



Terms of Reference

Lived Experience Expert Panel

This Terms of Reference (TOR) defines the purpose, structure and processes of the MS Australia Lived Experience Expert Panel. This living document can be amended by the MS Australia Board of Directors at any time.

1. Background

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. Leveraging the valuable expertise, 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.

Lived Experience Expert Panel members are those that provide advice and input on a specific subject based on their expertise, work experience and/or qualifications, together with their lived experience as a person with MS or carer of a person with MS.

2. Purpose

The purpose of the LEEP is to provide a formal mechanism to facilitate advice from experts across the MS community. This will support the work of MS Australia by:

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

The LEEP will have opportunities to provide feedback and/or advice on projects and outputs delivered across the organisation's policy, communications, research and corporate services teams.

3. Membership

Members will be selected by MS Australia and invited by the CEO to join. A Letter of Appointment, including important information on confidentiality, intellectual property and conflicts of interest will be provided to each appointed member.

Members of the LEEP will be selected for their capacity to assist in achieving the purpose of the LEEP and to provide meaningful feedback and input on MS Australia's policy, research and communications work. LEEP members should be able to provide input and advice on an area of expertise or interest to MS Australia, including:

- The experiences of people living with Relapsing-remitting MS or Progressive MS
- The experiences of people with MS who live in rural, regional or remote Australia
- The experiences of people with MS who are members of a vulnerable and/or diverse community, such as LGBTQI+, CALD and socially and economically disadvantaged
- The experiences of older people with MS including navigating the Australian aged care system

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- The experience of younger people living with MS and/or caring for younger people with MS
- Employment, training and the labour market for people living with MS
- Housing, home modifications and assistive technologies
- The social and economic barriers facing people living with disability with a focus on people living with MS
- Understanding of the role of carers including navigating carer supports and services
- Understanding of government services and supports relating to disability including navigating and accessing the National Disability Insurance Scheme and the Disability Support Pension
- Understanding of government policy processes, with a focus on disability, health and aged care
- Understanding of medical research, with a focus on MS
- Understanding of MS treatments and medications

There is no strict minimum or maximum number of members of the LEEP.

4. Terms of Appointment

Members of the LEEP will be appointed for a three-year term. Members may be re-appointed at the end of their terms for additional terms. Membership of the LEEP may be terminated by the MS Australia Board without cause. As volunteers, members of the LEEP may elect to step down from their role at any time.

5. Expectations

MS Australia will undertake 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.

Secretariat support will be provided by the MS Australia Advocacy team. Engagement processes will be accessible, flexible and designed to support effective participation for LEEP members. LEEP Members are to abide by MS Australia corporate policies when representing or advising MS Australia.

6. Authority

Members of the LEEP serve in an advisory capacity only. They are not MS Australia Directors or staff members and do not have any executive powers, supervisory functions or decision-making authority in relation to the operations of MS Australia. LEEP members have no authority to act on behalf of MS Australia unless specifically requested by the Board. MS Australia is not bound by advice received from LEEP members but will consider it appropriately in the context of the overall strategy and direction of MS Australia.

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7. Remuneration

LEEP membership is voluntary. Members will not be remunerated for their participation, however, all reasonable expenses associated with travel or accommodation requested by MSA would be reimbursed in accordance with MSA guidelines.

8. Confidentiality

LEEP members will maintain confidentiality over discussions and meetings relating to MS Australia, unless specifically authorised by MS Australia to share relevant information with external stakeholders. Please refer to the MS Australia [Privacy Policy](#).

9. Legal Liability

Neither the LEEP nor any of the members shall be held liable for any direct, incidental, consequential, indirect or punitive damages arising out of any activity, policy, and/or other action undertaken by any MS Australia staff or any LEEP member, in the context of the LEEP and its functioning.

10. Administration

The Head of Advocacy and the National Policy Manager are responsible for managing the LEEP members and activities.

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