MS AUSTRALIA

RESEARCH & ADVOCACY PRIORITIES SURVEY REPORT 2025

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Survey purpose and design

To inform the future strategic direction of MS Australia, we designed and implemented a survey with questions focused on research priorities, areas of advocacy, communication and overall strategy. The core questions were adapted from our previous Research Priorities Survey (2016) and the Research and Advocacy Priorities Survey (2021), enabling us to track shifts in stakeholder perspectives over time.

The original 2016 survey design was based on the framework developed by the UK MS Society in 2012, which used the James Lind Alliance methodology. This approach brings together health professionals and people with lived experience to collaboratively identify and prioritise unanswered research questions in specific disease areas.

In 2016, a total of 1,034 people completed the survey, including 754 individuals living with MS. In 2021, participation increased significantly, with 2,174 people completing the survey, of whom 1,533 were people living with MS. These responses provided valuable insights into consumer perspectives.

The survey was developed and administered online using the SurveyMonkey platform.

Survey dissemination

To ensure broad and inclusive participation, the survey was disseminated through a multi-channel strategy. Email invitations were sent to MS Australia's and The May 50K networks, including people living with MS, carers, researchers, clinicians, and state MS organisations. The survey was also promoted via MS Australia's website, MS Wire newsletter, and social media platforms to reach a wider audience and encourage engagement. In addition, it was shared with the MS and Neuroimmunology Special Interest Group of the Australian and New Zealand Association of Neurologists, MS Nurses Australasia, and relevant medical research institutes. Flyers were also shared with staff at state MS organisations to encourage participation among allied health professionals.

The survey was open from 28 February 2025 to 13 April 2025, providing a six-week window for responses.

Participant information and data collection

Participants were informed that the survey was anonymous, with an option to provide contact details. No personally identifiable information was collected unless contact details were voluntarily submitted. Basic demographic information, including gender, age, citizenship status, geographic location, and connection to MS, was collected to help assess the diversity of the participant pool and to explore whether research and advocacy priorities varied based on these characteristics.

Analysis methods

This section outlines the analytical approaches used to interpret both quantitative and qualitative data collected through the survey.

Quantitative Analysis

For many of the closed-ended questions, weighted averages were calculated to reflect the relative importance assigned by participants. This method ensured that higher priority selections had a proportionally greater influence on the final rankings. In other cases, response frequencies and percentages were used to summarise trends and highlight the most commonly selected options.

Qualitative Analysis

Free-text responses were analysed using a thematic coding approach. Each response was reviewed and categorised based on recurring keywords and contextual meaning. Responses were grouped into overarching themes to identify common concerns and emerging priorities. This method was applied to open-ended questions related to both research and advocacy priorities.

For the analysis of additional symptoms, a word cloud was generated using wordclouds.com to visually highlight frequently mentioned terms. Responses were pre-processed to remove common stop words and standardise similar terms before uploading the cleaned text to the platform.

Overview of survey participants

The 2025 survey closed with 2,081 participants, of whom 1,299 completed all questions (62%). Given the estimated 30-minute duration and 53-question format, this is a strong completion rate and reflects high engagement with the topics. Surveys of this length typically see lower completion rates, often below 50%. Responses from incomplete surveys were still included in the analysis.

Connection to MS

Table 1 provides a breakdown of survey participants by their connection to MS. These categories were not mutually exclusive, meaning participants could identify with more than one group. The majority were people living with MS (67.5%), followed by people affected by MS, which included family, friends and carers (56.9%). Participants with a professional connection to MS made up 13.9%, while 4.0% reported another type of connection or general interest in MS.

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)

MS-Specific Participant Characteristics

The demographic and clinical characteristics of survey participants living with MS were closely aligned with those of participants in the Australian MS Longitudinal Study which has previously been validated as a representative sample of the Australian MS community.

The proportion of different types of MS among survey participants was broadly consistent with the current Australian MS Longitudinal Study cohort, with 67.3% reporting relapsing remitting MS (RRMS), 16.3% secondary progressive MS (SPMS), and 9.2% primary progressive MS (PPMS). A further 6.2% were unsure or reported another form of demyelinating disease (Figure 1A).

Participants living with MS ranged in age from 18 to over 60, with a slightly younger average age of 52 years compared to the Australian MS Longitudinal Study average of approximately 64 years (Figure 1B). The proportion of female participants was also somewhat higher than expected, with 80.9% identifying as female, compared to the national average of approximately 75%, where around three out of four people diagnosed with MS are female.

There was also a broad range in time since diagnosis, reflecting the diversity of experiences within the MS community (Figure 1C). People living with MS across the full spectrum of disease severity were well represented, from those living well with minimal symptoms to those experiencing significant levels of disability (Figure 1D).

Figure 1. The survey captured the views of a very broad spectrum of people living with MS including across disease type, ages, disease duration and disease severity. (A) Participants who indicated that they live with MS were asked the type of MS they live with. (B) The ages of people with MS who took part in the survey. (C) The length of time since people with MS were diagnosed. (D) The extent their MS impacts their lives.

Geographic Distribution

People were asked about their geographic location according to the Health Workforce Locator from the Australian Department of Health, Disability and Ageing.

Over half of survey participants reported living in major cities, nearly 20% in inner regional areas and another 20% in outer regional areas, while a smaller proportion resided in remote or very remote areas. This distribution reflects the broader population trends in Australia, where most people live in metropolitan centres. Understanding the geographic spread of participants is important for interpreting research and advocacy priorities, as access to healthcare and support services can vary significantly depending on remoteness.

Results

Overall research priorities

Survey participants were first asked to rank the overall goals for MS research from 1 to 6, where 1 indicated the most important priority and 6 the least important. The results are shown in Figures 2 and 3.

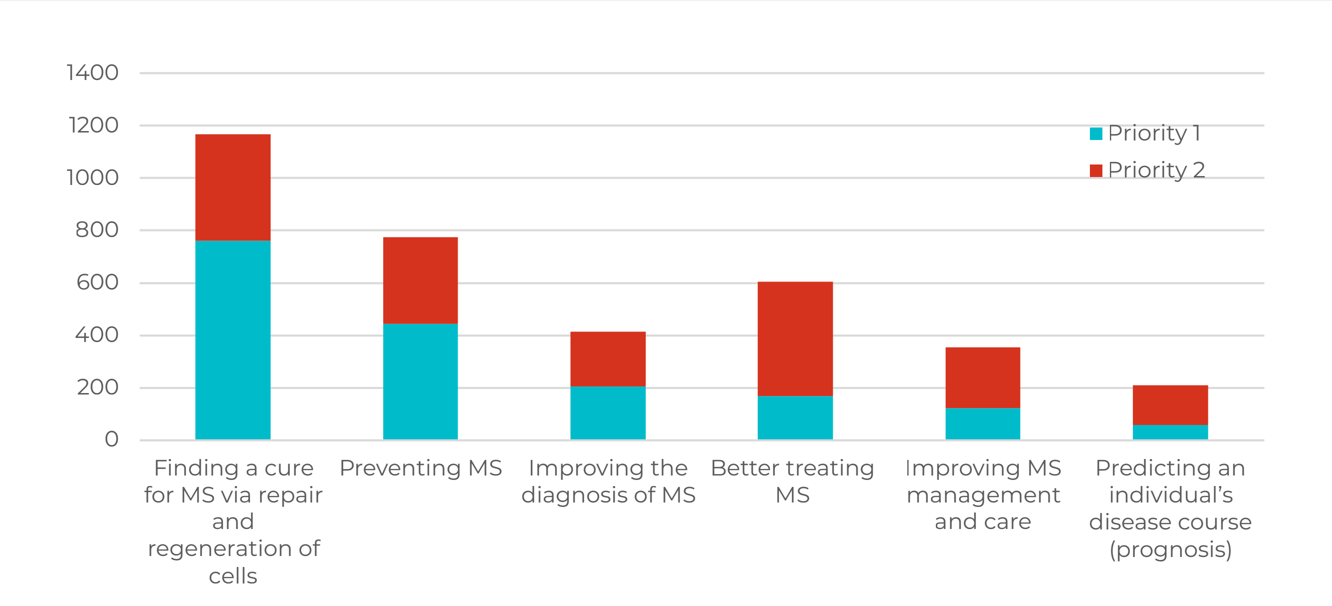

Figure 2. Participants ranked six research areas from 1 (most important) to 6 (least important). This graph shows the top two rankings for all the participants.

The results indicate that *Finding a cure* was most frequently ranked as most important, followed by *Preventing MS*, consistent with findings from the 2021 surveys. Interestingly, *Improving the diagnosis of MS* received more 'most important' rankings in the current survey, marking a shift from 2021, when *Better treating MS* was more frequently ranked as the top priority. However, substantially more participants ranked *Better treating MS* as the second-highest priority compared to *Improving the diagnosis of MS*.

There could be several reasons influencing this shift. Australia has a wide range of disease-modifying therapies (DMTs) available, and some participants may feel that treatment is no longer as high a priority. It is important to note, however, that while there have been several new medications approved for relapsing forms of MS in the last few years, there is still a great unmet need for additional treatments for progressive forms of the disease, as highlighted by the top priority of *Finding a Cure*.

There is likely also an increased awareness that early and accurate diagnosis can significantly improve long-term outcomes for people living with MS. Advocacy efforts by MS Australia, particularly the 2024 World MS Day 'My Diagnosis' Report, have spotlighted the diagnostic challenges still experienced by many people today. This campaign has likely influenced public perception and priorities.

The order of these research goals did not change when the responses were analysed according to the type of clinically definite MS (Figure 3). Clinically definite MS refers to a confirmed diagnosis of MS, including RRMS, SPMS and PPMS.

Among those with clinically isolated syndrome (CIS), *Improving the Diagnosis of MS*, *Preventing MS*, and *Finding a Cure* were most frequently identified, and equally ranked, as the most important research goals. However, it must be noted that the number of participants in this group was relatively small.

Figure 3. Participants ranked six research areas from 1 (most important) to 6 (least important). The graphs display responses from individuals with different MS subtypes. A) RRMS - Relapsing remitting MS, B) SPMS - Secondary progressive MS, C) PPMS - Primary progressive MS, D) CIS - Clinically isolated syndrome. Only the top two response categories are shown.

While the top ranked priorities provide a snapshot of the research goals most frequently identified as most important, the weighted average (as detailed in the Methods section) provides a more nuanced view of overall importance across all responses. Using this, *Finding a Cure* and *Preventing MS* were considered the two highest-priority research goals overall, reaffirming their status as the top concerns for the MS community (Figure 4).

When considering the full range of responses across the priority scale, *Improving the Diagnosis of MS* drops to the fifth position overall. In contrast, *Better Treating MS* received a weighted average score very close to *Preventing MS*, indicating it was consistently rated as a high priority, even if fewer participants selected it as their single most important goal.

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.

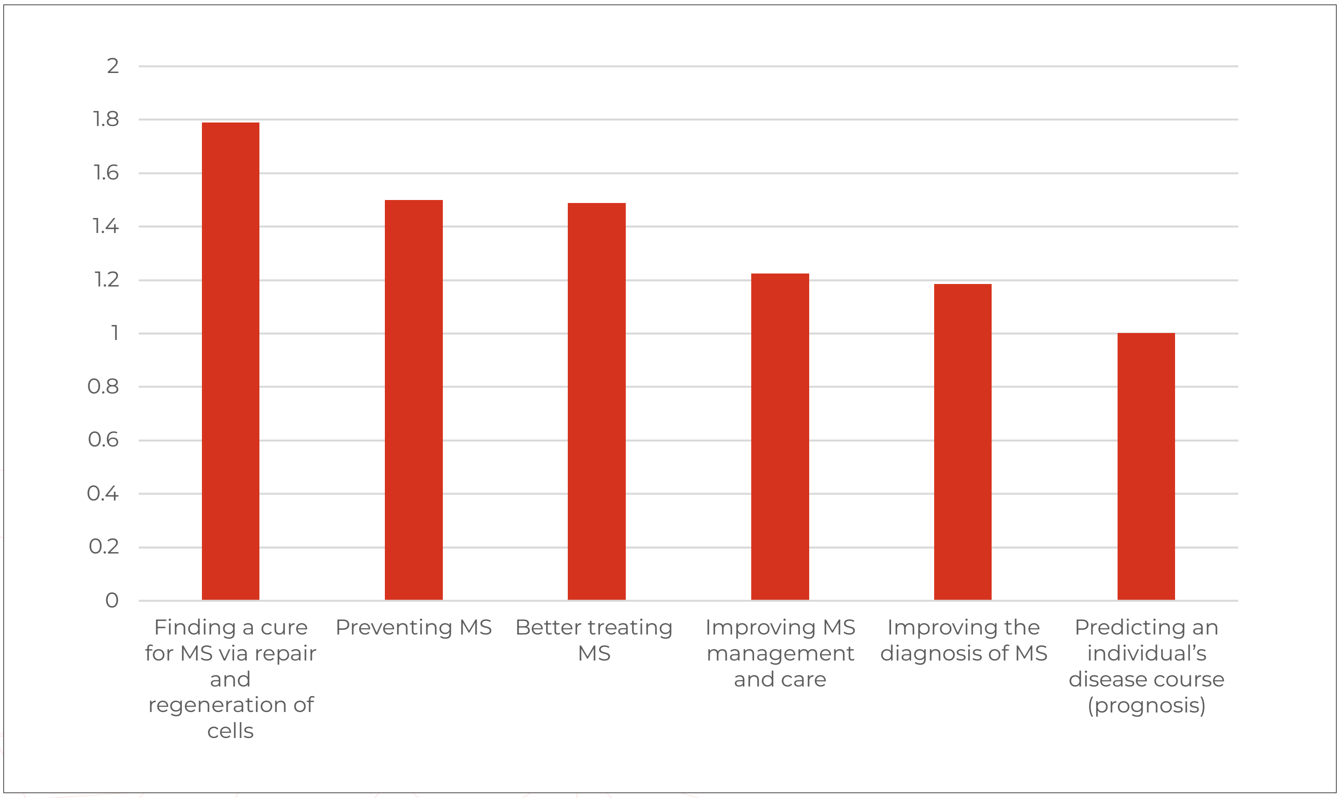

Figure 4. Participants ranked six research areas from 1 (most important) to 6 (least important). The weighted average ranking for each area was calculated across all responses and normalised relative to the research goal of lowest priority. In this graph, higher values indicate higher overall priority among participants.

Research fields or 'streams'

To advance our research goals, MS Australia allocates funding to a range of research fields, referred to as 'streams'. The survey participants were asked to indicate the importance they placed on each stream of research using a 5-step scale ranging from 'very important' to 'not important at all'. Each research question was rated independently, rather than being ranked against each other.

When a weighted average of all responses was applied, the resulting order of priority was as follows:

1. Neurobiology
2. Immunology and Virology
3. Clinical Trials
4. Genetics and Epidemiology
5. Social and Applied research

This is consistent with the results from the 2021 survey. *Immunology and Virology* and *Clinical Trials* were ranked quite similarly overall.

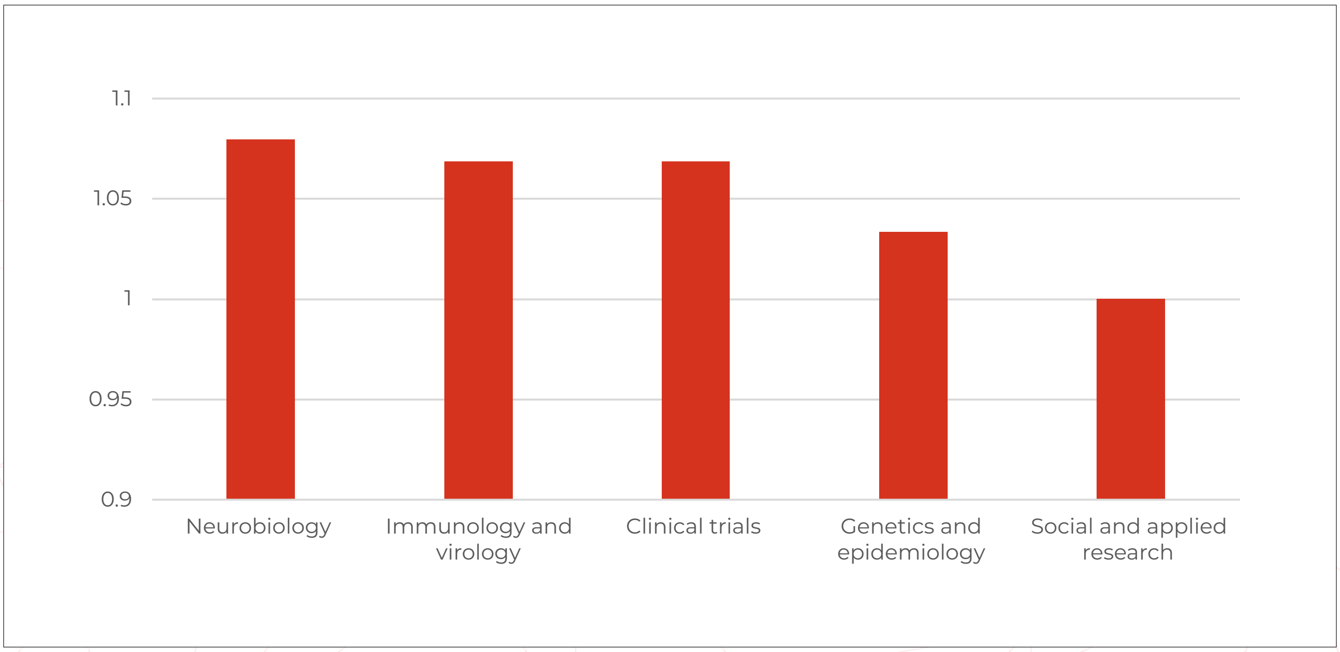

Figure 5. Participants rated the importance of five research streams independently from 'very important' to 'not important at all'. A weighted average score was calculated for each stream and used to determine their relative priority. In this graph, higher values indicate higher overall priority among participants.

When focusing on participants with different types of MS, the order of the streams shifted (Figure 6). *Immunology and Virology* was viewed as most important by people with CIS and RRMS, possibly because these individuals are earlier in the disease course, where the immune system remains highly active in the disease process. People with SPMS viewed *Clinical Trials* as most important, while people with PPMS viewed *Neurobiology* as most important. In contrast, *Genetics and Epidemiology* consistently had the second-lowest frequency of 'very important' rankings, while *Social and Applied Research* was ranked lowest across all groups.

Figure 6. Participants living with MS were asked to indicate how important each of the research streams is, without needing to rank them relative to one another. The graphs display responses from individuals with different MS subtypes. A): RRMS - Relapsing remitting MS, B) SPMS - Secondary progressive MS, C) PPMS - Primary progressive MS, D) CIS - Clinically isolated syndrome. Only the top two response categories - 'very important' and 'important' - are shown.

The research spectrum – fundamental research through to the clinic

Survey participants were asked the priority they believed should be placed on the different stages of research, including fundamental research, translational research and clinical research. Each option had an approximate time in which the research is likely to have an impact.

- Fundamental Research: Laboratory-based research to understand the causes and biology of MS, which may have a long-term impact (10 years or more).
- Translational Research: Research that bridges laboratory findings to clinical applications, potentially impacting within five years or less.
- Clinical Research: Studies and clinical trials that could have an immediate impact once completed.

The results show that *Clinical Research* had the most support from all participants, being rated as 'very high priority' by greater than 75% of participants (Figure 7). *Translational Research* and *Fundamental Research* received a similar proportion of 'very high priority' ratings from participants, with *Fundamental Research* rated slightly higher.

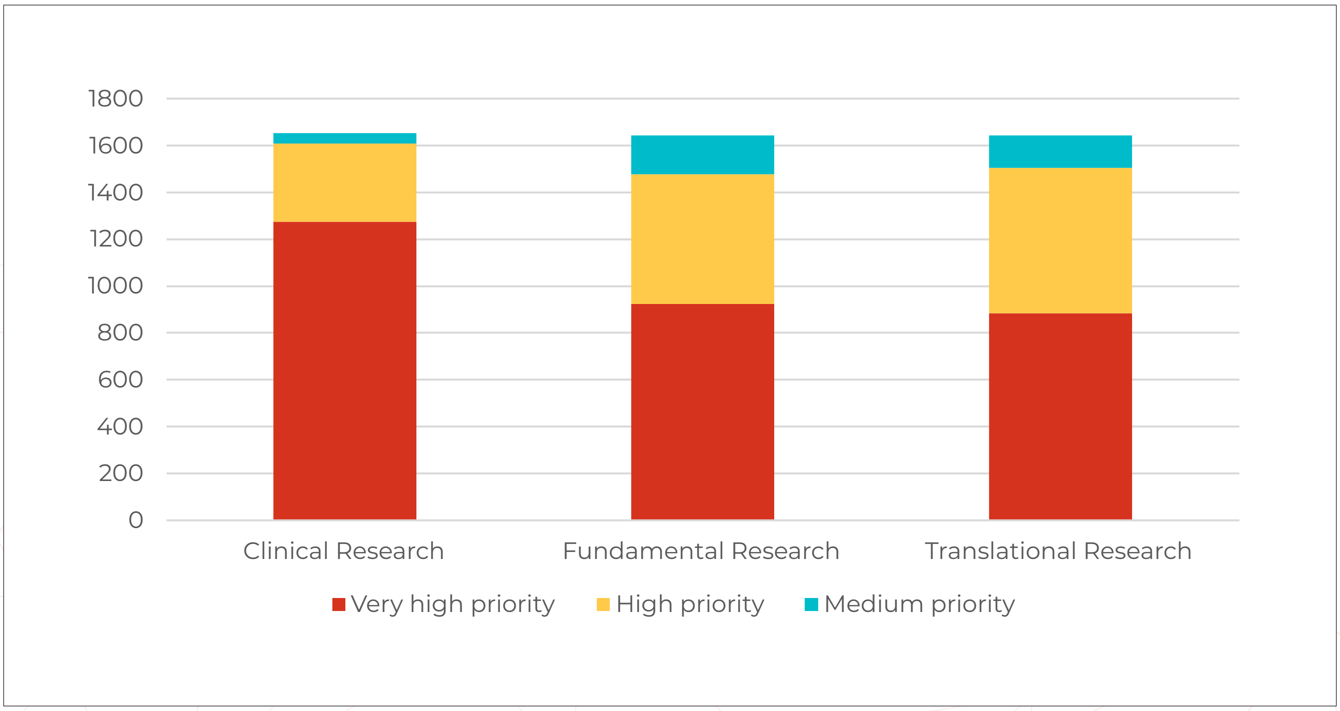

Figure 7. Participants were asked to indicate the level of priority they believe should be given to different stages of MS research, ranging from fundamental research to clinical research. They were not required to rank the research stages relative to one another. The figure displays the distribution of responses across the various research stages, highlighting the proportion of participants who rated each as a very high priority, high priority, or medium priority.

When a weighted average was applied, *Clinical Research* remained the top priority, with minimal difference between the other two research types. This is consistent across the different subgroups of clinically definite MS and varying disease durations and aligns with findings from the 2021 survey.

Specific fields of MS research – a closer look

Survey participants were asked about specific areas of MS research where important knowledge gaps remain. These topics were grouped into broad research categories: *Prevention*, *Diagnosis*, *Prognosis*, *Treatment*, *Finding a Cure*, and *MS Management and Care*. Participants were asked to rate the level of priority they believe each research topic should be given, using a predefined scale. Importantly, participants were not required to rank the topics relative to one another, allowing each to be assessed on its own merit. Weighted averages were used to reflect the relative importance of each topic.

Preventing MS

The most supported research topic within the field of preventing MS was the broadly phrased question of *How can MS be prevented?,* which is consistent with the 2021 survey results (Figure 8). This was consistent across all subgroups of participants.

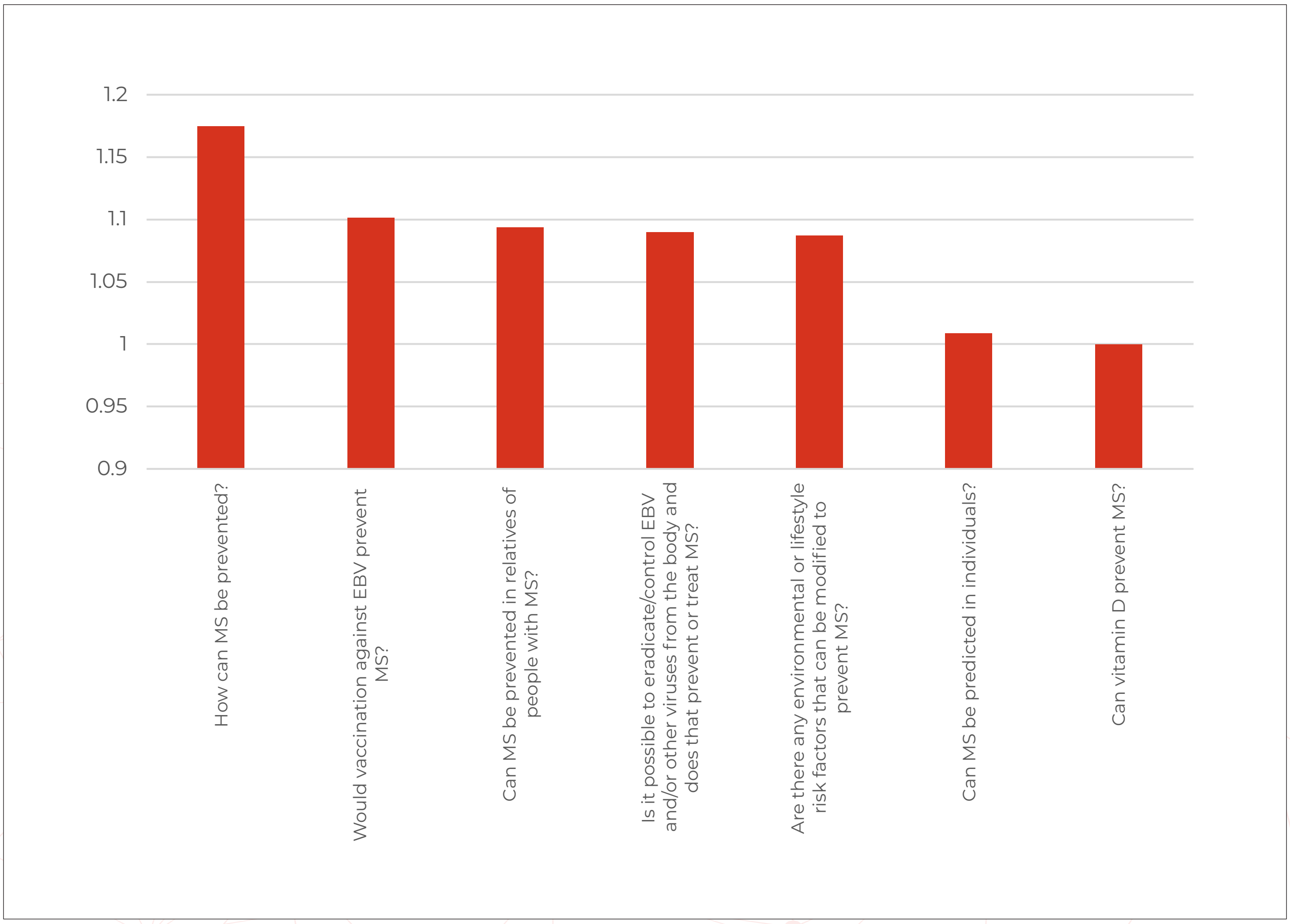

Figure 8. Participants were asked to rate the priority of each topic within *Preventing MS*, from 'very high priority' to 'not a priority'. The weighted average ranking for each topic was calculated across all responses and normalised relative to the topic of lowest priority. In this graph, higher values indicate higher overall priority among participants.

Following this in priority, but rated similarly, were the research questions:

- Would vaccination against EBV prevent MS?
- Can MS be prevented in relatives of people with MS?
- Is it possible to eradicate/control EBV and/or other viruses from the body and does that prevent or treat MS?
- Are there any environmental or lifestyle risk factors that can be modified to prevent MS?

This is a slight change compared to the 2021 results, with more interest now in preventing MS in family members and decreased interest in lifestyle factors for prevention. There is also increased interest in vaccination against EBV. In the past year, MS Australia has established the EBV in MS platform, which has likely attracted interest from the MS community.

The lowest levels of support across all participants were for the questions *Can MS be predicted in individuals?* and *Can vitamin D prevent MS?* It's not surprising the priority given to research into vitamin D as a preventative measure for MS has declined, following results from the Vitamin D Prevention (PrevANZ) trial, which showed that vitamin D did not prevent MS in individuals at high risk.

Improving the Diagnosis of MS

The most supported research topic within the field of diagnosing MS was *How can we diagnose MS earlier?* (Figure 9).

MS is a complex disease, and diagnosis is not always straightforward. According to MS Australia's 2024 World MS Day 'My Diagnosis' Report, while the average time from first symptoms to diagnosis has decreased since the introduction of the first MS DMT in 1996, it still takes nearly four years on average for people to receive a diagnosis. Early diagnosis is critical for initiating treatment sooner, potentially slowing disease progression and improving long-term outcomes. The very high priority placed on this question reflects the community's desire to reduce diagnostic delays, which are often associated with missed opportunities for early intervention.

The next two priorities, which received similarly high rankings, focused on research into accurately diagnosing PPMS and identifying the transition from RRMS to SPMS. This reflects a shared concern in the difficulty in identifying and confirming progressive forms of the disease among people with MS. It is clear that people want greater diagnostic clarity, not only at the initial point of diagnosis, but throughout the disease course.

As with the 2021 survey, *Is there variation around Australia in the way that MS is diagnosed and treated?* had the least support.

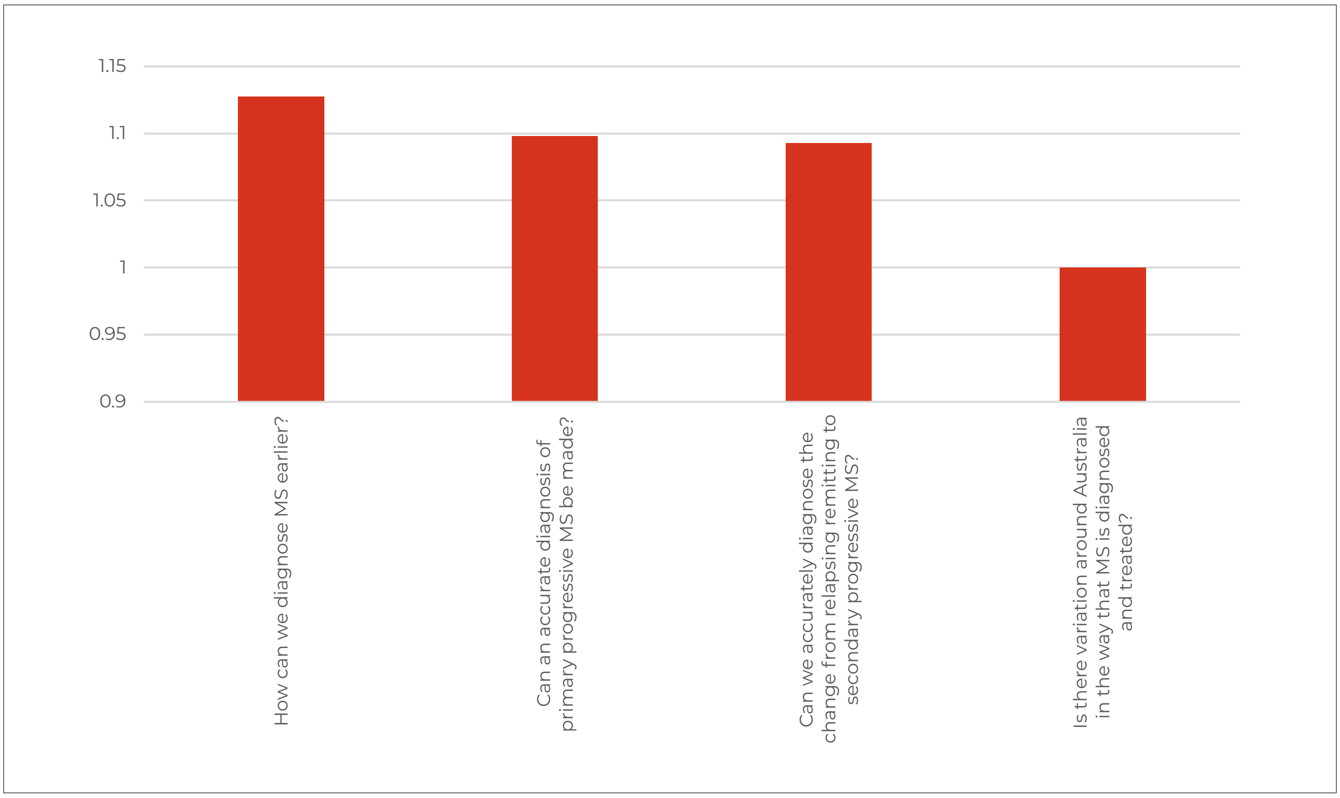

Figure 9. Participants were asked to rate the level of priority each topic within *Diagnosing MS* should receive, from 'very high priority' to 'not a priority'. The weighted average ranking for each topic was calculated across all responses and normalised relative to the topic of lowest priority. In this graph, higher values indicate higher overall priority among participants.

Prognosis of MS

Although *Prognosis of MS* received comparatively less support as a research priority, exploring specific questions within this area remains important for understanding and improving long-term outcomes in MS.

The most supported research topic within the field of prognosis of MS was *Is it possible to predict whether a person will respond to a particular MS medication?* followed closely by *Are there any environmental or lifestyle risk factors that affect the long-term progression of MS?* (Figure 10). This is consistent with the 2021 survey results.

The strong interest in predicting treatment response reflects a growing desire for personalised medicine in MS care. People living with MS are aware that treatment effectiveness can vary widely between individuals. Being able to predict who will benefit from which medication could lead to faster, more effective treatment decisions and fewer side effects or delays in care.

The second highly rated topic was *Are there any environmental or lifestyle risk factors that affect the long-term progression of MS?* This highlights the community's interest in empowerment through modifiable lifestyle factors. People are interested in how they can influence their long-term outcomes, whether through diet, physical activity and exercise, stress management, or other lifestyle changes. This underscores the community's ongoing interest in taking a proactive role in managing the disease and a strong desire to feel more empowered in shaping its course.

The following five research topics were ranked similarly in priority. These include:

- What is the best way to measure progression in people with MS?
- Is it possible to predict how severe a person's disease will be or how fast they will progress?
- Is it possible to predict whether a person will experience side-effects/adverse events in response to a particular MS medication?
- Do other medical conditions influence the prognosis of MS?
- Is it possible to predict when a person may transition from relapsing remitting MS to secondary progressive MS?

As with both the 2016 and 2021 surveys, the question *What effect does pregnancy have on the long-term progression of MS?* received the least support. The broad demographic diversity of participants likely influenced the overall ranking of this question, as it may not have been directly relevant to all respondents. That said, this topic may still be especially important to certain subgroups.

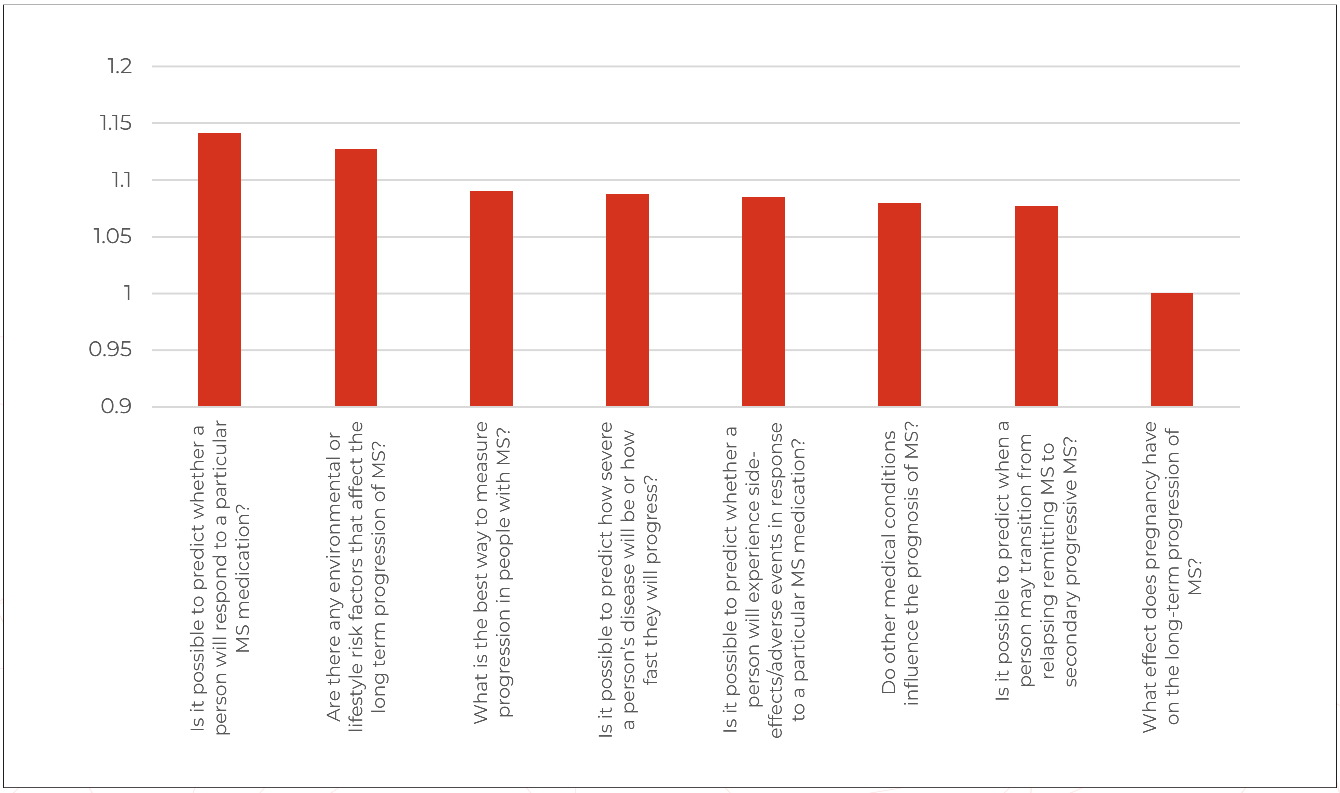

Figure 10. Participants were asked to rate the level of priority each topic within *Prognosis of MS* should receive, from 'very high priority' to 'not a priority'. The weighted average ranking for each topic was calculated across all responses and normalised relative to the topic of lowest priority. In this graph, higher values indicate higher overall priority among participants.

Better Treating MS

The research question most commonly ranked as a very high priority in this field was *Which MS medications are effective to slow, stop or reverse the accumulation of disability associated with progressive MS?* (Figure 11). There were two other questions that stood out as high priorities:

- Which interventions are most effective at preventing a relapse?
- Which medications were effective in preventing the transition to secondary progressive MS?

This prioritisation mirrors the results of the 2021 survey, indicating consistent research interests and concerns within the MS community in this field.

The current results reflect a strong collective concern among participants about long-term disease progression and the preservation of function. The emphasis on progressive MS and relapse prevention suggests that people with MS are not only focused on managing current symptoms but are also deeply invested in halting or reversing the disease trajectory.

The high prioritisation of these topics may also reflect gaps in the current treatment landscape, particularly for progressive forms of MS, where treatment options remain limited compared to those for relapsing forms of MS. It underscores the urgent need for research that delivers tangible improvements in long-term outcomes, especially for those at risk of accumulating disability or transitioning to more advanced stages of the disease.

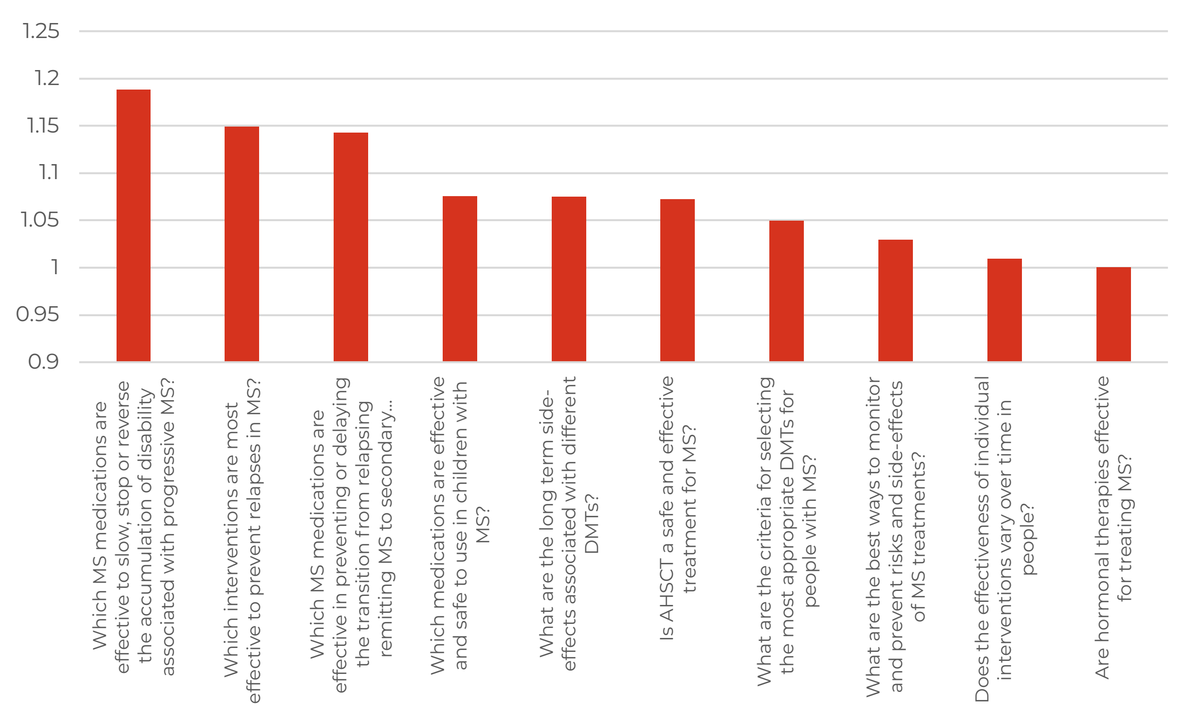

Figure 11. Participants were asked to rate the level of priority each topic within *Better Treating MS* should receive, from 'very high priority' to 'not a priority'. The weighted average ranking for each topic was calculated across all responses and normalised relative to the topic of lowest priority. In this graph, higher values indicate higher overall priority among participants.

Finding a Cure for MS via Repair and Regeneration

The four questions related to *Finding a Cure for MS via Repair and Regeneration* were rated similarly in priority based on weighted averages (Figure 12A). A closer look reveals that over 70% of the survey participants rated each research question as ‘very high priority’, reflecting a strong and consistent desire for research that focuses on restoring function and reversing damage caused by MS (Figure 12B). Notably, this high level of interest is consistent with the findings from the 2021 survey, reinforcing that this area has remained a top priority over time.

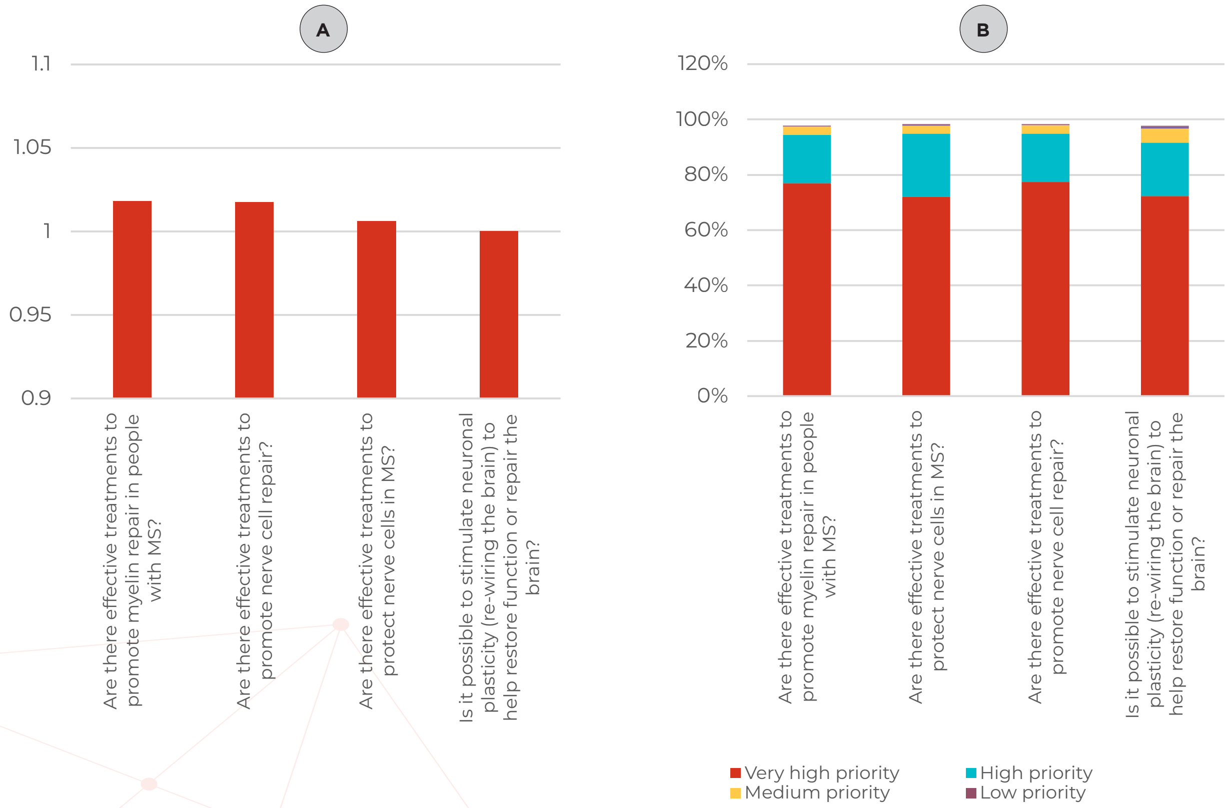

Figure 12. Participants were asked to rate the level of priority each topic within *Finding a Cure for MS via Repair and Regeneration* should receive, from ‘very high priority’ to ‘not a priority’. A) The weighted average ranking for each topic was calculated across all responses and normalised relative to the topic of lowest priority. In this graph, higher values indicate higher overall priority among participants. B) The percentage of participants who rated each research topic within Finding a Cure for MS via Repair and Regeneration from ‘very high priority’ to ‘not a priority’.

Improving MS Management and Care

As with the 2021 survey results, *What impact does stress have on MS?* was of highest priority overall, and *What effects does MS have on other family members and family life?* was considered the lowest priority overall when it came to research topics within MS management and care (Figure 13).

The high prioritisation of stress-related research likely reflects the link between chronic stress and both the worsening of MS symptoms and an increased risk of relapse. It also indicates a desire from the MS community for practical tools that could improve daily quality of life and self-management of their disease.

In contrast, the lower priority given to research into the effects of MS on family members and family life suggests that while family dynamics are important, they are seen as less urgent compared to more immediate clinical or psychological concerns.

It is important to note that while some priorities may receive less support from the broader community, they remain highly important to a significant proportion of individuals within the population.

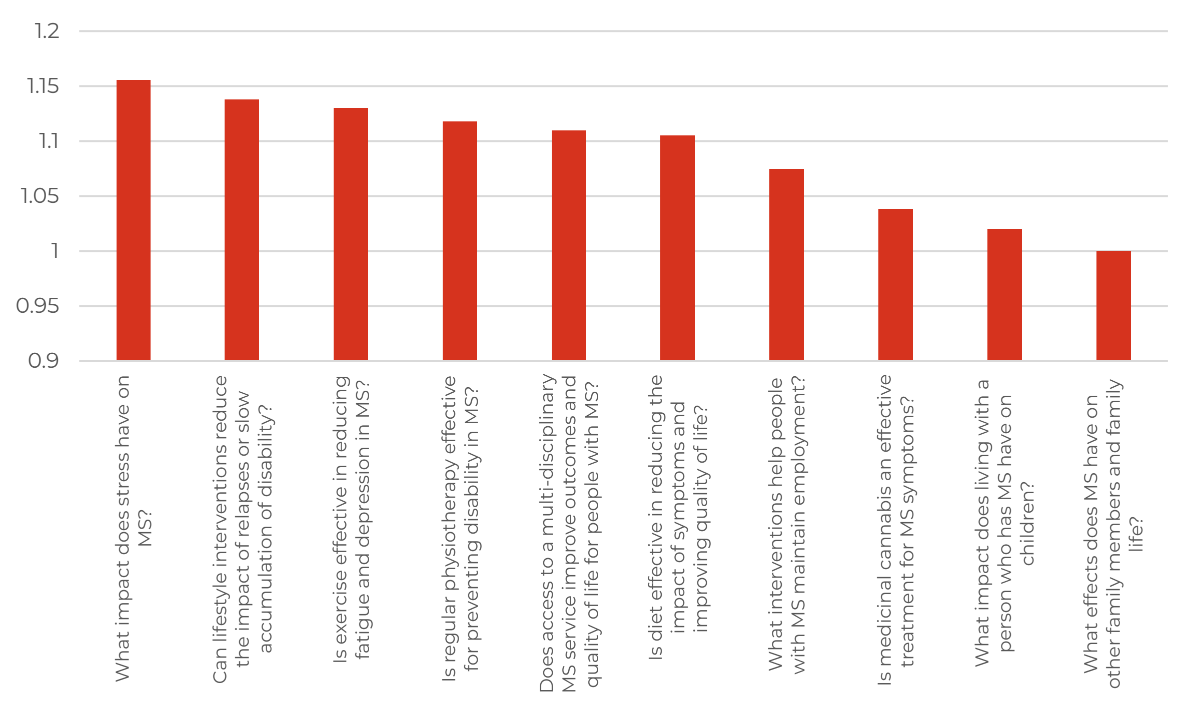

Figure 13. Participants were asked to rate the level of priority each topic within *MS Management and Care* should receive, from 'very high priority' to 'not a priority'. The weighted average ranking for each topic was calculated across all responses and normalised relative to the topic of lowest priority. In this graph, higher values indicate higher overall priority among participants.

Research topics within “symptoms of MS”

A dedicated section of the survey focused on prioritising research into 20 specific MS symptoms, ranging from cognitive function and pain to sexual function, foot drop, and hearing problems. Participants were asked to rate each symptom as either very high priority, high priority, medium priority, low priority, not a priority or don’t know. Weighted averages were then calculated to account for the distribution of responses across the predefined priority scale (Figure 14).

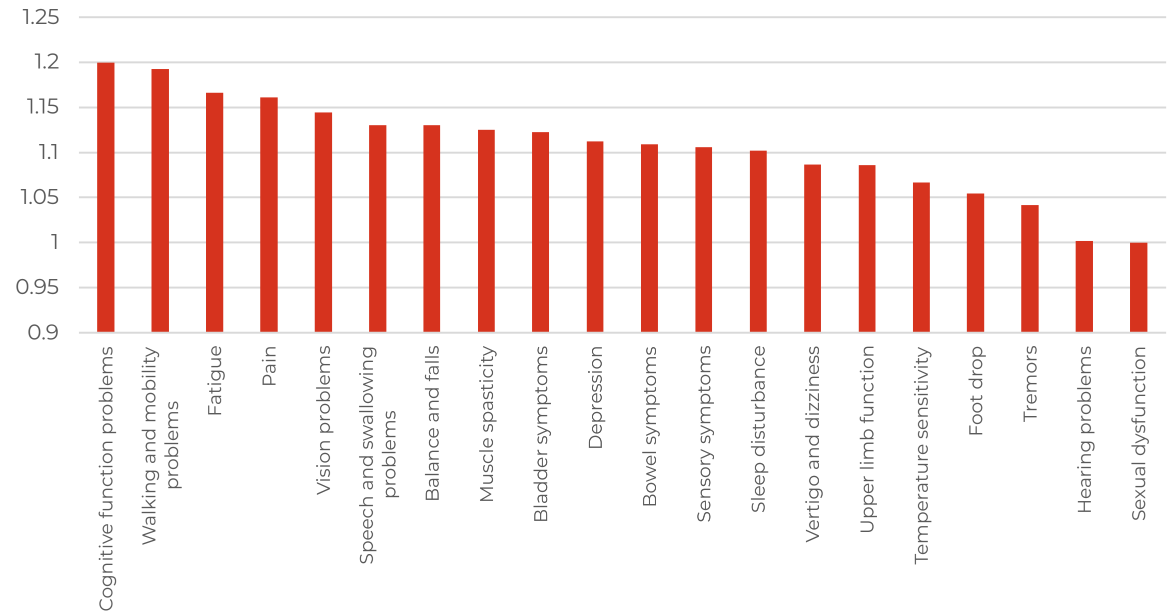

Figure 14. Participants ranked the priority that should be placed on research into treating and managing each symptom, from 1 (very high priority) to 6 (not a priority). The weighted average ranking for each area was calculated across all responses and normalised relative to the lowest priority. In this graph, higher values indicate higher overall priority among participants.

The six symptoms rated as the highest research priorities across the cohort, in descending order of importance, were:

1. Cognitive function problems
2. Walking and mobility problems
3. Fatigue
4. Pain
5. Vision problems
6. Speech and swallowing problems

While the top six priorities varied across participants with different types of MS, cognitive function problems and fatigue consistently appeared among the top six symptoms rated as ‘very high priority’ for research, highlighting their importance across the cohort (Figure 15).

People with CIS ranked cognitive function problems, vision problems, pain, speech and swallowing problems, fatigue, and vertigo and dizziness as their top six priorities (in descending order of importance), but it is important to note that there was only a small number of people in this group.

For those with RRMS, the top six priorities were cognitive function problems, fatigue, walking and mobility problems, vision problems, pain, and speech and swallowing problems. For those with SPMS, the top six were walking and mobility problems, balance and falls, cognitive function problems, bladder symptoms, fatigue, and pain. For those with PPMS, the top six were walking and mobility problems, balance and falls, bladder symptoms, bowel symptoms, cognitive function problems and fatigue.

These variations reflect the highly individualised nature of the disease, where symptoms can differ significantly in type, severity, and impact from person to person.

Figure 15. Participants ranked the priority that should be placed on research into treating and managing each symptom, from 1 (very high priority) to 6 (not a priority). The graphs display responses from individuals with different MS subtypes. A) RRMS - Relapsing Remitting MS, B) SPMS - Secondary Progressive MS, C) PPMS - Primary Progressive MS, D) CIS - Clinically Isolated Syndrome. Only the top two response categories - 'Very High Priority and 'High Priority' - are shown.

To ensure all potential research priorities for symptoms were captured, participants were invited to identify any additional MS symptoms they felt required more research to better understand and treat in an open text field. These were analysed using a word cloud visualisation (detailed in the Methods), which helped highlight prominent themes and symptoms (Figure 16).

The overwhelming majority of participants identified *MS hug* and *anxiety* as key symptoms they felt required more research attention. This strong emphasis suggests that, despite not being included in the predefined symptom list, these issues are highly impactful and widely experienced within the MS community. Notably, MS hug and anxiety were also the two most frequently mentioned additional symptoms in the 2021 survey, reinforcing their continued relevance and importance to people living with MS.

Many responses reinforced key areas already captured in previous sections of the survey, including cognitive issues and pain.

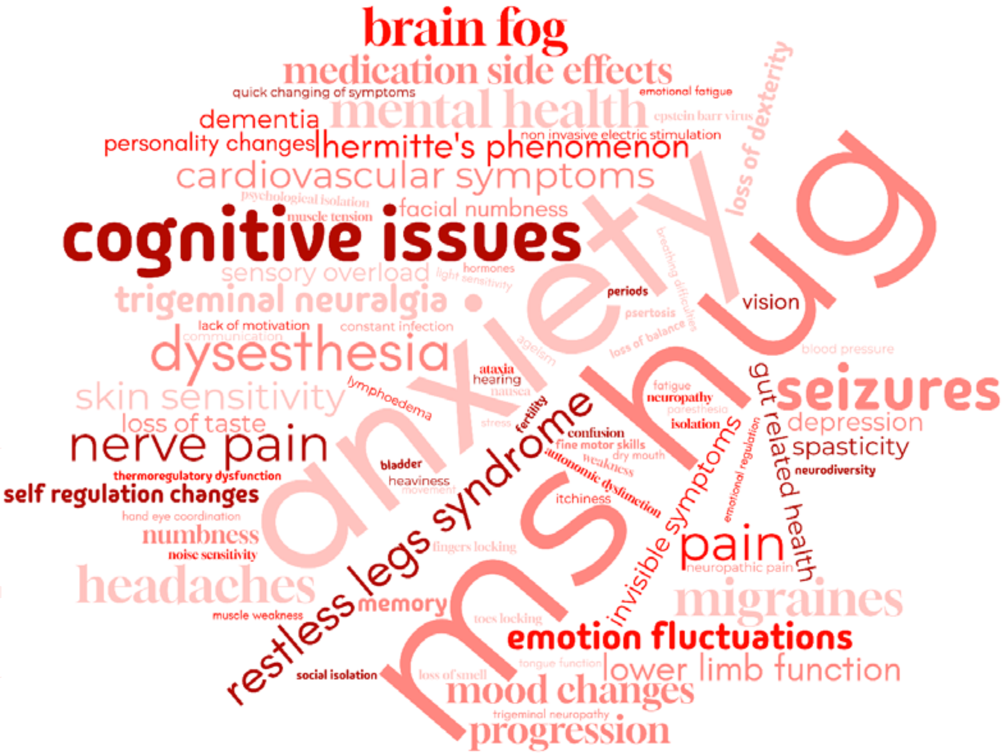

Figure 16. Participants were invited to identify any additional MS symptoms they felt required more research in an open-text field. The word cloud illustrates the most commonly mentioned symptoms. Words were filtered to remove stop words.

Additional research priorities

To complement the structured survey questions, participants were invited to share any additional research questions they felt were crucial but not covered elsewhere in the survey. This open-ended question provided an opportunity for participants to express unique concerns, emerging interests, or underrepresented research areas in their own words.

Using the thematic code approach described in the Methods section, the most frequently mentioned theme was *support and education for people with MS and their families*, highlighting a strong interest in research that improves quality of life through better information, emotional support, and community resources (Figure 17). Other notable themes included strong interest in *myelin repair and regeneration*, *stem cell therapy* – including autologous haematopoietic stem cell therapy (AHSCT) – as well as calls for more research into anxiety, menopause, fatigue, and the potential roles of EBV and genetics. While these themes are covered elsewhere in the survey, their reiteration here emphasises their importance to these participants.

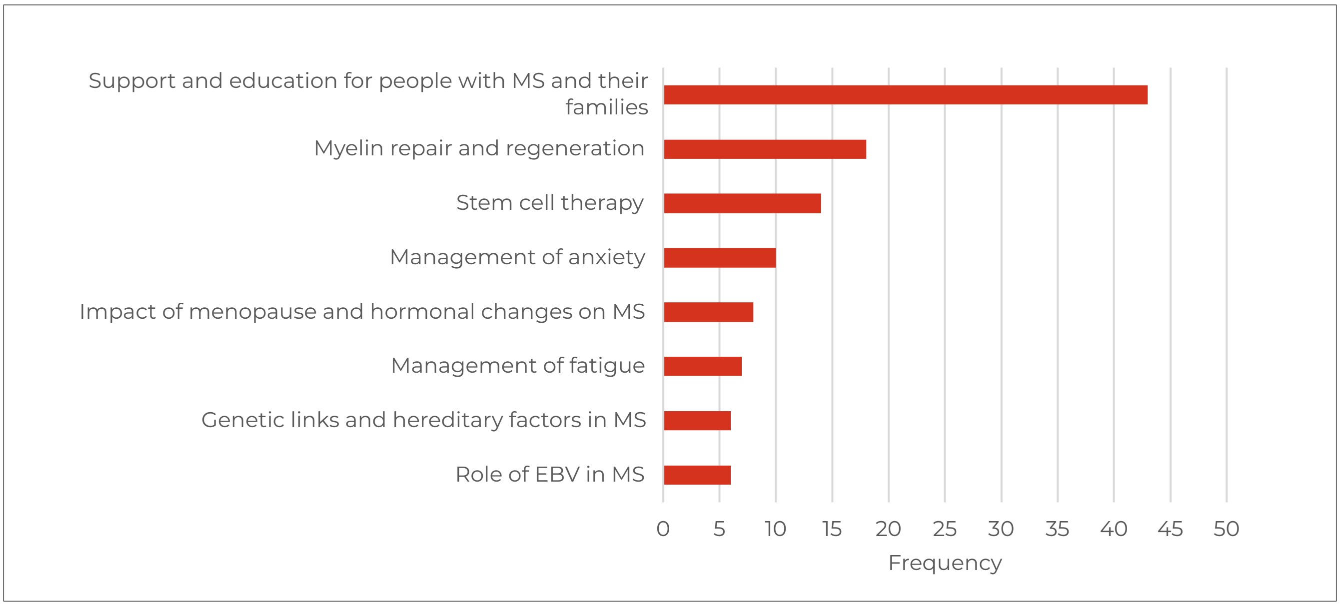

Figure 17. Participants were invited to identify any additional research themes they felt required more research in an open-text field. Top research themes identified from these free-text responses are shown.

Lifestyle changes and information needs

In this section, we aimed to understand participants' interest in making lifestyle changes that could potentially improve MS symptoms and overall quality of life, as well as any challenges faced in accessing or understanding reliable information regarding modifiable lifestyle factors such as physical activity, diet, and health supplements. Survey responses revealed a strong interest in lifestyle interventions among people living with MS, with 96% indicating they were interested in making changes to improve symptoms and overall quality of life. However, nearly three quarters (73.5%) reported difficulty accessing or understanding reliable information about modifiable lifestyle factors such as physical activity, diet, and health supplements, at least some of the time. Importantly, 76% of respondents stated they would be more likely to make lifestyle changes if provided with an easy-to-follow, MS-specific guide based on the latest evidence, highlighting a clear opportunity to support informed decision-making through tailored resources.

MS Australia's research program

Each year, MS Australia allocates a fixed amount of funding to support new investigator-led research across a range of priorities, including understanding the causes of MS, exploring prevention strategies, developing better treatments, and ultimately finding a cure. This funding is awarded through a competitive process involving independent peer review and final recommendations by MS Australia's Research Management Council. Grant categories include project grants, fellowships, scholarships, incubator grants and travel grants, all designed to foster impactful research at various stages of development.

MS Australia also commits funds towards national collaborative research platforms. These are initiatives designed to address key scientific questions in MS research that no single researcher could solve alone. These platforms bring together experts from various fields to collaborate on groundbreaking research, aiming to accelerate significant breakthroughs in understanding, treating, and ultimately curing MS.

For the first time, MS Australia sought community input on perceptions of research funding through a series of targeted questions. This provided valuable insights into perceptions of the effectiveness, priorities, and areas for improvement within both investigator-led grant funding and national collaborative research platforms.

The responses were analysed across all survey participants, with particular attention to three key groups: people living with MS, professionals working in the MS space, and MS researchers. For reporting purposes, ‘MS professionals’ refers to individuals in clinical, support, or service roles (e.g., nurses, neurologists, allied health professionals, care staff, and MS organisation staff), while ‘MS researchers’ refers to those engaged in scientific or academic research. This approach provides a more nuanced understanding of how perspectives on funding priorities and research effectiveness may vary depending on lived experience, professional involvement, or research expertise.

The responses offer important guidance for shaping future funding strategies to ensure they align with both research priorities and community expectations.

Investigator-led Funding

Community perspectives on the adequacy and allocation of funding towards investigator-led research were explored. Participants were asked to reflect on the effectiveness of current grant categories, the potential benefits of redistributing funds toward specific research types, and the value of collaborative, interdisciplinary approaches.

When asked whether current funding levels across different grant categories (i.e. project grants, fellowships, scholarships, incubator grants and travel grants) adequately support impactful MS research, a large proportion of participants were unsure (Figure 18A). Among MS researchers specifically, responses were relatively evenly divided; some believed the funding was adequate, others disagreed, and a significant portion remained unsure.

Participants were invited to provide suggestions regarding funding levels and how they could be improved to better support impactful MS research. A significant number of responses called for increased funding, highlighting the need for greater investment to support a broader range of research initiatives. Many participants emphasised the importance of ensuring that funding is used efficiently and directed toward projects with the greatest potential impact, such as those focused on finding a cure or improving quality of life. Others advocated for stronger government support and more involvement from corporate and philanthropic sectors. A few responses also noted the need for greater transparency in how funds are allocated and encouraged more community engagement in funding decisions. These insights reflect a strong desire for both increased resources and more strategic, inclusive, and outcome-focused funding approaches.

When participants were asked whether they would support a redistribution of funding to prioritise specific stages of research, such as fundamental, translational or clinical, a large proportion expressed either support for a more targeted approach or were unsure (Figure 18B). Once again, responses were relatively evenly divided among MS researchers; nearly half believed funding should be redistributed, another 40% were unsure, and a small proportion disagreed.

Responses to the question about the effectiveness of MS Australia’s investigator-led grants in supporting research that leads to tangible clinical or policy outcomes varied. However, over 90% of all participants believed the grants were at least moderately effective (Figure 18C). This suggests a substantial overall confidence in the value of investigator-led research. People living with MS also expressed support for investigator-led grants, with a large proportion rating them as moderately effective. In contrast, a greater proportion of professionals and researchers considered them to be very effective.

The survey also explored perspectives on whether research funding should prioritise collaborative, interdisciplinary projects over individual investigator-led initiatives. Approximately half of all participants preferred greater emphasis on funding collaborative, interdisciplinary research rather than individual investigator-led grants (Figure 18D). While only about 5% of participants disagreed with this approach, nearly 40% were unsure, suggesting some uncertainty or need for further information about the benefits of collaborative models. Notably, around 25% of researchers expressed a preference for individual grants, significantly higher than other participant groups, highlighting differing perspectives based on professional background.

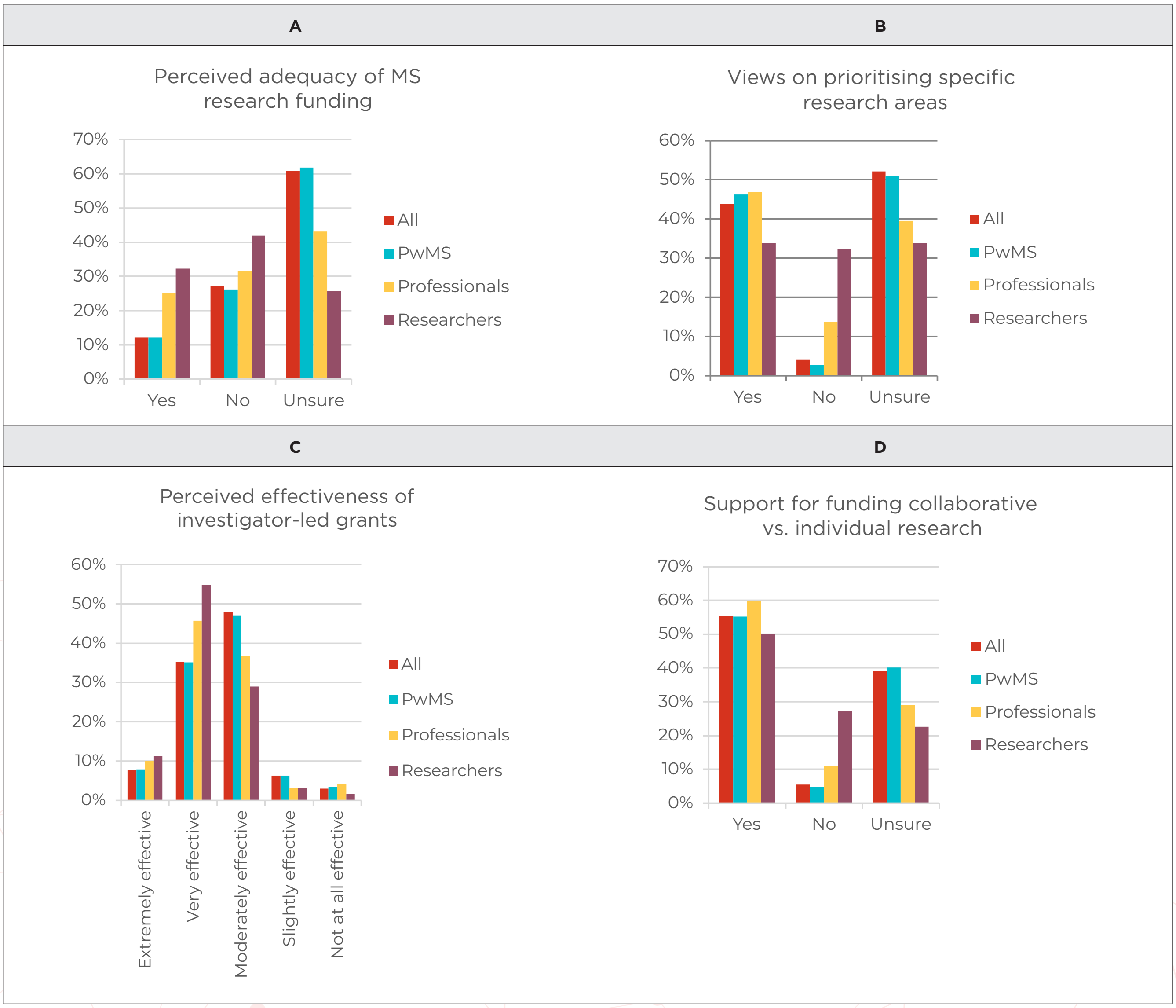

Figure 18. MS community perspectives on the adequacy and distribution of funding for investigator-led research. A) Perceptions of whether current grant funding levels adequately support impactful MS research. B) Support for funding redistribution prioritising fundamental, translational, and clinical research. C) Perceived effectiveness of investigator-led grants leading to tangible clinical or policy outcomes. D) Support for funding collaborative rather than individual projects. PwMS refers to people with MS.

National Collaborative Research Platforms

Community perspectives on several aspects of the national collaborative research platforms were also explored. These included awareness, data usage and contribution, perceived usefulness, funding levels, and suggestions for improvement.

Over 80% of professionals reported being familiar with at least one national collaborative research platform, indicating a strong level of awareness and engagement within the research and clinical community (Figure 19A). Among these platforms, the Australian MS Longitudinal Study and MS Australia Brain Bank emerged as the most widely recognised, with nearly 60% of professional participants indicating familiarity.

As expected, people living with MS were less familiar with the platforms as they may not encounter these unless they are directly involved in a study or are particularly engaged with the research community. This highlights an opportunity to improve communication about the role and impact of these platforms, especially how they contribute to advancing MS research and care.

To better understand engagement with MS Australia's national collaborative research platforms, participants were asked whether they had ever used or contributed data to one of these platforms. The analysis focused primarily on researchers, as they are the primary users and contributors to these platforms. Nearly half of the researchers surveyed reported having used or contributed to a national collaborative research platform, indicating a moderate level of engagement (Figure 19B).

Researchers were also asked to rate the usefulness of MS Australia's national collaborative research platforms in facilitating research, providing insight into how well these initiatives are supporting the research community. Over 70% of researchers rated these platforms as 'very useful' in facilitating research (Figure 19C). This suggests that these platforms are effectively meeting the needs of the research community by providing access to critical data that would be difficult to obtain independently.

Views on future funding levels for existing national collaborative research platforms offer insight into whether current investment is seen as sufficient or in need of adjustment. Nearly 70% of MS professionals thought funding levels should increase, showing strong support for growing these initiatives, which are seen as valuable tools for driving progress in MS research (Figure 19D).

Participants were invited to indicate any gaps or redundancies in research infrastructure that they believed required consideration in an open text field. Many highlighted the need for improved data infrastructure and digital platforms to support collaboration and access to research. Funding issues were also frequently mentioned, including calls for increased investment and more equitable distribution of resources. Other key concerns included requests for research into lifestyle changes to manage MS, and more research on progressive MS and symptom management. Some voiced concerns about perceived inefficiencies or redundancies in current research efforts. These insights underscore the value of continued investment in infrastructure, transparency, and inclusive research strategies that reflect the diverse needs of the MS community.

Specific suggestions for ways MS Australia can improve coordination and data-sharing between research platforms were requested in an open text field. Responses highlighted several key themes, including the need for enhanced digital infrastructure and tools such as artificial intelligence and real-time data tracking apps, as well as stronger collaboration and communication across states and institutions. Many participants called for greater transparency in data sharing and reporting, while others emphasised the importance of adequate funding and resources to support these efforts. A smaller number suggested creating a centralised platform for consistent access to research data. These insights reflect a clear desire for a more connected, transparent, and technologically supported research environment.

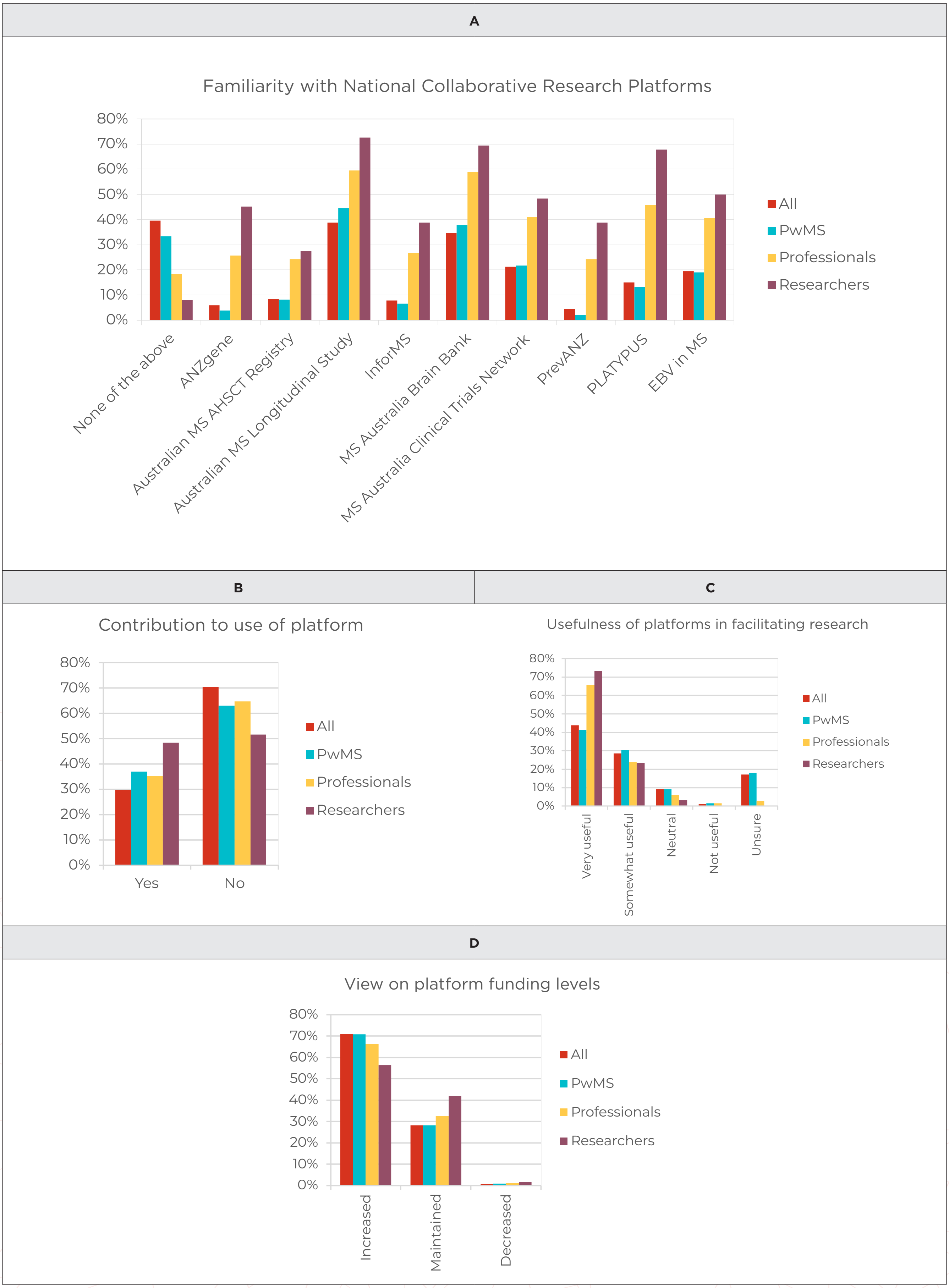

Figure 19. Awareness, engagement, and perceptions of MS Australia-supported collaborative research platforms. A) Familiarity of participants with national collaborative research platforms. B) Use or contribution to data to national collaborative research platforms by participants. C) Perceived usefulness of national collaborative research platforms in facilitating research. D) Perspectives on whether funding for these platforms should be increased, decreased, or maintained at current levels. PwMS refers to people with MS.

International Collaborations

MS Australia plays an active role in international research collaborations, working closely with the global scientific and health professional community to tackle the most pressing and complex questions in MS research. These partnerships enable Australian researchers to contribute to and benefit from large-scale studies, share data and expertise, and remain at the forefront of global scientific progress.

To understand how this aligns with the views of the MS community, participants were asked how important they believe it is for MS Australia to engage in internationally collaborative research efforts. Over 80% of all participants thought these international collaborations were extremely important, highlighting strong community support for MS Australia's involvement in global scientific efforts (Figure 20). This likely reflects a shared understanding that solving complex challenges in MS requires a united, international approach.

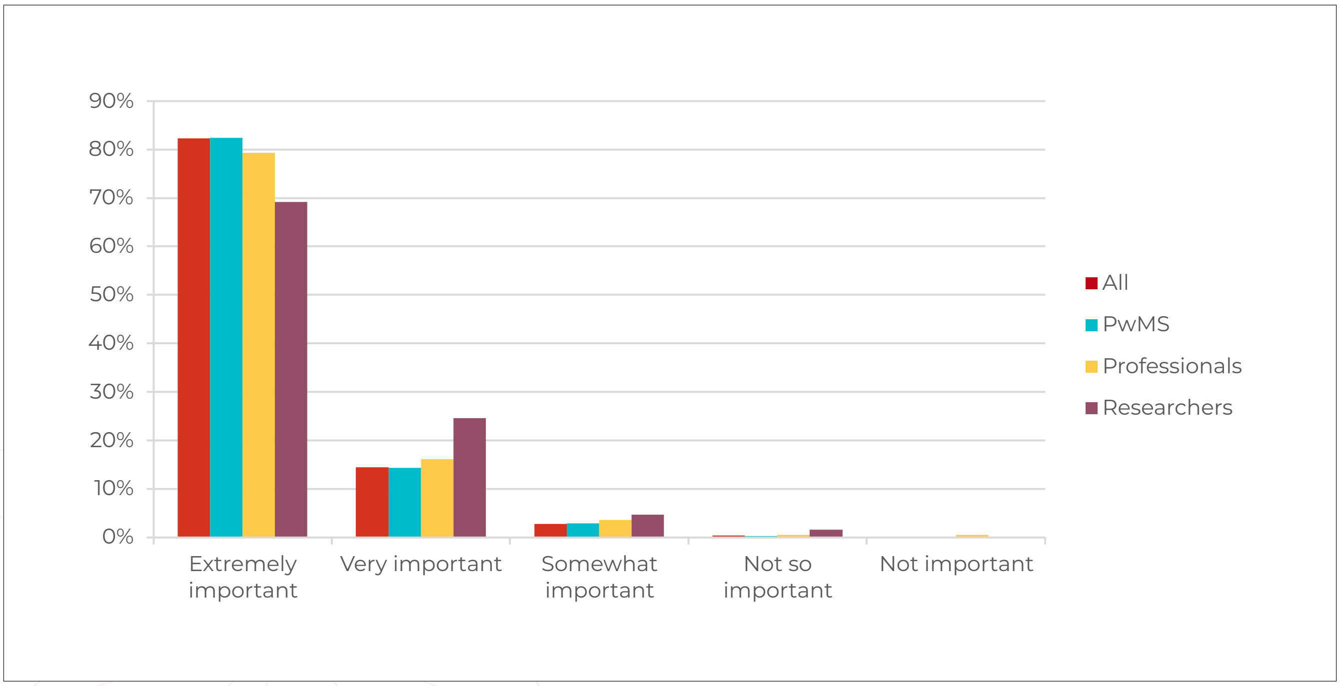

Figure 20. Support for MS Australia's participation in international research collaborations to address complex global research challenges. PwMS refers to people with MS.

Overall advocacy priorities

Advocating on behalf of the MS community is a core function of MS Australia. As part of this commitment, the survey presented a range of areas that can significantly impact the lives of people living with MS. Participants were asked to indicate the priority they placed on advocacy efforts in each of these areas, without needing to rank them in relation to one another.

Using a weighted average to reflect the broader perspective by incorporating all rankings, the top six priorities were as follows:

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 are in alignment with the results of the 2021 survey. The full list of priorities is shown in Figure 21.

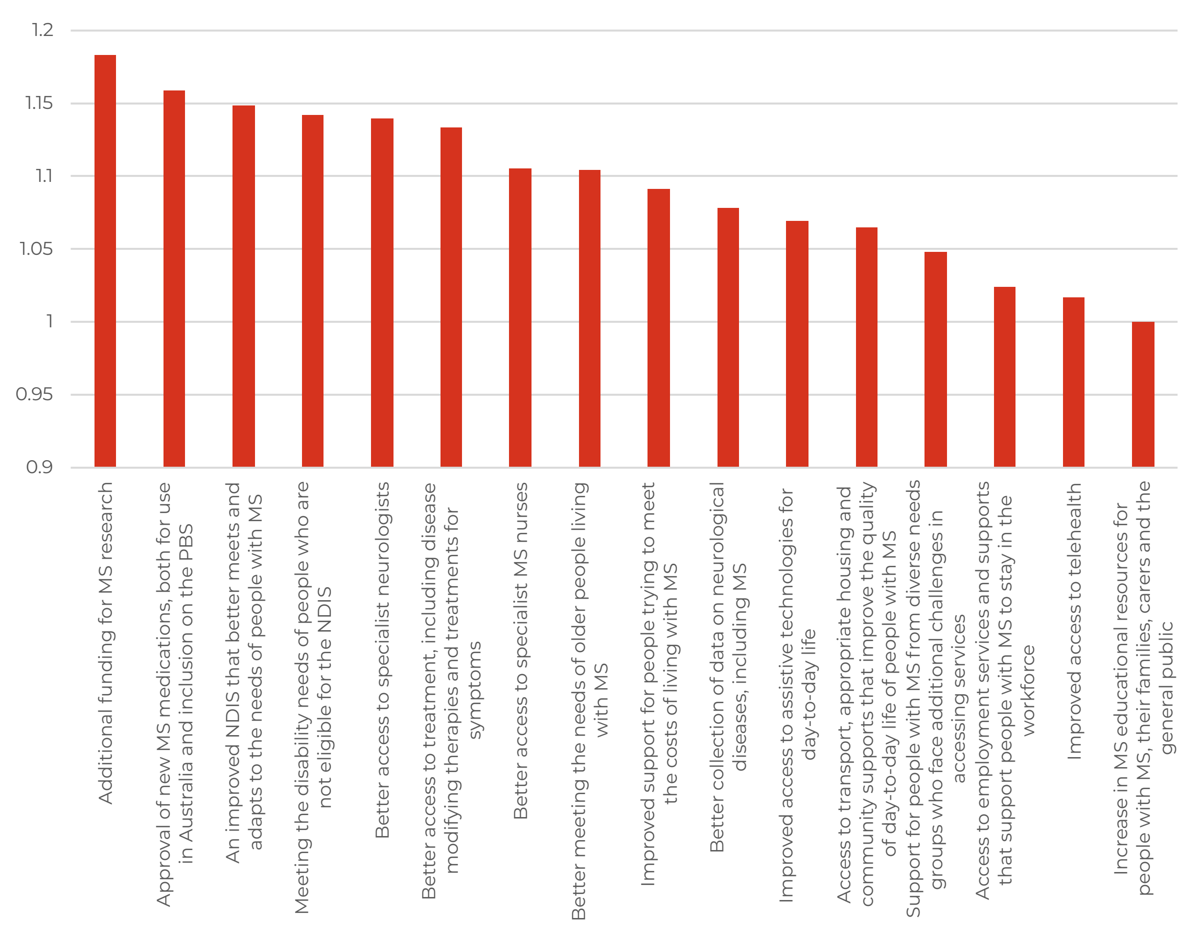

Figure 21. Participants were asked to indicate the level of priority they placed on advocacy efforts across various areas, ranging from 'very high priority' to 'not a priority'. The weighted average ranking for each topic was calculated across all responses and normalised relative to the area of lowest priority. In this graph, higher values indicate higher overall priority among participants.

When focusing on participants with different types of MS, the order of the advocacy priorities shifted. Figure 22 shows the top six advocacy priorities for people with different types of MS. *Additional funding for MS research* had the highest number of 'very high priority' rankings among participants with RRMS, SPMS and PPMS. In contrast, participants with CIS most frequently ranked *better access to treatments* and *better meeting the needs of older people living with MS* as 'very high priority'. It is important to note, however, that the number of participants in the CIS group was relatively small.

Approval of new MS medications received the second-highest number of 'very high priority' rankings among participants with SPMS and PPMS, likely reflecting the limited treatment options currently available for progressive forms of MS.

Figure 22. Participants living with MS were asked to indicate the level of priority they placed on advocacy efforts across various areas, ranging from 'very high priority' to 'not a priority'. The graphs display responses from individuals with different MS subtypes. A) RRMS - Relapsing remitting MS, B) SPMS - Secondary progressive MS, C) PPMS - Primary progressive MS, D) CIS - Clinically isolated syndrome. Only the top two response categories - 'Very high priority' and 'high priority' - are shown.

To complement the structured survey questions, participants were invited to share any additional advocacy issues they felt were crucial but not covered elsewhere in the survey in an open text field.

Using the thematic code approach outlined in the Methods section, the analysis identified *NDIS access and eligibility* as the most frequently mentioned theme (Figure 23). This was followed by *support for carers and families*, *healthcare and treatment access*, and *regional and remote service gaps*. Other notable themes included *employment and workplace inclusion* and *research*.

Importantly, several of these themes echoed priorities already identified in the structured sections of the survey, particularly the importance of funding for research, reinforcing their significance across the MS community. These findings highlight the diverse and complex needs of people living with MS, particularly around equitable access to treatment, services and support systems.

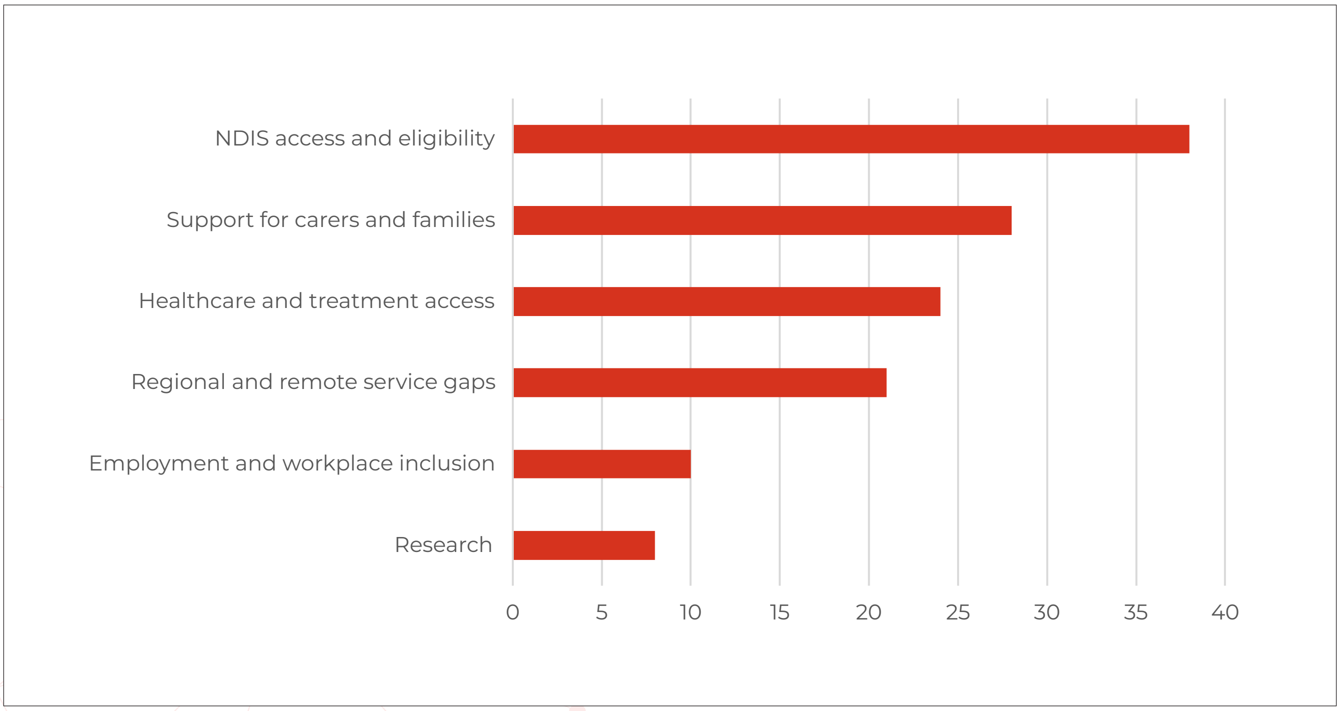

Figure 23. Participants were invited to identify any additional advocacy themes they felt required prioritisation in an open-text field. Top ranked advocacy themes identified from free-text responses.

Campaign awareness

To assess the reach and visibility of MS Australia's advocacy and engagement efforts, participants were asked about their awareness of various national campaigns, programs, and outputs, including *A Better NDIS for People Living with MS*, Count Us In, What is MS? *video resource* and the Lived Experience Expert Panel. This question aimed to gauge how effectively these initiatives are being communicated to the community and to identify potential gaps in outreach or engagement.

Around 40% of participants reported being aware of at least one of MS Australia's national campaigns, programs or outputs (Figure 24). This suggests that many in the community are engaging with our national initiatives, with some key target groups showing particularly strong awareness.

A case in point: around one in four participants recalled the *Better NDIS for People Living with MS* campaign. This is a strong result when viewed against the proportion of the MS community who are NDIS participants, showing that the message resonated strongly with those most affected.

Awareness levels are naturally influenced by the audiences each campaign is designed to reach. Some initiatives are targeted to policymakers or highly engaged groups most likely to take action, rather than the broader MS community, so widespread recognition is not always the primary objective.

Notably, younger participants (18–30) reported the highest awareness of the Lived Experience Expert Panel (LEEP). While this was not a campaign targeted to young people specifically, it suggests that younger members of the MS community are particularly engaged with initiatives that highlight lived experience and opportunities for direct involvement.

The Count Us In campaign, although shared across MS Australia's channels, was led by the Neurological Alliance Australia (NAA) and carried NAA branding, which may have influenced recall.

These results indicate that we should continue targeting the right people with the right messages, while also working to gradually increase awareness of our campaigns across the wider community.

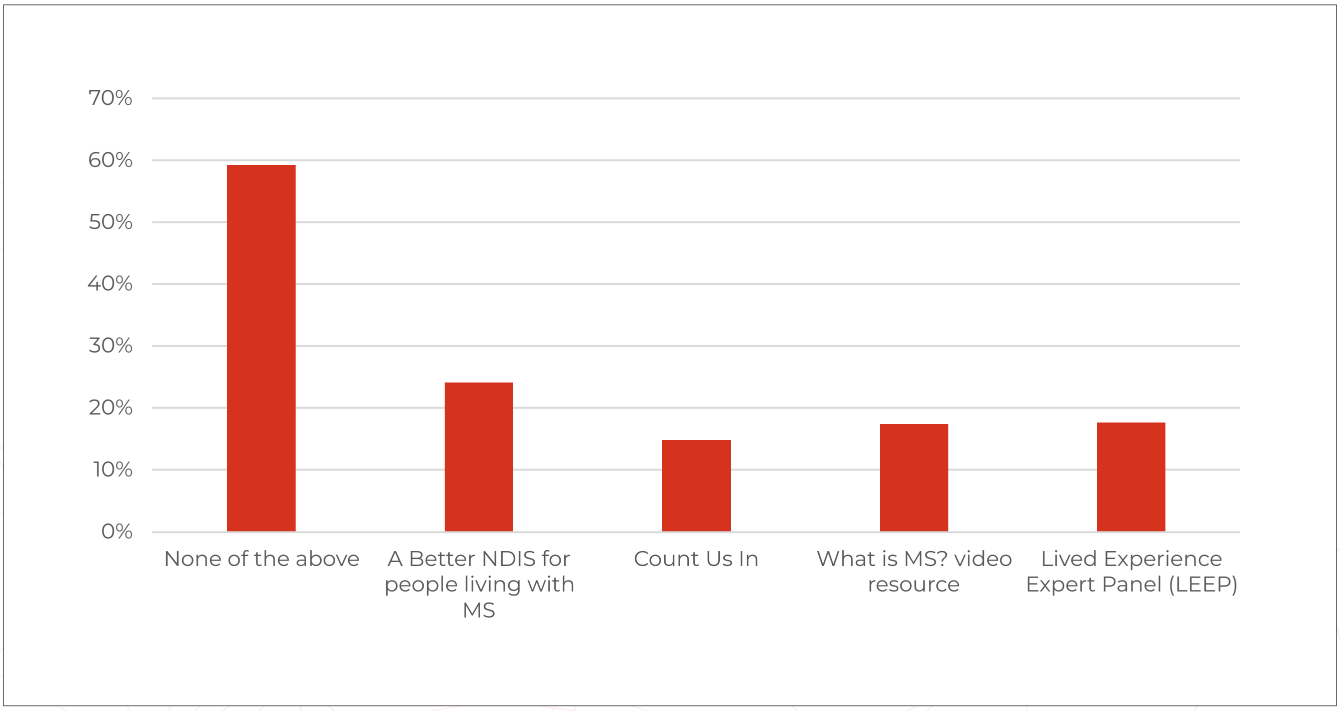

Figure 24. Awareness of national campaigns, programs, and informational resources among survey participants.

Communication

To evaluate the effectiveness of MS Australia's communication efforts, survey participants were asked to rate how well the organisation communicates its research and advocacy activities. Nearly 70% of participants reported that MS Australia communicates its research and advocacy efforts at least *well* or *very well*, showing a strong level of trust and confidence in the organisation's outreach (Figure 25).

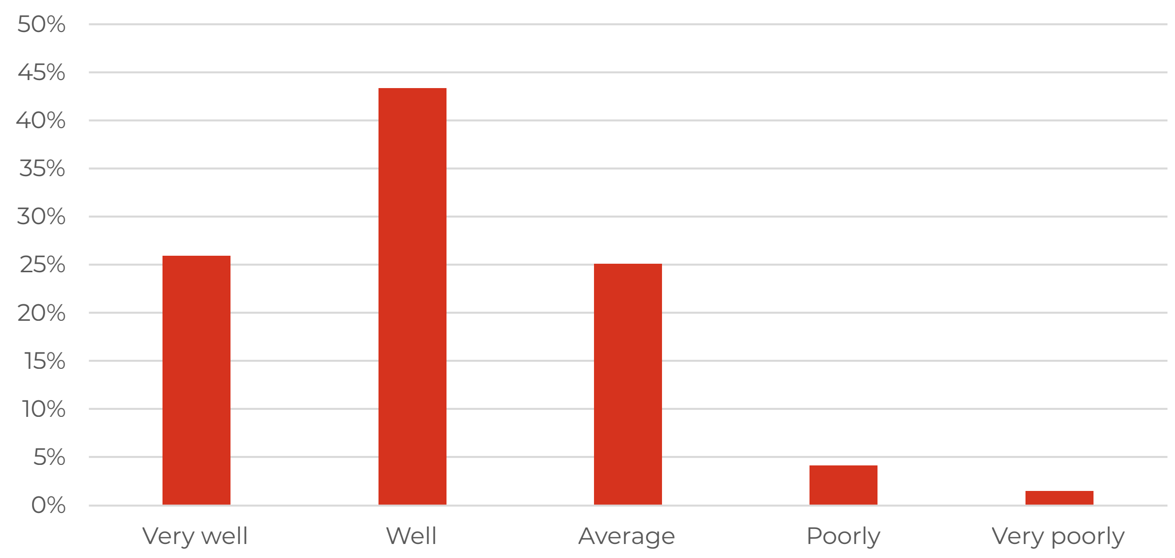

Figure 25. Survey participants were asked to rate how well the MS Australia communicates its research and advocacy activities, ranging from 'very well' to 'very poorly'.

Survey participants were also asked about their satisfaction with how outcomes and impacts from research funding decisions are communicated. Nearly 50% of participants reported being satisfied with the current approach, providing a solid foundation on which to build.

Differences in satisfaction likely reflect the diverse ways people engage with information. Many in the community primarily access updates through MS Australia's digital channels or the MS Wire newsletter, while others rely on information provided by state-based MS organisations. The survey also revealed that some participants were unclear about the distinction between MS Australia and the state organisations, which may influence how people perceive and recall national communications (see next section on 'Resources').

Taken together, these findings highlight that MS Australia's communication of research and advocacy is well regarded and that there are clear opportunities to further increase visibility and clarity.

Resources

Participants were invited to share which MS Australia resources and activities they found most helpful in supporting their needs and experiences. Over half of the survey participants reported that the MS Wire newsletter was helpful, suggesting it is one of the most visible and widely accessed resources (Figure 26). Other resources and activities were recognised by smaller proportions of the community, but this may reflect their more specific purpose. For example, the Crisis Toolkit, may only be needed in particular circumstances, yet it is especially valuable to those who rely on it.

Together, these results highlight the importance of offering a broad mix of resources to meet the diverse needs of people living with MS.

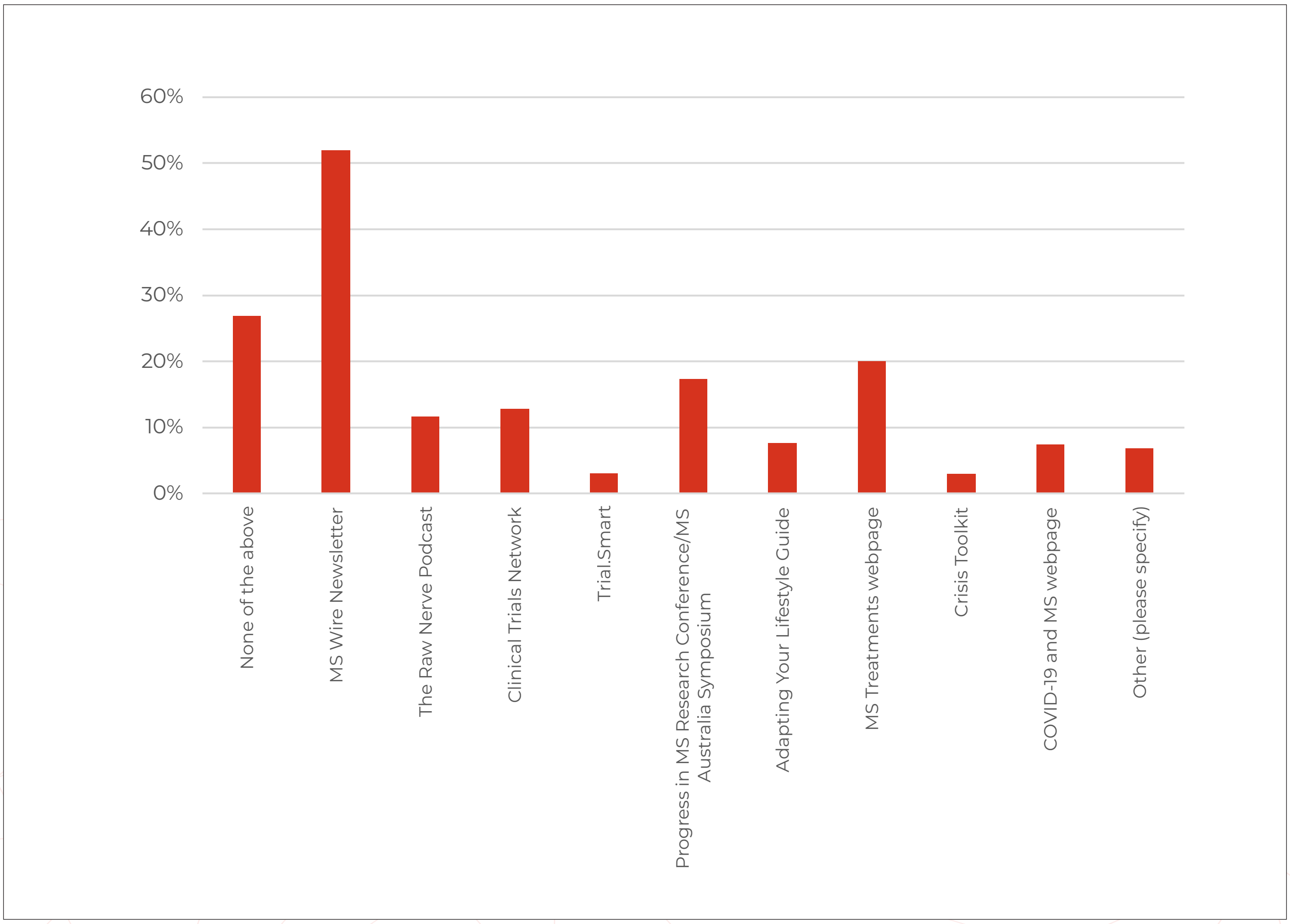

Figure 26. Survey participants were asked about which MS Australia resources and activities have been helpful to them.

Participants were invited to indicate any additional information or resources they would like MS Australia to provide in an open text field. Many participants requested clearer and more accessible information about MS research, treatments, and services, including updates on clinical trials and simplified summaries of research findings. Others highlighted the need for improved emotional and peer support, such as counselling, support groups, and compassionate communication from MS staff. A significant number of responses focused on better access to services and practical support, especially for those in regional areas or with less advanced forms of MS.

Some participants called for more resources tailored to families and caregivers, while others emphasised the importance of public awareness and advocacy to improve understanding and funding. Finally, several responses suggested more personalised communication, such as targeted newsletters or podcasts, and easier ways to navigate the full range of resources available.

From these responses, it was also evident that some participants were unclear about the distinction between MS Australia and state-based MS organisations, with several responses suggesting that service delivery responsibilities were being attributed to MS Australia rather than the relevant state organisations.

Digital engagement

This section of the survey explored how individuals engage with MS Australia’s digital platforms, including website visits and social media following, to assess the reach and effectiveness of our online communication channels.

MS Australia’s digital platforms continue to play an important role in connecting with the community. Among participants who follow our channels, Facebook is the most popular, with more than 40% engaging on that platform. This confirms Facebook’s role as a key touchpoint for information and updates, while also showing the potential to expand engagement across other platforms.

Smaller but significant groups of participants also follow MS Australia on LinkedIn (8%) and X (formerly Twitter) (33%), indicating a presence across both professional and broader public audiences. While just over half of survey participants indicated that they are not currently connected with MS Australia on social media, this highlights a strong opportunity to grow the online community and reach new audiences.

Engagement patterns did not vary greatly by age, although younger participants reported slightly higher use of certain platforms. These results suggest that continued investment in tailored digital strategies, alongside offline communication and community-based approaches, will enable MS Australia to expand its reach, strengthen connections, and ensure key messages resonate with a broader cross-section of the MS community.

Overall strategy

To understand community perspectives on MS Australia's overall strategic direction, survey participants were asked whether the organisation should prioritise efforts in MS research, advocacy, and the provision of evidence-based information and resources. This question aimed to gauge support for a focused approach that addresses both scientific advancement and the practical needs of people living with MS. An overwhelming 93% of participants either agreed or strongly agreed with this approach, highlighting strong community endorsement for these core areas of focus.

Conclusions, reflections and next steps

Research priorities

The survey results indicate that a top priority for the community is research into a cure via repair and regeneration, followed by prevention and better treatments. There is a strong preference for clinical research, which is likely to have an immediate impact, but the community appreciates that a long-term approach is also needed, with translational research and fundamental research also being prioritised. Regarding the streams of research, neurobiology was favoured, with strong support for immunology and virology, and clinical trials. There was less support for genetics and epidemiology, and social and applied research.

Research program

There were a range of perspectives on how investigator-led funding should be allocated and its effectiveness. While many participants were unsure whether current funding levels across grant categories are adequate, there was broad support for investigator-led research, with over 90% rating it at least moderately effective. Some participants, particularly researchers, expressed a preference for maintaining individual grants, though many supported or were open to redistributing funds toward specific research types or prioritising collaborative, interdisciplinary projects. These findings suggest strong overall confidence in the value of current funding models, while also pointing to opportunities for greater clarity, flexibility, and collaboration in future funding strategies.

In addition to views on investigator-led funding, participants also shared their perspectives on MS Australia's national collaborative research platforms. Platforms such as the Australian MS Longitudinal Study and MS Australia Brain Bank, were well recognised among professionals, who generally viewed them as valuable tools for supporting research. People living with MS were less familiar with these initiatives, pointing to an opportunity to improve communication about how these platforms contribute to advancing knowledge and care. Researchers reported using and benefiting from these resources, and there was strong support for increasing investment to ensure they continue to grow and meet the evolving needs of the MS research community.

MS Australia's support of top research goals

MS Australia supports a comprehensive research program that addresses the complex nature of MS. Our investment spans a wide range of scientific disciplines, including neurobiology, immunology and virology, clinical trials, genetics, epidemiology, and social and applied research. We also support research into the symptoms of MS as part of our commitment to improving day-to-day life for people living with the disease. This reflects multifaceted challenges of understanding, treating, and ultimately curing MS. By funding and supporting research across these interconnected streams, we aim to accelerate discoveries that inform prevention strategies, lead to better treatments, and ultimately find a cure for MS.

A cure for MS via repair or regeneration of cells

In 2025, nearly half of the grant funding awarded by MS Australia was dedicated to the field of neurobiology, the top research stream identified by the MS community. Neurobiology focuses on understanding how MS affects the brain and spinal cord, providing essential insights into the disease's underlying mechanisms. This fundamental research is essential for building the scientific framework upon which future breakthroughs can be developed.

Neurobiology serves as a critical springboard for multiple areas of investigation, including the MS community's top priority of discovering a cure through the repair and regeneration of damaged cells.

Supporting this effort, the MS Australia Brain Bank provides researchers with access to donated brain and spinal cord tissue enabling direct investigation into the neurobiology of MS. This resource underpins studies aimed at uncovering the causes of MS, identifying changes at the neurobiological level, and exploring the molecular mechanisms that drive progressive forms of the disease, all of which align with the overarching goal of developing reparative and regenerative treatments.

Further reinforcing this focus is the PLATYPUS trial (PLatform Adaptive Trial for remYelination and neuroProtection in mUltiple Sclerosis) – Australia's first adaptive clinical trial for MS. PLATYPUS is the Australian extension of the UK OCTOPUS trial, funded by the UK MS Society. Supported in Australia by MS Australia and MSWA, this innovative trial is testing repurposed drugs that may promote remyelination and neuroprotection, towards repair of damaged nerve cells in people with progressive MS. Using a multi-arm, multi-stage (MAMS) design, PLATYPUS accelerates the evaluation of potential therapies, offering renewed hope for reversing neurological damage and moving closer to a cure.

Prevention of MS

The next highest priority identified by the MS community is the *Prevention of MS*, an area that is receiving growing attention from the research community.

In 2025, MS Australia significantly advanced its investment in prevention-focused research and initiatives, reflecting the growing priority placed by the MS community on stopping the disease before it starts. Prevention research explores the earliest biological and environmental triggers of MS, aiming to reduce the incidence of the disease and enable earlier intervention.

A cornerstone of this effort is the Global MS Prevention Initiative, launched in partnership with MS Canada. This international collaboration brings together researchers, clinicians, and people with lived experience to investigate how MS develops at its earliest stages. The initiative is focused on identifying biological markers and risk factors that could allow for ultra-early detection and intervention, potentially halting the disease before symptoms appear.

Complementing this is the EBV in MS platform, which has brought together researchers to explore the role of EBV, a factor strongly linked to the onset of MS. By understanding how EBV may trigger MS, researchers hope to develop preventive strategies, including vaccines or antiviral therapies, that could dramatically reduce new cases of MS.

The Australia and New Zealand MS Genetics Consortium (ANZgene) plays a key role in prevention-focused research by investigating the genetic factors that contribute to MS susceptibility and progression. By identifying genetic changes associated with increased risk, ANZgene is helping to build a clearer picture of the biological pathways involved in the onset of MS. This foundational knowledge is essential for developing strategies to prevent the disease before it begins, including identifying at-risk individuals and informing early intervention efforts.

In addition, over a quarter of grants awarded in 2025 are dedicated to uncovering the causes and risk factors of MS, including cellular signatures, genetics, immune system behaviour, and environmental influences such as EBV exposure. These studies are essential to building a comprehensive prevention strategy that addresses both biological and lifestyle-related contributors to MS.

Better treatments

Another top priority identified by the MS community is the development of better treatments, which continues to gain momentum as researchers work to improve outcomes and quality of life for people living with MS.

Over a quarter of the grants awarded in 2025 are focused on better treatments for MS. This includes exploring new therapies, advancing precision medicine approaches, and addressing symptom management. These studies are essential for developing more effective and personalised treatment strategies that address the underlying causes of disease activity and progression, while also helping people manage the wide-ranging symptoms of MS more effectively.

A key contributor to this effort is the Australian MS Longitudinal Study, a long-running, survey-based research platform jointly managed by MS Australia and the Menzies Institute for Medical Research. The Australian MS Longitudinal Study collects real-world data from thousands of Australians living with MS, providing critical insights into treatment effectiveness, quality of life, and the long-term impacts of DMTs. This data helps shape clinical practice, inform policy, and guide the development of more targeted and responsive treatment strategies.

Complementing this, the InforMS patient-centred portal gives people with MS easy access to their personal health data – including reports or results from their neurologist or MS nurse, individual care plans, and their own Australian MS Longitudinal Study survey data. This will enable them to track their health outcomes over time, upload data from apps and wearables, and share this information with their healthcare team. It provides more timely and sensitive data collection to improve clinical care and research, towards a personalised or “precision” medicine approach to MS treatment.

The survey revealed that while almost all people with MS are interested in making lifestyle changes to improve their long-term outcomes, many face challenges accessing or understanding reliable information, and most would be more likely to act if provided with an easy-to-follow, MS-specific guide. In response to this continuing interest, and as part of its commitment to improving quality of life and treatment outcomes, MS Australia developed *Living Well with MS: Your Guide to Adapting Your Lifestyle* to help individuals make informed lifestyle choices that complement medical treatments and support overall wellbeing. This strong interest in lifestyle approaches highlights the community’s desire to take a proactive role in managing their MS and feel more empowered in shaping its course.

While also exploring prevention, the EBV in MS platform is investigating the potential of repurposed antiviral drugs to treat progressive MS and fatigue, two challenging aspects of the disease. Chronic EBV infection is increasingly believed to play a role in ongoing disease activity and symptoms like fatigue. Clinical trials such as FIRMS-EBV and STOP-MS aim to determine whether targeting EBV with antivirals can reduce progression and improve symptom management.

Similarly, while ANZgene’s primary focus is on understanding genetic risk, its discoveries also have important implications for treatment. Insights into the genetic mechanisms underlying MS can inform the development of more targeted therapies and support the advancement of precision medicine. By linking genetic profiles with disease progression and treatment response, ANZgene aims to contribute to the broader goal of delivering more effective and personalised care for people living with MS.

The PLATYPUS clinical trial also contributes to the better treatments landscape by testing repurposed therapies that may offer new options for people with progressive MS.

Advocacy priorities

The top advocacy priorities for people living with MS include increased funding for MS research, timely access to new and effective MS medications, and improvements to the NDIS to better meet their needs. These community-identified priorities reflect the real-world challenges faced by people living with MS and guide our efforts to influence policy, improve services, and drive systemic change.

MS Australia's support of top advocacy goals

Additional MS research funding

MS Australia has called for major investments MS research funding in its 2025-2026 Pre-Budget Submission. This includes $300 million over ten years for the establishment of a Neurological and Neuromuscular Health Research Mission within the Medical Research Future Fund (MRFF). The mission will coordinate, action and accelerate neurological and neuromuscular research to improve the prevention, detection, treatment and care of these conditions, including MS.

In addition, MS Australia has asked for an investment of $8 million over five years for the establishment of a National MS Biobank to advance research efforts focussed on the early detection and prevention of MS. Earlier detection of MS requires the development of reliable markers of early disease, an effort that is reliant upon MS biobanks to collect blood and other biological samples to enable medical research and generate scientific knowledge. A nationally collaborative approach to MS biobanks would significantly improve the impact of biobanking on MS research.

As a final ask, MS Australia has called for a $4 million investment over four years to improve access to life-changing MS Nurse care for people living with MS, including $1 million for a National Strategy to establish credentials, career pathways, and training programs, and $3 million for a pilot project to expand MS nursing capacity and conduct research and evaluation. The findings from the MS Nurse Care in Australia report indicate that people with MS who are unable to access MS Nurse care are adversely affected in terms of health outcomes. MS Nurse care delivers significant benefits, including improved health outcomes and more personalised, tailored care for people with MS. It helps reduce unplanned emergency department visits and hospital admissions, lowering overall MS care costs. Additionally, it decreases reliance on more expensive healthcare professionals by offering a cost-effective, specialised model of care.

Approval of new MS medications

MS Australia strongly supports equitable and affordable access to all medications that have been clinically proven to improve health outcomes for people living with MS. Ensuring timely access to effective treatments is essential for managing disease progression, enhancing quality of life, and reducing the long-term burden on individuals, families, and the healthcare system.

Multiple submissions have been made to the Pharmaceutical Benefits Advisory Committee (PBAC) in 2025 to support the listing of new MS medications on the Pharmaceutical Benefits Scheme (PBS), including ublituximab (Briumvi®) and subcutaneous ocrelizumab (Ocrevus®) for RRMS. Additionally, MS Australia provided a submission to the PBAC advocating for Pharmaceutical Benefits Scheme (PBS) amendments to allow nurse practitioners to prescribe key MS treatments. Empowering nurse practitioners in this way promotes equitable access to the best available therapies, particularly for people living in regional and remote areas. This change helps address critical access gaps, eases pressure on neurologists, and ensures more consistent, comprehensive care for people with MS.

An improved NDIS for people living with MS

Over the past decade and across more than 30 policy submissions, MS Australia has actively advocated on behalf of people living with MS for improvements to the NDIS.

MS Australia actively participated in the 2023 NDIS Review, submitting detailed recommendations and launching the *A Better NDIS for People Living with MS* campaign. They identified six key reforms to improve the NDIS for people living with MS, calling for better understanding of MS among NDIS staff, faster and more consistent access to the Scheme, and early intervention supports to prevent deterioration. MS Australia also advocated for improved access to assistive technology and appropriate housing, better recognition of the vital role MS Nurses play in delivering coordinated care, and a more inclusive and equitable system that addresses age discrimination and supports those not eligible for the NDIS.

In response to sustained advocacy, the National Disability Insurance Agency (NDIA) established the Neurodegenerative, Palliative Care and Rare Diseases Advisory Group in 2024 to provide expert guidance on the needs of people with neurodegenerative, neuromuscular or rare conditions, or those requiring palliative care. The group includes a diverse range of representatives from across the neurological and rare disease sectors, including MS, ensuring that the voices of people with MS and similar conditions are heard in the design and delivery of the NDIS.

MS Australia's strategic engagement and outreach

MS Australia maintains a strong and multifaceted communication presence through both digital and traditional channels. Its online platforms, including a regularly updated website, active social media accounts, and the widely circulated MS Wire newsletter, serve as key touchpoints for community engagement. Additionally, the quarterly hardcopy MS Wire newsletter ensures continued access to information for those who prefer or rely on printed materials. These channels collectively support the organisation's efforts to inform, connect, and advocate for people living with MS across Australia.

The survey results highlight both the strengths and opportunities in MS Australia's advocacy and engagement efforts. Building on a solid foundation, with nearly 70% of participants rating MS Australia's communication efforts highly and the survey results indicating the effectiveness of targeted campaigns, there exist valuable opportunities to strengthen communication and outreach efforts, ensuring that the full breadth of available resources is more visible and accessible to the MS community. Notably, younger participants (18-30) showed higher awareness of the LEEP, suggesting that age-specific outreach strategies may be effective.

Communication from MS Australia is generally well-regarded, although, the 50% who were either unsure or unsatisfied with how outcomes and impacts from research funding decisions are communicated point to a need for clearer, more transparent reporting.

The MS Wire newsletter stands out as a widely regarded resource in terms of helpfulness, while a smaller number of participants found other resources helpful. It should be noted, however, that some resources, such as the Crisis Toolkit, may be particularly valuable to smaller or more specific populations. This presents an opportunity to strengthen the perceived value and impact of the full range of MS Australia resources.

Participants highlighted the need for clearer, more accessible information on MS research, treatments, and services; stronger emotional support and peer networks; and practical assistance tailored to families, caregivers, and those in regional areas or with less advanced MS. Suggestions also emphasised personalised communication and broader public awareness.

While MS Australia publishes progress updates for all funded projects tailored to the MS community on its website, and maintains a dedicated MS treatments page, participant feedback indicates a need to improve visibility and engagement with these resources.

Notably, some responses reflected confusion between MS Australia and state-based MS organisations, with service delivery expectations occasionally directed toward MS Australia. This underscores the need to clarify organisational roles and improve communication across the MS community.

There is a strong opportunity to enhance digital engagement. While Facebook is currently the most used platform, more than half of participants are not yet connected with MS Australia on social media, highlighting significant potential to grow the online community.

To broaden reach, especially beyond digital platforms, MS Australia could consider more in-person and community-based approaches, such as local events, printed materials in clinics, and peer-led outreach. These strategies can complement online efforts and help ensure campaign messages resonate across diverse audiences.

Overall, the findings reflect a solid foundation of trust and engagement, with clear pathways to enhance visibility, communication clarity, and community connection.

Conclusion

The strong response to the survey highlights the deep engagement of the MS community in Australia. It underscores the community's strong support for MS research and advocacy and for the work of MS Australia. The breadth and depth of participation ensure that the findings are representative of the wider MS community, offering valuable and credible insights into their evolving priorities. These insights will play a critical role in shaping MS Australia's research and advocacy strategies, ensuring they remain aligned with the needs, expectations, and aspirations of MS community.

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