

Policy for Engaging with Members of the National MND Lived Experience Network

Approved by Board on		Last Reviewed	N/A
Version	1	Review frequency	Annually
Responsible person	CEO	Scheduled review date	May 2025

1. POLICY STATEMENT

This document provides information and guidance for professional groups who are seeking lived experience input via the 'National MND Lived Experience Network'. MND Australia is referred to as "we, "our" or "us" throughout the document. "You" refers to the requesting group or organisation.

2. SCOPE

This policy is relevant for any group or organisation, who submits a request to connect with members of the National MND Lived Experience Network.

3. DEFINITIONS

Word or acronym	Meaning
Consumer	A person who uses, has used or is a potential user of health services and information. Consumers can participate as individuals, community groups, consumer organisations or consumer representatives. Consumers can play various roles when participating in consumer engagement activities: patient, person with lived experience, carer, co-designer, co-producer, active citizen and representative. ¹
Lived Experience	Lived experience refers the first-hand knowledge and understanding a person gains by living with a specific health condition, or being involved in the healthcare journey, as either a patient or carer . It focuses on experiences, thoughts, emotions, challenges, coping strategies and overall journey as people connect with the health system. ²
Member	A person who is a member of the National MND Lived Experience Network.
MND	Motor Neurone Disease
MNDA	MND Australia
MND community	In this document, 'MND Community' refers to people living with MND, their families, carers, as well as researchers, health professionals, or other organisations with an interest in MND. The MND community may connect through a community of: place (such as a region or state), interest, or specific issue.
National MND LEN	National MND Lived Experience Network
Reasonable adjustments	A type of workplace adjustment that enables people with disability to perform their role and address the impacts, if any, of their disability.

4. POLICY DETAILS

(i) Why engage people with lived experience of MND?

- People impacted by MND have a right to be involved in activities and decisions that are relevant to them:

“People living with MND have the right to provide input on the healthcare and support systems, including policy-making, care delivery and the implementation of medical research procedures and protocols.”

(International Alliance of ALS/ MND – Fundamental Rights for People Living with ALS/ MND).

- There is growing evidence that engaging health consumers leads to improved relevance and positive outcomes for health policy and research, as well as safety and quality improvements for services.^{3,4}
- The Australian Government, Department of Health and Aged Care have listed ‘Partnerships and Community Engagement’ as a critical enabler to shifting the focus of the health system, as part of the National Preventive Health Strategy for 2021-2030. This emphasises the importance of consumers being recognised as equal participants in health partnerships.⁵
- Lived experience provides balance to the views of professionals, contributing to more robust decisions and ensuring that projects or programs better meet the needs and priorities of people impacted by MND.
- It can help to create a sense of purpose and empowerment for those involved.
- Engagement can strengthen and improve relationships between people with lived experience and the broader MND community. When people can see how their experience and suggestions have led to system improvements, they are more likely to become advocates and supporters of those services, as well as being willing to become involved with future engagement work.

(ii) What is the ‘National MND Lived Experience Network’?

The ‘National MND Lived Experience Network’ (i.e. National MND LEN) includes members from across Australia who are either: living with MND, carriers of a positive genetic mutation, currently caring for, or previously cared for, someone living with MND. Members of the network are interested to share their first-hand knowledge and understanding of MND, including personal experiences, thoughts, emotions, challenges, coping strategies and overall journey connecting with the health, disability and aged care sectors.

MND Australia (ie. MNDA) acts to connect members of the National MND LEN with organisations or groups based in Australia, who want to work together with people with lived experience across Australia, on a specific activity.

Please refer to Table 1 below for details regarding the sorts of groups WHO might request lived experience input; WHAT the engagement topics might be about; and lastly, examples of HOW people with lived experience might contribute.

Table 1:

WHO might submit requests?	WHAT might the topic relate to?	HOW might LEN members contribute?
<ul style="list-style-type: none"> - Not-for-profit organisations - Researchers - Health professionals - The pharmaceutical industry - Other groups - (eg. community service providers, consumer groups, or government agencies) 	<ul style="list-style-type: none"> - Care and support - Raising awareness of MND - Developing information materials - Advocacy or policy - Research 	<ul style="list-style-type: none"> - Working group or committee - Complete a survey - Help to develop or update information resources. - Provide feedback on ideas for new projects/ programs, or grant applications - Help design a research project - Act as a participant in a clinical trial or other research study (if eligible) - Support a media release

(iii) What does the National MND LEN hope to achieve?

We hope that the National MND LEN contributes to:

- More lived experience voices being included in activities and decisions that affect people impacted by MND.
- Members feeling empowered to get involved in activities that help the MND community.
- Ensuring projects, programs and research better meets the needs and priorities of people impacted by MND.
- Better care and support services for people impacted by MND.
- Information material that is more relevant, readable and understandable for people impacted by MND.
- Stronger relationships between people with lived experience and professionals working in the MND community, so we can work together to inform and create positive change.

(iv) How to best engage members of the National MND LEN:

There are risks, challenges and ethical considerations when engaging people impacted by MND, because it is a complex, progressive, terminal illness. At any one time, there are around 2100 Australians living with MND. The estimated life expectancy is just 27 months and is associated with a steady loss of function over time, potentially impacting on mobility, swallowing, communication, cognition and breathing. Other issues that people might experience include fatigue, anxiety and depression. Carers can also present with high levels of stress, burnout and grief.

Hence it is imperative for professional groups to approach their engagement with National MND LEN members in a thoughtful and meaningful way, being alert to and actively managing these challenges. For useful tips on how to plan, deliver and evaluate, meaningful engagement with people impacted by MND, please refer to MND Australia's [Checklist to Support Meaningful Engagement with People Impacted by MND](#).

(v) Reimbursement and remuneration

The requesting organisation or group is required to reimburse any out-of-pocket expenses incurred by the member, as well as a carer, who may need to accompany a person living with MND. This might include costs associated with conference fees, parking, transport, flights, accommodation, meals or fuel.

Where possible, MNDA also supports remuneration for members, to acknowledge their time and input. Some organisations or groups may be able to offer remuneration, particularly for funded projects, or if the requesting group sits within the private sector. Other groups may not have the funds available to provide this. This is to be made clear to members before they accept a request.

Remuneration may be in the form of a:

- *Gift*: for example a gift voucher, or pre-paid credit card.
- *Honorarium*: a one-off payment that a person is offered in return for their involvement in recurring activities.
- *Sitting fee*: payment for a person's time to prepare for and attend scheduled meetings, a workshop or conference (NB: this includes video or phone meetings).

Remuneration rates vary depending on the funds available, the role of the member, and the level of participation required.⁶ As a guide, the current rate for 'sitting fees' as per the Commonwealth Remunerations Tribunal for part-time office holders is \$89.60/hour or \$448/day (based on a 5-hour day).⁷ Health Consumers NSW have also developed guidelines for remuneration payment rates for consumer involvement in research (2022):⁸

[CLICK HERE TO VIEW](#)

Members are free to choose either to accept or decline any offers of remuneration or reimbursement at their discretion.

(vi) How to submit a request to connect with National MND LEN members:

Groups or organisations are invited to seek lived experience input via the National MND LEN, with the aim of improving the lives of people impacted by MND. Any requests related to fundraising will be declined, as will any requests that seek to advertise a service or product for commercial purposes.

All requests seeking lived experience input via the National MND LEN are required to submit an online request form via MNDA's website. Prior to submission, groups should read this policy. Evidence of ethics approval from a Human Research Ethics Committee, and evidence of approved participant recruitment pathways, will be required for any activities promoting participation in a clinical trial, or other research study (including survey completion).

All online requests will be forwarded to the LEN Approval Panel for review, for which MNDA will act as the Secretariat. This panel will include representatives from: MNDA, lived experience, State MND Association and FightMND. The panel will assess the suitability of each application, ensuring roles and expectations of LEN members are clearly defined, and that the group or organisation are able to safely and adequately support LEN members. The Panel will also review any relevant ethics documents submitted (as noted above).

Following panel review, MNDA staff will notify the requesting group whether their request has been approved.

Please allow 6-8 weeks lead time for Approval Panel processing, promotion of your activity amongst relevant LEN members and managing expressions of interest for your activity.

(vii) What happens after a request is approved?

MNDA distributes regular circulars via email that will list opportunities for members to get involved in approved activities. Circulars may be distributed to all members listed in the network, or a specific subgroup, for example, only people living with MND, only people living within a specific state, or only members of the Lived Experience Research Advisory Panel (linked to the MND Research Collective). This will depend on the nature of the request submitted.

Members who are interested to participate in a listed opportunity, are encouraged to contact MNDA to express their interest. MNDA cannot guarantee that members will express interest in your activity.

MNDA staff will collate all expressions of interest submitted for an activity, ensuring that the member meets the listed requirements. If an activity is over-subscribed, principles of diversity and inclusion will be applied to select the final candidate/s. This may require consultation with the Approval Panel and/ or the requesting group (Nb: no identifiable information will be shared with the requesting group at this point).

After being matched with an activity, MNDA will notify the selected members, and seek consent to share their contact details with the requesting group. At this point, the member may also like to advise of any reasonable adjustments that would support their ability to participate, such as: shorter meeting times due to fatigue, a preference for all communication to be via writing/typing due to speech impairment, or the need for a support person to attend meetings.

MNDA will then forward member contact details and other relevant information to the requesting group, who will then be responsible for coordinating initial and ongoing contact arrangements with members.

(viii) Reporting Requirements

Following completion of an engagement activity, all requesting groups are required to submit a short 'Final Feedback Report' report to MNDA. LEN members also have the option of submitting a feedback report of they wish to.

All feedback reports will be reviewed by the LEN Approval Panel, and if required, MNDA's CEO. This information is intended to provide feedback so that we can undertake ongoing evaluation and improvement of the program and protocols, as well as report to external and partner organisations on the benefits and challenges of the program.

(ix) Future requests for new activities

Please refrain from directly approaching National MND LEN members that you may have worked with in the past, about a new activity. All new activities seeking lived experience input

are encouraged to be submitted via the National MND LEN. This helps to ensure the safety and wellbeing of members; encourages regular rotation of lived experience voices in activities; and allows MNDA to adequately evaluate and support the program.

5. CONTACT US

If you have any questions about this policy, please contact:
MND Australia
Email: info@mndaaustralia.org.au

6. CHANGES TO THIS POLICY

We may update this Policy from time to time to reflect changes in our practices, legal requirements, or industry standards. Any updates will be posted on our website, and we encourage you to review this Policy periodically for changes.

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. [IAP2 Spectrum of Public Participation](#)
7. [Remuneration Determination Tribunal](#) (compilation number 4, registered 20.3.2024, for offices not-specified): part 2 /general provisions /page 5 (*link is external – cited 18.7.2024*);
8. Health Consumers NSW: [Remuneration and reimbursement guidelines for consumer involvement in health and medical research \(October 2022\)](#) (*link is external – cited 18.7.2024*)