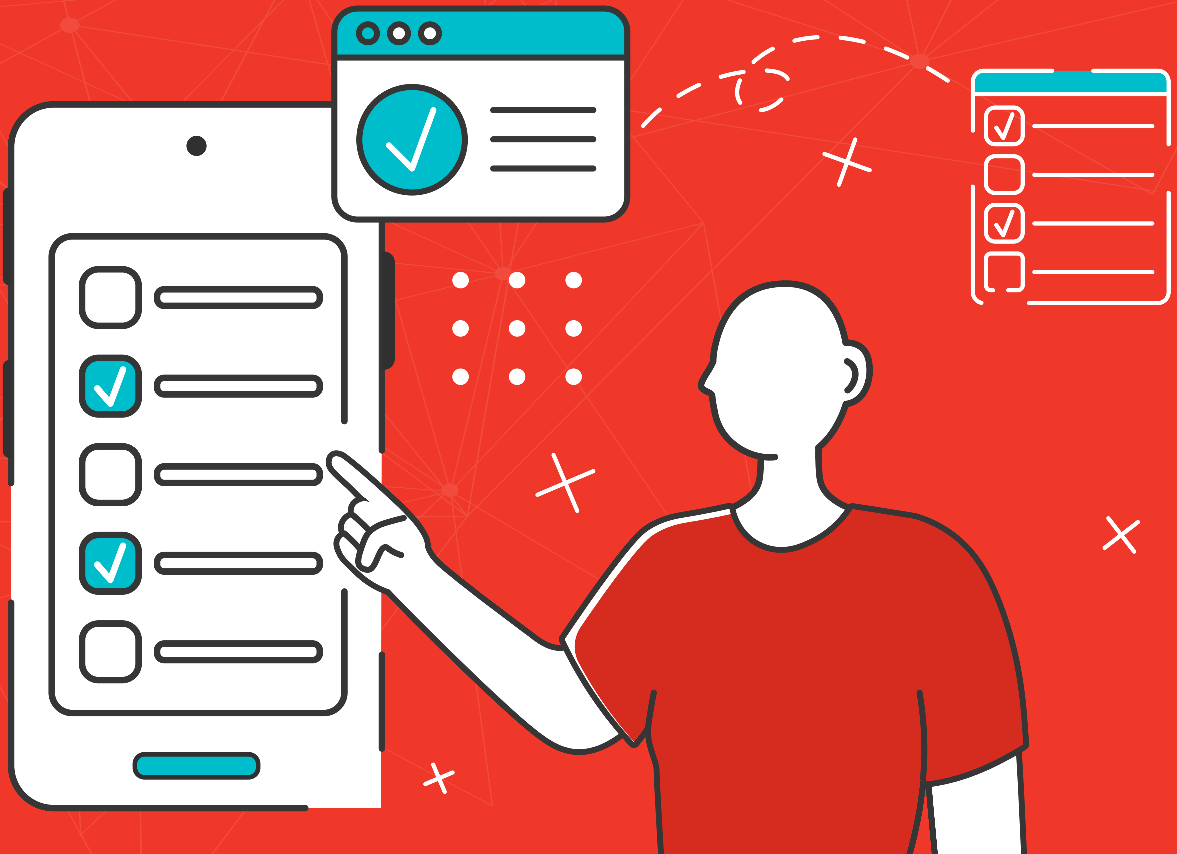
RESEARCH & ADVOCACY PRIORITIES SURVEY REPORT 2025

EXECUTIVE SUMMARY



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MS Australia is Australia's national MS not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS.

Executive summary

The 2025 Research and Advocacy Priorities Survey conducted by MS Australia provides a comprehensive and community-driven roadmap for future research, advocacy, and engagement strategies. With 2,081 participants and a strong 62% completion rate, the survey captured a wide spectrum of experiences and perspectives across the MS community.

Table 1. Survey participants by connection to MS. Numbers in brackets indicate those who completed the survey in full. Participants may belong to more than one category (e.g. a person with MS who is also a professional).

CONNECTION TO MS	NUMBER OF PARTICIPANTS (BRACKETS=FULLY COMPLETED)
Person with MS	1405 (904)
Affected by MS	1184 (759)
Professional	289 (184)
Other	83 (33)

The distribution of MS types closely mirrored the Australian MS population, and participants represented a broad demographic spread across age, gender, disease duration, severity, and geographic location. This inclusive participation reinforces MS Australia's commitment to shaping its strategic direction in alignment with the lived experience and the evolving needs of those affected by MS.

Survey methodology and participant profile

The survey was disseminated through a multi-channel strategy, including email invitations, website, newsletter, social media, and professional networks, and remained open for six weeks.

The survey employed both quantitative and qualitative methods, including weighted averages and thematic coding of open-text responses, to ensure a robust and representative analysis of community priorities.

Research priorities

Survey participants were asked to rank six key research goals for MS from most to least important. The order of priorities based on how often each was ranked as most or second most important were:

1. Finding a cure for MS through repair and regeneration
2. Preventing MS
3. Improving the diagnosis of MS
4. Better treating MS
5. Improving MS management and care
6. Predicting an individual's disease course

The top two priorities remain consistent with findings from the 2021 survey; however, improving the diagnosis of MS has overtaken better treating MS in 'most important' rankings in the current survey, marking a shift from 2021. This shift in priorities may reflect broader access to MS therapies in Australia, making treatment feel less urgent for some.

However, there remains a significant need for new treatment options for progressive MS, as shown by the continued focus on finding a cure through repair and regeneration. Increased awareness of the benefits of early diagnosis, supported by MS Australia's World MS Day 'My Diagnosis' Report, has also likely influenced priorities.

While the top ranked priorities provide a snapshot of the research goals most frequently identified as most important, the weighted average provides a more nuanced view of overall importance across all responses. The weighted average results show that the order of research priorities were:

1. Finding a cure for MS through repair and regeneration
2. Preventing MS
3. Better treating MS
4. Improving MS management and care
5. Improving the diagnosis of MS
6. Predicting an individual's disease course

The top three research priorities – finding a cure for MS through repair and regeneration, preventing MS, and better treating MS – were unchanged from the 2021 survey. While improving the diagnosis of MS received more top rankings this year, it drops to fifth when considering all responses. This suggests that while long-term solutions like prevention and a cure remain top of mind, there is also strong and widespread support for improving current treatment approaches across the MS community.

Research stage and stream

Research typically progresses through three stages: fundamental, which explores basic scientific mechanisms; translational, which bridges discoveries to practical applications; and clinical, which evaluates interventions in real-world settings. Clinical research emerged as the most valued of the three stages of research, with strong support also shown for translational and fundamental research.

Among five research streams, neurobiology was ranked highest, with immunology, virology, and clinical trials also receiving strong endorsement.

These preferences reflect a desire for both immediate impact and long-term scientific advancement.

Specific fields of MS research

Participants emphasised the importance of improving diagnosis, particularly for progressive forms of MS, and understanding prognosis through personalised medicine approaches. There is also a clear call for research into symptom management, with cognitive function, mobility, fatigue, and pain identified as the most pressing areas. Notably, anxiety and MS hug were frequently mentioned in open-text responses, highlighting gaps in current research agendas.

MS Australia’s research program

MS Australia annually awards competitive grants for investigator-led research and funds national collaborative research platforms, enabling multidisciplinary teams to address complex MS challenges through large-scale collaboration and data sharing.

For the first time, community input was specifically sought on the effectiveness of MS Australia’s investigator-led grants program and national collaborative research platforms. This feedback provides valuable guidance to ensure future strategies are aligned with the needs of people living with MS, professionals, and researchers.

Responses revealed mixed views on whether current grant funding is adequate, with many unsure and MS researchers divided. There was strong support for increased funding, more efficient allocation, and greater transparency. Over 90% of participants viewed investigator-led grants as at least moderately effective, with professionals and researchers especially positive. Many participants also supported prioritising collaborative, interdisciplinary research, though some researchers preferred individual grants. These insights highlight a desire for more strategic, inclusive, and outcome-focused funding approaches.

Over 80% of professionals were familiar with at least one national collaborative research platform, with the Australian MS Longitudinal Study and MS Australia Brain Bank being the most widely recognised. Nearly half of researchers have used or contributed data to these platforms, and over 70% rated them as ‘very useful’ for facilitating research. Nearly 70% of MS professionals supported increased funding for these initiatives. Participants highlighted the need for improved digital infrastructure, greater transparency, and enhanced data sharing, reflecting strong support for continued investment in collaborative, technologically advanced research environments.

Finally, MS Australia actively partners with the global research community to address complex MS challenges through large-scale studies and data sharing. Over 80% of survey participants consider international collaboration extremely important, reflecting strong community support for MS Australia’s ongoing involvement in global scientific efforts.

Advocacy priorities

Survey participants were asked to rank key advocacy goals for MS from most to least important. The MS community’s top six advocacy priorities were:

1. Additional funding for MS research
2. Approval of new MS medications
3. An improved NDIS for people living with MS
4. Meeting the disability needs of people who are not eligible for the NDIS
5. Better access to specialist neurologists
6. Better access to treatment

The top two priorities remain consistent with the 2021 survey results. Open-text responses further highlighted the importance of NDIS access and eligibility, support for carers and families, healthcare and treatment access, and addressing regional and remote service gaps. These findings reinforce the need for equitable access to treatment, services, and support systems for all people living with MS.

Campaign awareness

Approximately 40% of participants were aware of at least one major MS Australia initiative, such as A Better NDIS for People Living with MS, Count Us In, the What is MS? video, and the Lived Experience Expert Panel (LEEP). Awareness was strongest among key target groups, particularly younger participants (18–30 years) who showed high engagement with the LEEP. While some initiatives are designed for policymakers or highly engaged audiences, the findings suggest both strong advocacy reach and opportunities to broaden visibility across the wider MS community.

Communications and resources

Nearly 70% of participants rated MS Australia's communication on research and advocacy as 'good' or 'very good', reflecting strong trust in the organisation's outreach. The MS Wire newsletter was the most widely accessed and helpful resource, serving as a central channel for updates. About half of participants were satisfied with how research funding outcomes are communicated, suggesting a solid foundation on which to build. While many participants accessed information through digital channels, others relied on state-based organisations. There was also a clear call for more accessible information on research, treatments, and services, along with increased emotional and peer support, and resources tailored to families and caregivers. These findings highlight ongoing confusion about the respective roles of MS Australia and state-based organisations.

Overall, they reinforce the importance of delivering a diverse and accessible mix of resources to meet the varied needs of people living with MS.

Digital engagement

Facebook was the most popular platform, with over 40% of participants engaging there. LinkedIn and X (formerly Twitter) had smaller but notable followings. Just over half of participants were not yet connected with MS Australia on social media, indicating a strong opportunity to grow the online community. Engagement was consistent across age groups, with slightly higher digital use among younger participants.

Overall strategy and conclusion

An overwhelming 93% of participants endorsed MS Australia's strategic focus on research, advocacy, and evidence-based resources. These results provide a strong mandate for MS Australia to continue investing in high-impact research, driving policy change, and enhancing community engagement. They also highlight opportunities to refine funding strategies, improve communication, and expand outreach, ensuring that MS Australia remains responsive to the needs of the MS community. These insights will inform future planning, resource allocation, and program development across the organisation.

Scan the QR code to read the full report

or visit www.msaustralia.org.au/prioritiessurvey2025

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