concerns and aspirations are consistently considered. They may, or may not, be involved in some aspects of decision-making.	Role: Provide input on development of a new project, program, resource, policy, or grant application. Via: focus group, working group, stakeholder group, workshop	Per hour	\$40 - \$95

Consult: Asked to provide once-off, ad-hoc feedback.	Role: Provide feedback on a proposed project, program, resource, policy, grant application, or research results. Via: Surveys, polls, questionnaires, document review, focus group, blog, featured story-telling.	Per hour	No payment - \$50
Speaker or Educator:	Role: Invited to: contribute to an advocacy or awareness campaign; share personal story, experiences or insights; or educate others re: the lived experience of MND. Via: interview (written or verbal), video recording, blog, or presentation (in-person or online).	Per hour	\$40 - \$95
		Day rate**	\$200 - \$476
Inform: Information is communicated to an individual or the community.	Information received via: newsletters, ad-hoc communications via email, open forum, webinar, or conference.	N/A	No payment

The above rates are correct as at October 2025 and should be reviewed in alignment with subsequent 'Commonwealth Remuneration Tribunal'¹² updates.

* This generally includes activities with a defined purpose and timeframe.

**Calculated on a 5-hour day, consistent with recommendations outlined by the Commonwealth Remuneration Tribunal.¹²

Discussing payment

Conversations about payment can feel sensitive, but they are an important part of working together respectfully and fairly. These discussions should happen one-on-one, in a safe space, to maximise privacy and trust. Professionals should clearly explain if payment will be provided, and if so, the available payment rate and method/s. If possible, try to be flexible and responsive to how each person prefers to be paid. If a person chooses to decline payment, this should be respected, however, avoid asking directly if someone wants to 'opt out', as this may create pressure to decline.

Encouraging people to seek independent financial advice

The payments people receive may affect their tax or government benefits. The effect will be different for each person, depending on their individual circumstances. Individuals are responsible for knowing their legal obligations to report their income to the Australian Taxation Office and other relevant parties such as Centrelink. If the person is unsure, they may choose to seek advice specific to their circumstances from either: the ATO, Services Australia (Centrelink), or their financial advisor. The [ATO's Tax Help program](#) is a free resource for anyone unable to afford help with their tax.

Contributors:

MND Australia acknowledges the following individuals for their contributions to this document:

- *Cate Bourke - Carer and Lived Experience Network member, VIC*
- *Neil Dyson - Living with MND and Lived Experience Network member, VIC*
- *Kim Jansen - Living with MND and Lived Experience Network member, SA*
- *Sue Wyatt – Former carer and Lived Experience Network member, NSW*
- *Rebecca Francis - Speech Pathology Lecturer and MND Care Researcher, Flinders University, SA*
- *Andrew Collins - Support Services Manager, MND NSW*
- *Julie Labra - Program Manager, [Lived Experience Network](#), MND Australia*
- *Isobel Shearman - Advocacy and Policy Manager, MND Australia*

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