

## MS Australia's Guideline for External Stakeholders Engaging with the LEEP

### About the LEEP

The MS Australia Lived Experience Expert Panel (LEEP) is a panel formed by MS Australia to provide expert advice on core areas of interest to MS Australia. The LEEP is made up of [40-60 people living with MS or carers of people with MS](#) and to join the LEEP, they have undergone a competitive selection process by MS Australia.

The MS Australia LEEP was established in October 2023. The LEEP provides a formal and meaningful way to hear advice from people with lived experience and experts across the MS community. The LEEP support MS Australia's work by:

- Enhancing MS Australia's advocacy agenda through evidence, insights and advice from the MS community
- Ensuring the MS community has a strong voice into MS Australia's governance, research, policy & advocacy, education & awareness

Leveraging the valuable expertise, diverse backgrounds, qualifications, and relevant knowledge of its members, the LEEP will provide input and advice, as required, into MS Australia's policy, research and communications work and support the goals identified in the [MS Australia Strategic Plan 2022-26](#).

The LEEP brings a diverse and wide range of lived experience and expertise that strengthens the work of MS Australia, the MS research community and a range of organisations across disability, health and medicines. Many LEEP members have contributed to MS research including providing feedback on grant applications or funding proposals, research questions or how a study will be conducted. They have also taken part in focus groups and been members of reference groups, project teams or advisory groups. Some members have also taken part in clinical trials. [Find out more here](#).

### Glossary

- **Engagement:** The specific opportunity(s) that would benefit from LEEP member expertise and involvement, including sharing their experiences at either in-person or online events, providing input and reviewing submission and research proposals, participating on a podcast, etc.
- **Honorarium:** An honorarium is generally (but not always) a tax-free one-time or project-based payment provided to LEEP members who volunteer their time and expertise to support not-for-profit activities. The [Australian Tax Office \(ATO\) provides guidance](#) on whether an honorarium may be assessed.
- **Lived experience:** The sharing of one's own perspective and personal experience on an issue, drawn from lived or caring experience rather than from a professional or educational role. LEEP members share their experiences of living with MS or being a carer of someone with MS.

- **Reimbursement for out-of-pocket expenses:** A reasonable cost incurred by the LEEP member to participate in the engagement opportunity(s). Receipts for out-of-pocket expenses must be retained and shared electronically (scanned or photographed) for reimbursement along with an expense claim form. Examples direct expenses include:
  - public transport costs
  - private transport and parking expenses – claims for the use of private cars should be calculated in accordance with the [Australian Taxation Office's Claiming motor vehicle expenses as a sole trader – Cents per kilometre policy](#).
  - Taxi or ridesharing fares
  - Meals (if not provided)
  - Accommodation costs

### LEEP Engagement

MS Australia's policy team, Katie Snell and Christy Cushing, manage the LEEP and undertakes direct engagement with LEEP members as required and based on members areas of expertise and interest. Input and advice may be sought from individuals, a limited number of members or all members depending on the subject matter. On occasion there may be a need for a subgroup to be formed on specific issues. In this case, meetings may be held online or in person to facilitate any necessary discussion.

Engagement processes will be accessible, flexible and designed to support effective participation for LEEP members.

If you are interested in engaging with the LEEP, please contact Katie or Christy at [advocacy@msaustralia.org.au](mailto:advocacy@msaustralia.org.au).

### Engagement Requests

If there is a request to engage a LEEP member for an activity, then there are two pathways:

- If the activity is straightforward or has a short turnaround, then the policy team should determine which LEEP members would be most appropriate, for example, an external media interview or opportunity to be on a panel. The policy team will then directly communicate with the chosen LEEP member/s.
- If the activity is more complex (e.g. participation in research) then the person requesting should provide all details and any relevant documents to the policy team, who will follow up if further information is needed. The policy team will review the information and send to relevant LEEP members. There are three options for choosing participants:

- Policy team to provide details of all LEEP members who are interested, and the external requester will decide who to use for the project OR
- Policy team to review the list of interested LEEP members and make a recommendation to the requester OR
- The first LEEP member to respond who has relevant expertise/lived experience is selected and details forwarded to the requester
- The policy team will finalise the request by providing an e-introduction to the LEEP member(s) who have been chosen for the activity.

Please refer to the **Engaging with LEEP members** section below for tips on how best to work with LEEP members.

### Timeframes

Where possible, a minimum of two weeks' notice should be given when engaging LEEP members. If the policy team determines there is not adequate time to engage and prepare LEEP members then the opportunity may have to be declined. Special consideration will be given to time-sensitive situations such as media responses. Even if you do not have full details of the opportunity, let the policy team know as soon as possible so they can commence planning.

### Communication with the LEEP

There are various opportunities for MS Australia to reach the LEEP and inform them of future engagement opportunities which can be shared directly with them as follows:

- **In the LEEP Newsletter – 1<sup>st</sup> Wednesday of each month**

LEEP members are sent a monthly email newsletter, *In the LEEP*, on the first Wednesday of each month.

- If there is interest in including engagement opportunities in the monthly newsletter, please share them with the policy team by **COB on the first Tuesday of each month**. The policy team prefers that all requests for the LEEP are included in the newsletter but will make an exception for urgent work with a limited turnaround.
  - To avoid a short turnaround or missing the newsletter deadline, please talk to the policy team as soon as you have an idea for engaging the LEEP, even if you don't have all the details and they can determine how to engage the LEEP.

- **Monthly LEEP Catch Up Meetings – 3<sup>rd</sup> Tuesday of each month**

The policy team facilitates a monthly LEEP Catch Up Meeting using Microsoft Teams to provide LEEP members the chance to get together, share lived experience and build community. There is no expectation that LEEP members attend, but often about 20-30 join the meetings. The meetings are recorded and

available to be shared within 60 days of the meeting. Currently the LEEP Catch Up meeting is held on the third Tuesday of each month at:

- During non-daylight-savings time (May – September):
  - 12:00pm-1:00pm ACT, NSW, TAS, QLD, & VIC
  - 11:30am-12:30pm SA & NT
  - 10:00-11:00am WA
- During daylight savings (October – April):
  - 12.00pm – 1.00pm ACT, NSW, TAS, & VIC
  - 11.30am – 12.30pm SA
  - 11.00am – 12.00pm QLD
  - 10.30am – 11.30am NT
  - 9.00am – 10.00am WA

LEEP members have requested that the LEEP Catch Up meetings have a standing agenda with a combination of topics, updates, speakers, and discussion.

- The policy team shares the Catch Up meeting agenda on the 2<sup>nd</sup> Tuesday of each month. If you'd like to have an update included on the Catch Up meeting agenda, please share them with the policy team by **COB on the first Tuesday of each month**.
- LEEP members have requested that materials and documents for a LEEP Catch Up meeting (i.e. PowerPoint slides, reports, etc.), be provided to them in advance, so they can reflect on the material and come prepared.

### **Recognising and Paying an Honorarium for the LEEP Member's Contributions**

MS Australia recommends that organisations inviting LEEP members to participate in engagement opportunities provide an honorarium in recognition of members' time and lived experience expertise.

While LEEP members engage in a volunteer capacity, they may need to take time off work, manage childcare, and balance other day-to-day responsibilities. At a minimum, LEEP members should be reimbursed for out-of-pocket expenses incurred through their involvement. Providing an honorarium to LEEP members recognises the value of their lived experience contributions.

An honorarium can be provided by setting rates for specific engagement tasks or projects, or on an hourly basis, and should include reasonable preparation time (for example, reviewing materials prior to a meeting).

While vouchers for third-party establishments may be appreciated, MS Australia recommends providing honorarium payments (rather than vouchers or gift cards) to remunerate LEEP members for their time and expertise.

Generally, an honorarium is paid to recognise time contributed to an engagement activity on a voluntary basis and does not constitute a formal employment contract. Prior to LEEP member involvement, organisations should communicate the fixed honorarium allocated for the specific engagement opportunity.

MS Australia recommends the following honorarium benchmarks: \$50 per hour for research meetings and other agreed research-related activities (including reasonable preparation time), and \$150 per hour for engagements with the pharmaceutical industry. See Appendix 1 for more resources on paying Lived Experience Experts.

If a financial honorarium or gift card is offered, organisations should ensure that this is provided as soon as possible after the LEEP members involvement and that LEEP members do not have to follow up outstanding payments.

MS Australia also recognises the importance of non-financial forms of recognition, such as co-authorship, formal acknowledgements, and opportunities for professional development opportunities for LEEP members involved in research.

### Engaging with LEEP Members

Engaging with LEEP members can be improved by following the tips below:

- **Sensitivity to the Lived Experience:** when incorporating lived experience narratives from LEEP members, please prioritise consent, emotional wellbeing, and psychological safety for LEEP members. Preparation of the LEEP member is essential to ensure that interactions are respectful and safe. In addition, recognise that sharing lived experience can be emotionally taxing. LEEP members should be given the option to pause, take a break or step back from an engagement at any time, and should not be pressured to share more than they are comfortable with.
- **Consent:** Where lived experience stories have been obtained for a previous project/purpose, they cannot be used for a new project/purpose without specific consent for re-use, including confirming whether the LEEP member wants to remain public or chooses to be anonymous. Consent requirements must be clarified by the MS Australia policy team.
- **Advance materials:** LEEP members have requested that materials related to an engagement activity be shared in advance of the activity (i.e. PowerPoint slides, questionnaires, reports, etc.), so they can reflect on the material and come prepared to the engagement activity.
- **Clear expectations:** provide LEEP members with a clear outline of the purpose and scope of the engagement opportunity, expected time commitment, key dates or deadlines, and how their input will be used. This should also include clear information about how LEEP members will be recognised for their contribution, including whether an honorarium, reimbursement or other form of payment will be offered. This helps members make an informed decision about whether they are able to participate.

- **Flexible participation:** offer multiple ways for LEEP members to contribute, such as written feedback, online meetings, phone calls, one-on-one conversations or small group discussions. This helps accommodate fluctuating symptoms, accessibility needs, fatigue and personal commitments.
- **Accessible documents:** where possible, you should provide documents in plain English so that they can be understood by the LEEP member. If more complex or scientific materials are provided, ensure they are understood by the LEEP member and offer to help them with interpreting and understanding.
- **Shared documents:** where possible make use of shared documents so that all project participants have oversight of the project and can simultaneously contribute and provide feedback transparency on the same documents, for example SharePoint or Dropbox.
- **Meeting times & rest periods:** many people living with MS experience fatigue and brain fog. Ensure that meetings are set at a time that best suits the person (usually morning but this varies with each person). If a meeting goes for more than one hour, it should include a break. Longer or all-day events should include multiple opportunities for people to rest, with breaks of at least 30 minutes.
- **Accommodation & travel time:** If attending an event in person, LEEP members should be offered adequate time between travel and attending the event. This may include offering a night's accommodation either side of the event.
- **Accessibility:** LEEP members should be provided with clear information about the accessibility of event and in-person project locations. This should include disability parking, access to public transport, distances from parking to the venue, accessible toilets, and availability of seating. Where possible, consider online or hybrid delivery to support inclusive participation for LEEP members with disability and/or those who live a significant distance from the in-person engagement opportunity.
- **Feedback:** ensure that you keep LEEP members updated on the event or project that they are involved in. This could include feedback on whether a grant was successful, feedback on input provided by a LEEP member, or feedback on how an event went (response from attendees, response on social media, etc.). This is a key form of respect and recognition that supports ongoing engagement.
- **Contact:** assign someone to be the contact point for the LEEP member while working on the project. This should be someone they can contact via email or phone and whom they feel comfortable asking questions and raising concerns. The nominated contact should also regularly check in with any LEEP members involved in the project and provide any support as needed.

## Review and updates

This guideline will be reviewed periodically and may be updated over time as the LEEP evolves and engagement practices mature.

## Questions

If you have any questions about the LEEP or want to engage with them, please contact Katie Snell or Christy Cushing at [advocacy@msaustralia.org.au](mailto:advocacy@msaustralia.org.au).

Please also contact Katie and Christy if you have any concerns regarding a LEEP member's wellbeing or participation in a project.

## Appendix 1: Resources on Paying Lived Experience Experts

The resources below may assist internal and external stakeholders to set fair, transparent and consistent payment arrangements when engaging lived experience experts (including budgeting, honorarium approaches, and reimbursement of expenses).

- Consumers Health Forum of Australia, *Consumer engagement – Partnering with consumers – for health professionals*, available at <https://www.chf.org.au/partnering-with-consumers-for-health-professionals>.
- Consumers Health Forum of Australia, *Remuneration and reimbursement of health consumers: recognising the value of expert contributions made by people with lived or living experience*, available at <https://hcnsw.org.au/training-resources/resources/remuneration-and-reimbursement-of-health-consumers/>.
- Consumers Health Forum of Australia, *Strategic Consumer and Community Group*, 18 March 2026, available at <https://www.chf.org.au/get-involved/consumer-engagement-opportunities/strategic-consumer-and-community-group>.
- Parliament of Victoria, Legislative Council Environment and Planning Committee 2026, *Inquiry into community consultation practices: Committee final report*, 3 March 2026, available at <https://www.parliament.vic.gov.au/get-involved/inquiries/inquiry-into-community-consultation-practices/reports>.
- The Social Change Agency n.d., *Paying for involvement – why it matters*, available at <https://thesocialchangeagency.org/blog/paying-for-involvement-why-it-matters/>.
- Youth Engagement Resource Platform (YERP) n.d., *For youth workers and volunteers – Youth participation: level up – Paying young people*, available at <https://www.yacvic.org.au/yerp/coordinating-youth-participation/remuneration/>.
- Medicines Australia 2025, *Factsheet 3: Remuneration framework of healthcare consumers – principles for remunerating healthcare consumers for interactions with pharmaceutical industry*, available at [https://www.medicinesaustralia.com.au/wp-content/uploads/sites/65/2025/10/Working-Together-Guide\\_Factsheet3\\_230725.pdf](https://www.medicinesaustralia.com.au/wp-content/uploads/sites/65/2025/10/Working-Together-Guide_Factsheet3_230725.pdf).
- Department of Families, Fairness and Housing (Victoria) 2024, *Guidance on payment, reimbursement and recognition*, page updated 25 October 2024, available at <https://www.dffh.vic.gov.au/publications/guidance-payment-reimbursement-and-recognition>.
- Black Dog Institute 2024, *Lived Experience paid participation policy*, version 6 (Jan 2024), effective February 2024, available at <https://www.blackdoginstitute.org.au/wp-content/uploads/2024/10/Lived-Experience-Paid-Participation-Policy-V6-Jan24.pdf>.

- Victorian Mental Illness Awareness Council (VMIAC) 2023, *Participation remuneration rates for the lived and living experience registers*, 4 October 2023, available at <https://www.vmiac.org.au/wp-content/uploads/Participation-Remuneration-Rates-v2023-10.pdf>.
- Alcohol, Tobacco and other Drugs Council (ATDC) Tasmania 2023, *Lived Experience Advocate Service finance policy*, effective May 2023, available at <https://atdc.org.au/wp-content/uploads/2024/05/LEA-Finance-Policy-MAY-23-FINAL.pdf>.
- Australian Red Cross 2021, *Lived Experience Framework*, September 2021, available at <https://www.redcross.org.au/globalassets/cms/publications/lived-experience-framework.pdf>.
- National Mental Health Commission 2020, *Paid participation policy: for people with a lived experience of mental health difficulties, their families and support people*, April 2020, available at <https://www.mentalhealthcommission.gov.au/sites/default/files/2024-03/paid-participation-policy-2020.pdf>.