MS Research Australia

MS Community Consultation on Priorities for MS Research

DETAILED REPORT

CONTENTS:

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1. SURVEY METHOD AND DISSEMINATION

To seek feedback on our current and future research strategy, MS Research Australia designed and implemented a survey with questions about the broad goals of MS research, the fields of research needed to achieve those goals, types of research (basic, or 'fundamental' research, translational and clinical trials) as well as specific unanswered research questions within each research goal area. The survey design utilised questions from a survey conducted by the UK MS Society in 2012, which was developed using the robust James Lind Alliance process which works with health professionals and health consumers to prioritise the unanswered research questions in a particular disease field. Our survey updated these questions for the Australian context, with additional questions directly relating to MS Research Australia's goals and research strategy.

Prior to implementation the survey was tested by a group of volunteers which included people with MS, people with a close connection to MS and people with a professional connection to MS. Feedback was collated and incorporated into the survey design where possible and appropriate.

The survey was set up online using the Survey Monkey tool. People who wished to participate but were unable to do so online were provided with a paper copy of the survey and returned survey responses were manually entered into Survey Monkey by MS Research Australia staff.

The survey was promoted and disseminated using a wide range of communication channels and stakeholder groups. MS Research Australia and Kiss Goodbye to MS publicised the survey via direct e-mail to our database of contacts, in monthly e-Newsletters during May and June 2016, in the MS Research Australia quarterly print newsletter (June 2016 issue) and via the MS Research Australia and Kiss Goodbye to MS websites and social media channels (Facebook, Twitter). The Facebook link to the survey was shared by individuals and other MS organisations and groups via their own Facebook pages. MS Australia and the state MS Societies also promoted the survey via their newsletters and social media channels and internal communications encouraged MS society staff to participate. Mass emails encouraging participation were also sent to researchers, neurologists, MS nurses and other health and allied health professionals via the MS Research Australia database and also to MS nurses with the help of MS Nurses Australasia.

Participants were advised that the survey was anonymous. No names were collected and only generic demographic details were collected to assist in determining whether a broad spectrum of the MS community had participated and to analyse any differences in priorities based on the type of connection a person had to MS.

To determine the statistical differences between the prioritised research areas and between the different groups of respondents, statistical analysis was carried out using contingency tables based on a statistic called Chi-square, differences were considered significant if the p value was equal or less than 0.05. This means that any differences are unlikely to be due to chance.

2. WHO RESPONDED?

We had a very impressive response to the survey with 1254 people responding. Of these, 1058 completed at least 75% of the survey and are included in the analysis. 774 of these respondents had a diagnosis of MS or a closely related condition (e.g. clinically isolated syndrome or neuromyelitis optica). 219 respondents had a close personal connection to MS (for example family member or friend) and 65 respondents had a professional connection to MS (researcher, health professional or allied health professional).

The demographic details of the people with MS who responded to the survey revealed a very broad cross section of people with MS had participated in the survey (see Figures 1-4). 81% of respondents with MS were women, which is only a little more than would be expected based on the knowledge that MS is diagnosed three times more frequently in women than men in Australia.

In an independent analysis conducted by researchers at the Menzies Institute for Medical Research in Tasmania, the survey demographics were statistically compared to the participants in the Australian MS Longitudinal Study (AMSLS) which has previously been validated as a representative sample of people with MS in Australia[1]. This showed a slightly higher proportion of women in our survey compared to the AMSLS (81.7% vs 77.7%) (Fig. 1). The survey did capture the views of a very broad spectrum of ages, right from 18 years through to 60 and over, however, the population of people with MS who responded to the survey were slightly younger with an average age of 50, compared to 55 years in the AMSLS (Fig.2).

Figure 1 Gender of people with MS who responded to the survey compared with gender of people with MS who are participants in the Australian MS Longitudinal Study

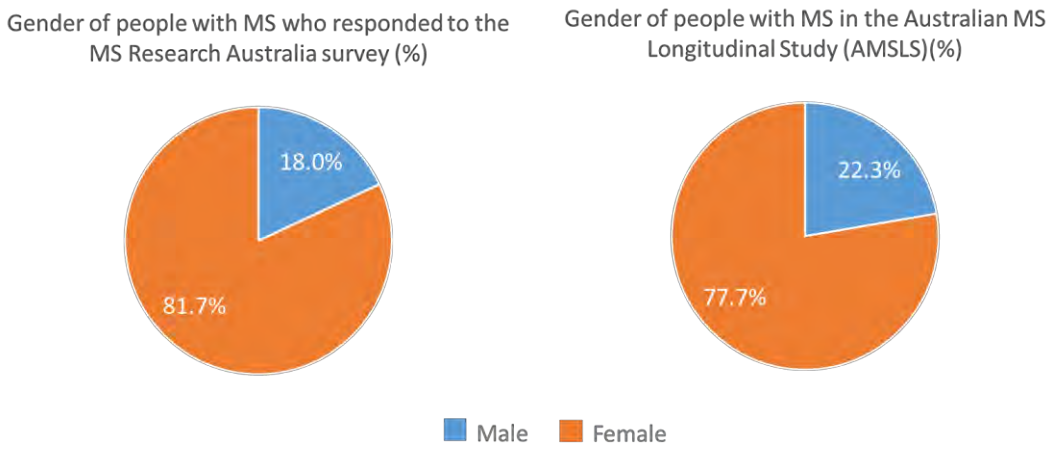
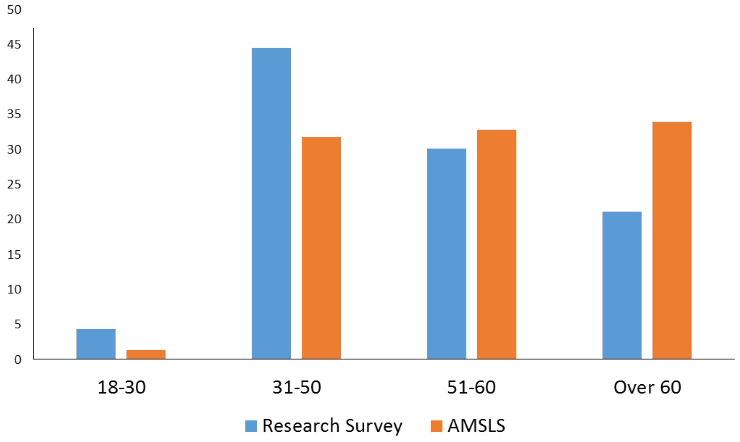
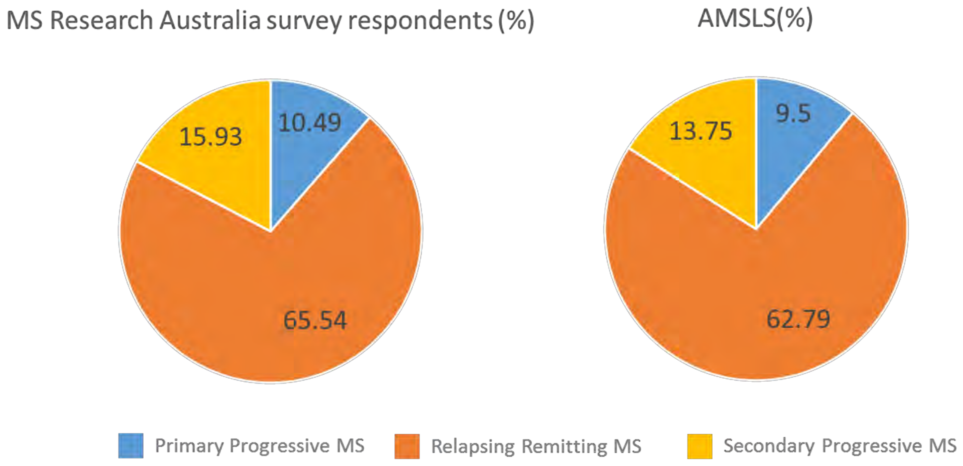


Figure 2 Percentage of people with MS in each age group who responded to the survey compared with people with MS who participate in the AMSLS



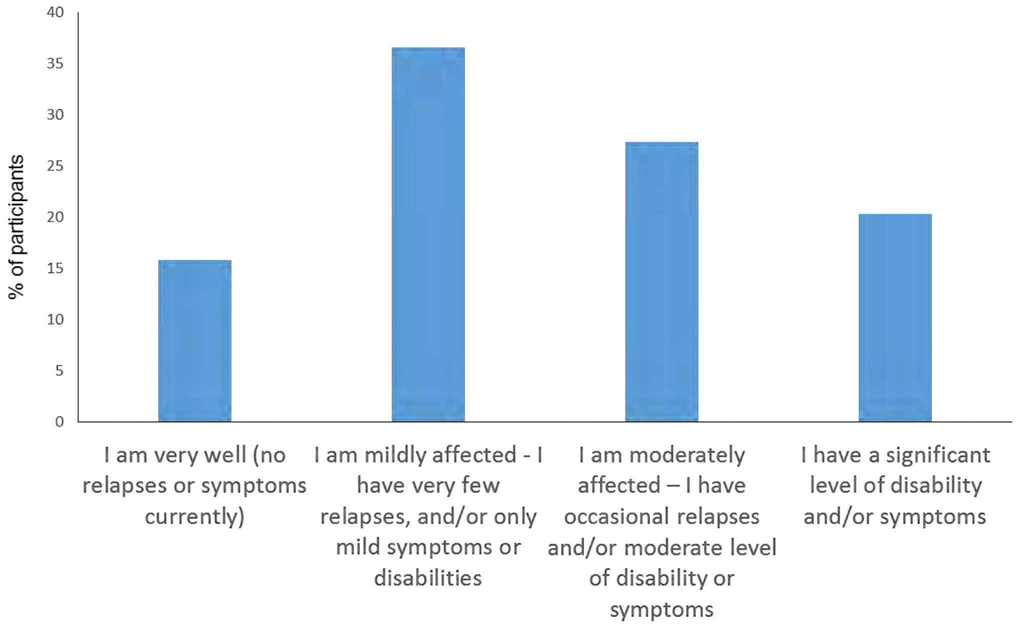
Comparing only the people with a diagnosis of MS in our survey, as is the case for the AMSLS (rather than Clinically Isolated Syndrome, neuromyelitis optica or ‘unknown’), the analysis found that we had a very representative cross section of the different types of MS (Fig. 3). People with relapsing remitting MS (RRMS) formed 65.5% of our sample vs 63% in the AMSLS, secondary progressive MS (SPMS) being 15.9% vs 13.7%, and primary progressive MS (PPMS) being 10.5% vs 9.5%.

Figure 3 Percentage of people with each type of MS who responded to the survey compared to the participants in the Australian MS Longitudinal Study (AMSLS)



We also asked people with MS who responded to the survey how they were affected by their MS. Approximately 50% of people with MS who responded to the survey were either very well or mildly affected. Just over 27% had occasional relapses and/or a moderate level of disability. 20% had a significant level of disability and/or symptoms (see Fig 4).

Figure 4 The degree of disability and symptoms experienced by people with MS who responded to the survey



We also gathered data on how the survey respondents with MS interact with MS organisations in Australia – this data is presented in the appendix.

The proportion of people with different types of professional connections to MS are shown in Figure 5. This illustrates that they were primarily made up of allied health professionals, nurses and staff from MS organisations, followed by researchers, and only a very small percentage of neurologists.

Researchers and neurologists are very well represented in other areas of MS Research Australia's governance processes, so it is particularly useful to have garnered here, the views of other types of professionals within the MS community.

Figure 5 The profession of people who responded to the survey who had a professional connection to MS

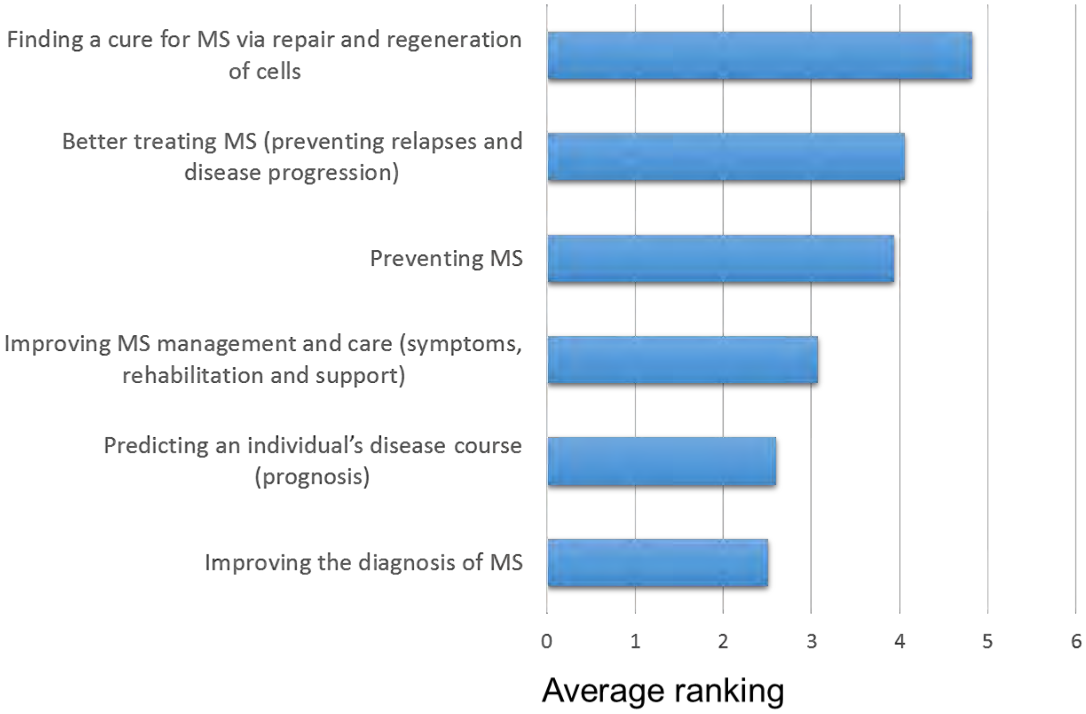
Professional Role	(%)
Researcher	28
Nurse	13
Doctor - Neurologist	2
Allied Health Professional (please specify below)	31
Social worker	2
Care/Health Service Manager	2
Complementary Therapist	2
Staff within an MS organisation	16
Admininstration	2

3. RESULTS

3.1. PRIORITIES FOR THE OVERARCHING RESEARCH GOALS

Respondents to the survey were first asked to rank from 1 to 6 the priority they placed on the overall goals for MS research. The average rankings are shown in Figure 6.

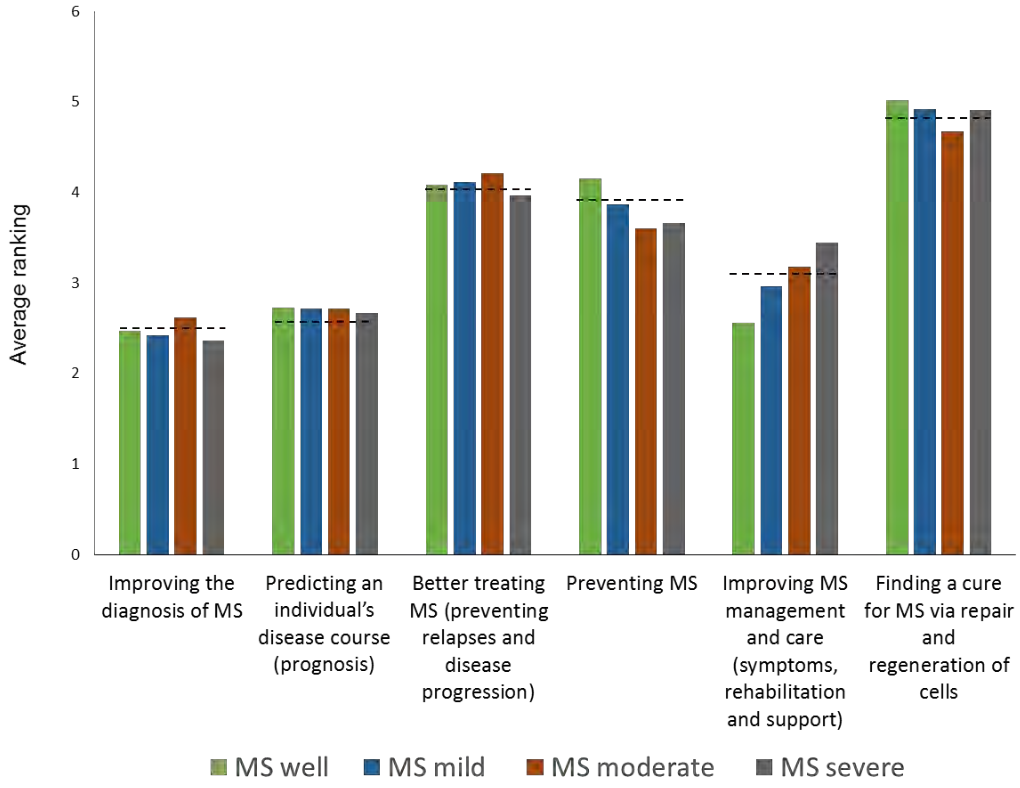
Figure 6 The ranking of research goals for the whole population of survey respondents



When looking at the rankings within the sub-populations of survey respondents, the top three priorities remained the same, and all sub-groups ranked 'finding a cure' as the top priority, however, people with a close connection to MS and people with a professional connection to MS placed 'preventing MS' second and 'better treating MS' third (data not shown). On average people with MS felt that the fifth ranked priority, 'prognosis', was a higher priority when compared to those with a close connection or professional connection to MS.

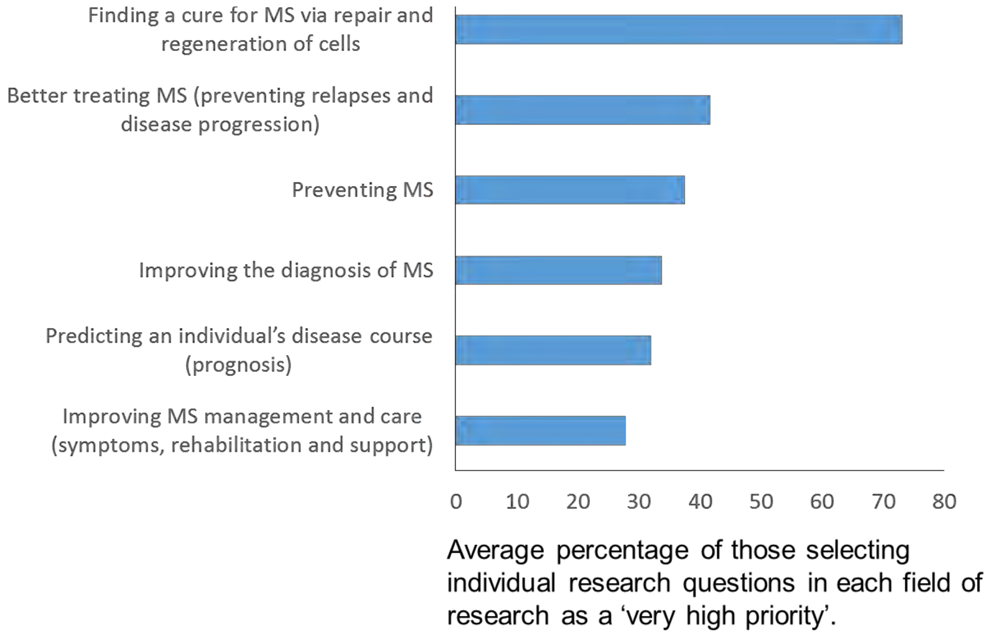
Amongst those that have MS, there was a progressively higher ranking for research to 'improve MS management and care (symptoms, rehabilitation, support)' with increasing severity of MS however, the top three priorities remained unchanged and 'improving MS management and care' remained in fourth place (Fig. 7).

Figure 7 Ranking of research goals by people with MS according disease severity (dotted lines indicate the average ranking for all respondents to the survey). Note the research goals were presented in survey in the order shown in the graph below.



Because this is a ranking question, extreme preferences either positive or negative are not revealed, however, when we looked at the average priority ratings for the individual research questions within each goal area in the later part of the survey we found that the average percentage of people selecting research questions as a 'very high priority' in the research goal area of 'Finding a Cure' was much higher than for the research questions in the other fields of research (see Fig. 8). This method also confirms the second and third priorities as 'finding better treatments' and 'preventing MS', but places 'Improving MS management and care' in sixth position.

Figure 8 The average percentage of people selecting 'very high priority' for each of the individual research questions in each field of research, shows that research questions in the field of 'A cure for MS via repair and regeneration of cells' were rated consistently as a 'very high priority' by a much higher percentage of respondents.

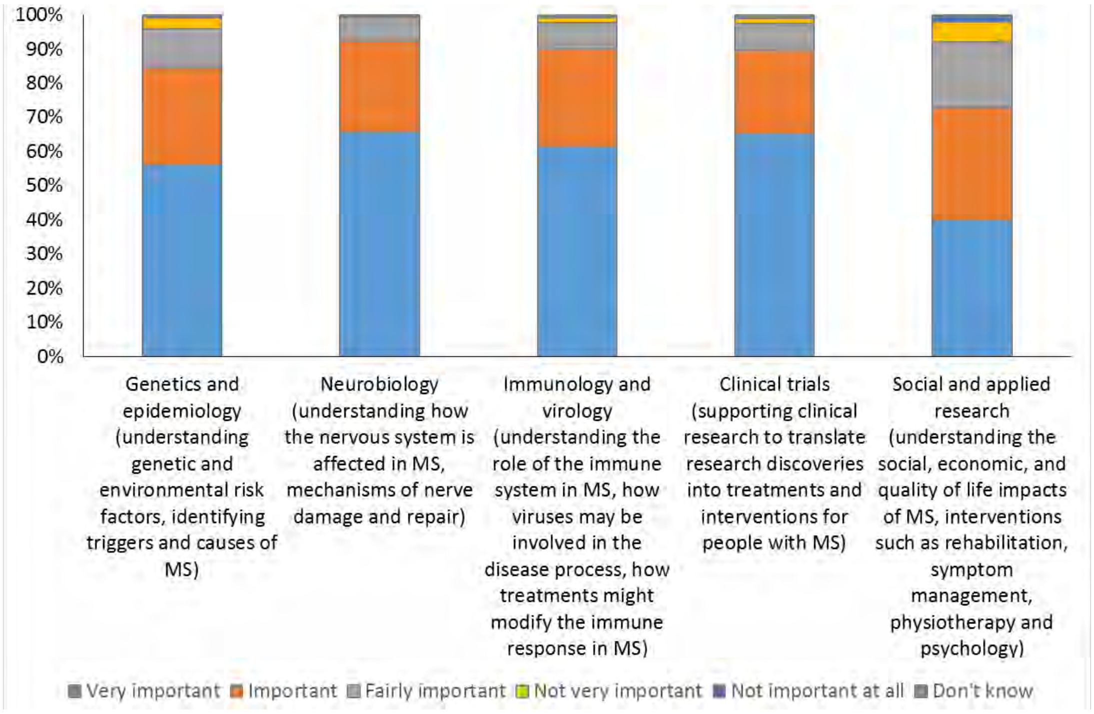


3.2. RESEARCH FIELDS

In order to work towards achieving our research goals, MS Research Australia allocates funding to a broad range of research 'fields' or 'streams'. Respondents were asked indicate the priority 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.

The streams which were rated equally as the most important were Neurobiology and Clinical trials. Immunology and virology was the third rated stream, followed by Genetics and epidemiology and Social and Applied research (Fig. 9).

Figure 9 'Please indicate how important each of these research streams is to you' – distribution of response categories



In Fig. 9 we have shown the percentage of all responses, ranging from 'very important' to 'not important at all' and 'don't know'. From now on, for simplicity, the graphs show only the percentage who selected the 'very important' or 'very high priority' rating.

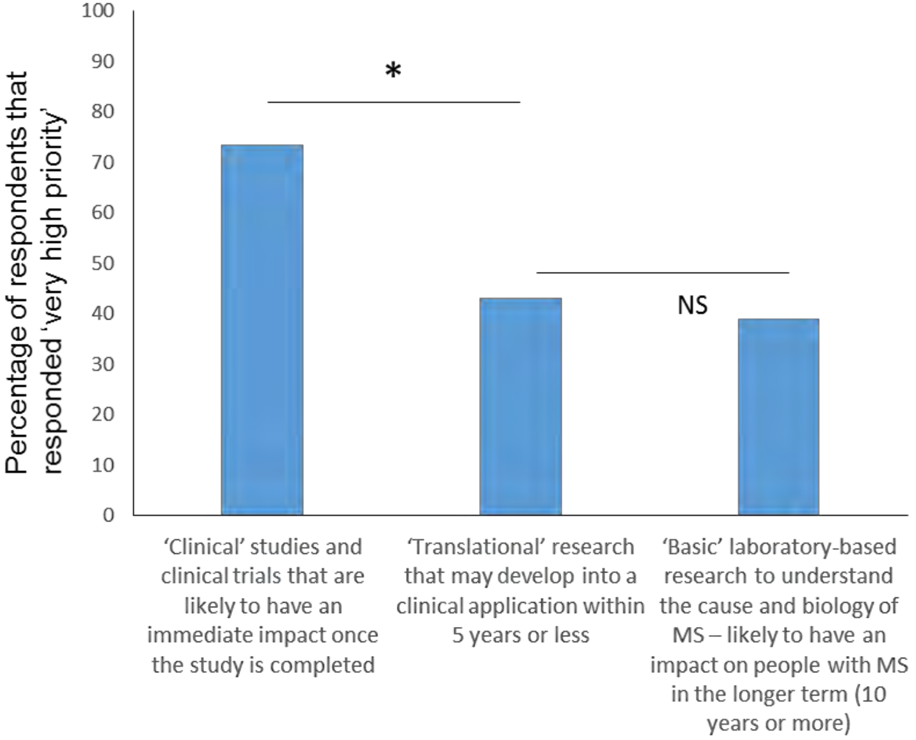
We next examined whether there were differences in the 'very important' rating for the different research fields by population sub-groups, such as MS type, disease severity or connection to MS. The most pronounced differences were seen in the category of social and applied research, with a clear increase in the percentage of people rating it as 'very important' as the severity of MS increases from those living well with MS (21%), to those with mild MS (36.5%), moderate MS (45%) and severe MS (47%). A higher percentage of people with primary progressive (44.4%) and secondary progressive MS (45.5%) also rated social and applied research as 'very important' than those with relapsing remitting disease (35.5%). A lower percentage of people with primary progressive MS (41%) rated genetics and epidemiology as 'very important' in comparison to 54% of people with relapsing remitting or secondary progressive MS.

3.3. THE RESEARCH SPECTRUM – fundamental, translational, clinical

Survey respondents were asked what priority they placed on the types of research within the spectrum from fundamental (basic) research, which would have a longer lag time to see an impact for people with MS, through to translational research and clinical trials, which would have progressively more immediate impacts.

Clinical research had the most support from all people who responded to the survey, being rated as 'very high priority' by greater than 70% of respondents. Translational research and fundamental research were rated equally as a 'very high priority' by approximately 40% of respondents (Fig. 10). Only the group with a professional connection to MS rated fundamental research as being more important than translational research (data not shown). It is interesting to note here the much higher proportion of people who rated clinical trials as a very high priority in this question, compared

*Figure 10 'Please tell us how much priority should be placed on the different types of research within this spectrum from 'laboratory bench' to clinical research'   * denotes statistically significant difference in priority placed on items connected by the line. NS = not statistically significant.*



with fundamental and translational research. This contrasts with the approximately equal importance placed on ‘neurobiology’ research and ‘clinical trials’ in the previous question relating to the different ‘fields’ of research (See section 3.2, Fig.9). This may indicate that the way this question was posed, giving likely time-frames for the outcomes, has influenced the responses.

3.4. WITHIN THE FIELD OF ‘PREVENTING MS’

The research goal of ‘Preventing MS’ was the third ranked overall research priority. Within this field of research, the most supported research topic within the field of ‘preventing MS’ was the broadly phrased question of “How can MS be prevented?” This was the same for all sub-groups of people.

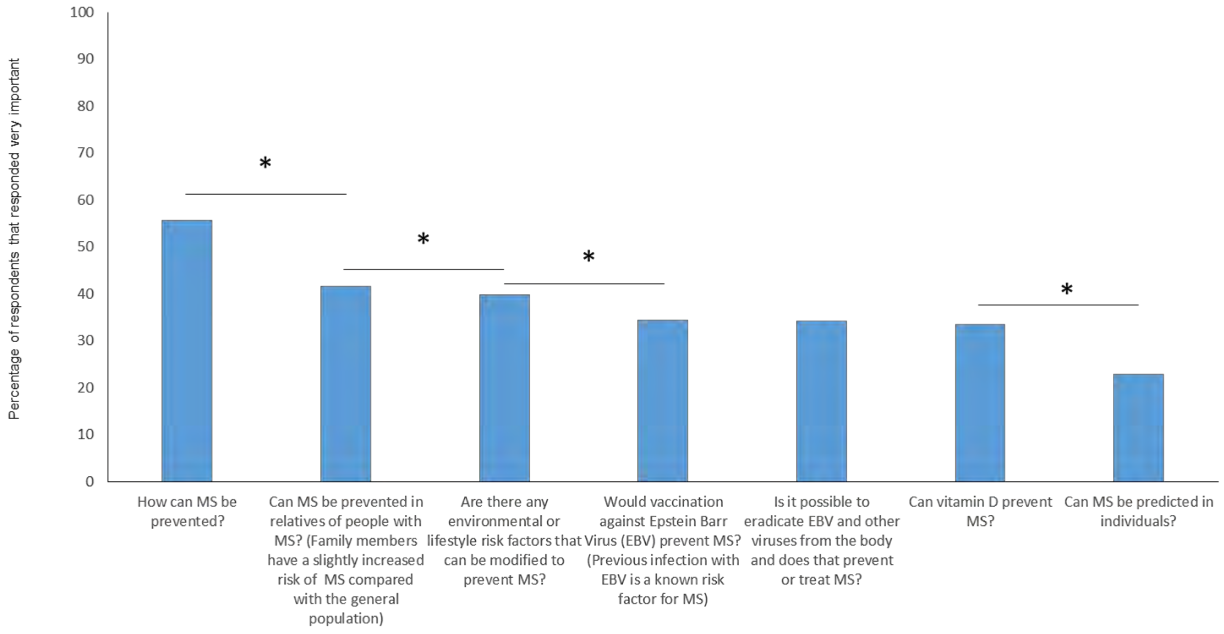
Following this were the topics of “Can MS be prevented in relatives of people with MS?”, and then “Are there any environmental or lifestyle risk factors that can be modified to prevent MS?” (Fig. 11).

People with MS placed more priority on research into preventing MS in relatives of people with MS than the people with a professional connection to MS. People with MS, those with a close connection, and those with a professional connection all rated the role that environmental and lifestyle risk factors might play in prevention equally in third place, however, people with MS who are well or mildly affected placed a higher priority on this field of research than those who are moderately or severely affected (data not shown).

All respondents placed less priority on the more specific topics of strategies to prevent MS involving targeting the Epstein Barr Virus or vitamin D deficiency (Fig. 11). However, those with a professional connection to MS rated vitamin D research more highly than those with MS, and those with relapsing remitting MS rated research into vitamin D as a preventative factor more highly than those with progressive forms of MS. The importance placed on vitamin D research also tailed off with increasing severity of disease. Whereas interest in research into the Epstein Barr virus increased with increasing severity of disease (data not shown).

The lowest priority for all groups of respondents was research aimed at predicting MS in individuals.

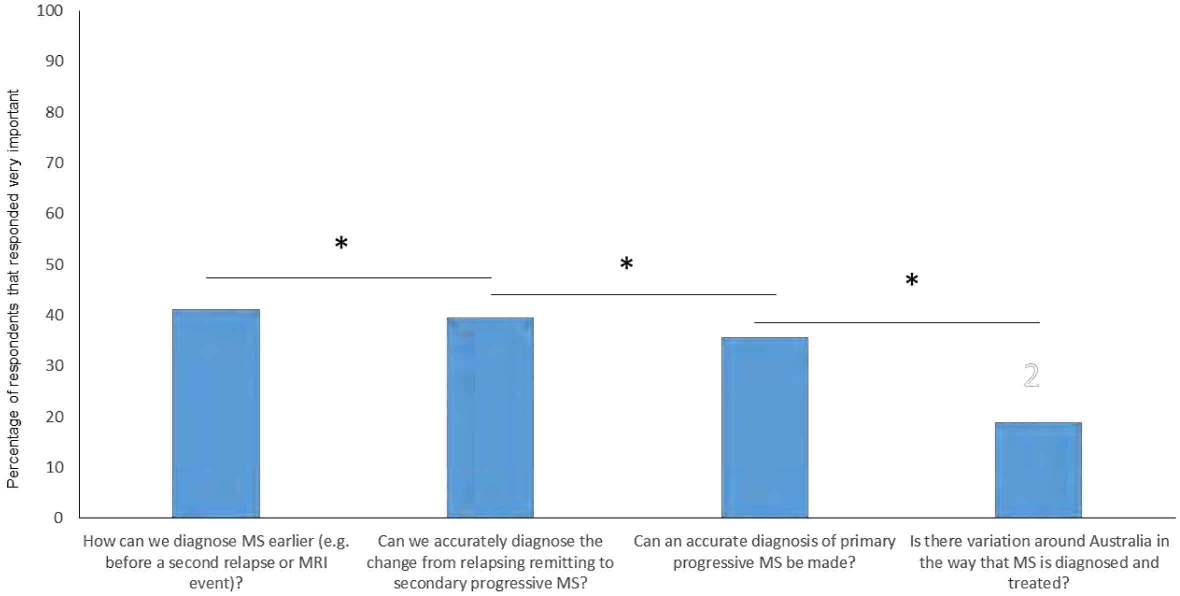
*Figure 11 Please indicate the level of priority you feel that each research topic should be given within the field of preventing MS * denotes statistically significant difference in the priority placed on items connected by the line. NB - research questions have been re-ordered in the graph in order of priority rather than the order in which they were presented in the survey.*



3.5. WITHIN THE FIELD OF DIAGNOSING MS

While there was relatively low support for the specific research questions relating to diagnosing MS (less than 40% rated these research questions as ‘a very high priority’), there was a significant difference in the priority placed on each of the questions. ‘How can we diagnose MS earlier?’ was rated most highly followed in succession by ‘Can we accurately diagnose the change from relapsing remitting to secondary progressive MS?’ and ‘Can an accurate diagnosis of primary progressive MS be made?’ There was considerably less priority placed on the question ‘Is there variation around Australia in the way that MS is diagnosed and treated?’ (Fig. 12).

Figure 12 Indicate the level of priority you feel that each research topic should be given within the field of diagnosing MS
** denotes statistically significant difference in the priority placed on items connected by the line.*



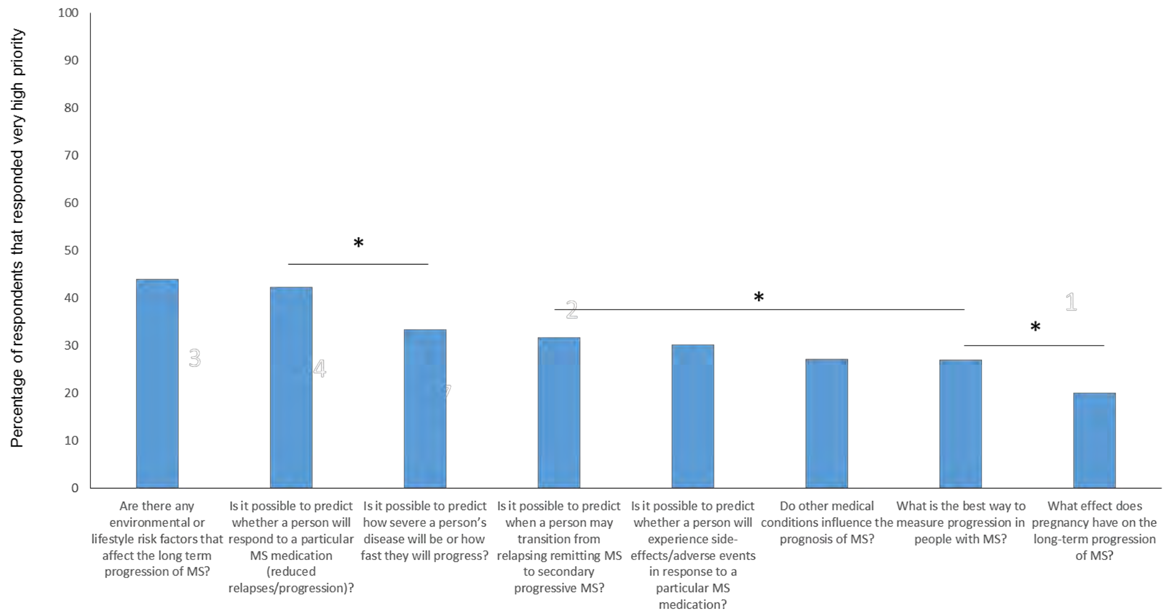
More people with a close connection to MS, considered ‘diagnosing MS earlier’ to be a very high priority (49%) when compared to those with MS (39%) or those with a professional connection to MS (35%).

The second highest rated topic, ‘Can we accurately diagnose the change from relapsing remitting MS to secondary progressive MS?’ was rated as a ‘very high priority’ by more people with MS (35.4%) and people with a close connection to MS (37.8%) than those with a professional connection to MS (24.6%). People with MS with more severe disease also rated it as a higher priority (48.7% of those with moderate disease and 47.8% of those with severe disease) than those who were well (32.8%) or have mild disease (36.9%). Perhaps unsurprisingly, fewer people with primary progressive MS considered it to be a ‘very high priority’ 28.6%) than people with relapsing remitting MS (40.8%) and secondary progressive MS (47.5%). 51.7% of people with primary progressive MS did rate the research question ‘Can an accurate diagnosis of primary progressive MS be made?’ compared with 31.1% of people with relapsing remitting MS and 39.2% of people with secondary progressive MS.

3.6. RESEARCH QUESTIONS WITHIN THE FIELD OF PROGNOSIS FOR MS

With virtually equal ratings, the two questions of ‘Are there any environmental or lifestyle risk factors that affect the long term progression of MS?’ and ‘Is it possible to predict whether a person will respond to a particular MS medication?’ were seen by more people as being a very high priority. This was followed by ‘Is it possible to predict the severity of a person’s disease?’. The questions of ‘Is it possible to predict when a person will transition to SPMS?’, ‘Is it possible to predict whether a person will experience side effects to a particular medication?' and 'Do other medical conditions influence the prognosis of MS' were then all rated equally below predicting the severity of disease. Finally, the research questions 'What is the best way to measure progression in people with MS?' and 'What effect does pregnancy have on the long term progression of MS?' were rated as the lowest priority (Fig. 13).

*Figure 13 Please indicate the level of priority you feel that each research topic should be given within the field of prognosis for MS   * denotes statistically significant difference in the priority placed on items connected by the ends of the lines.*



The sub-groups of respondents were all equivalent in their support of research into the environmental factors that may influence prognosis, and there were no statistically significant differences based on disease type or severity of disease.

People with MS who are well, placed less priority on the second rated research question of 'predicting a response to medication' (27.9% selected this question as 'very high priority') than people with MS with mild (46%), moderate (43.1%) or significant (42%) levels of disease.

The third rated topic, predicting the severity of disease, was rated as a 'very high priority' by more people with MS (34.8%) than those with a close connection to MS (28.8%) or professional connection to MS (26.1%). Amongst people with MS, people with relapsing remitting MS and secondary progressive MS give it near equal level of support (35.7% and 36% respectively), which is greater than those with primary progressive MS (20.6%). Those with more severe disease (28.7%) also rated it as a lower priority than those with milder disease (38.3%).

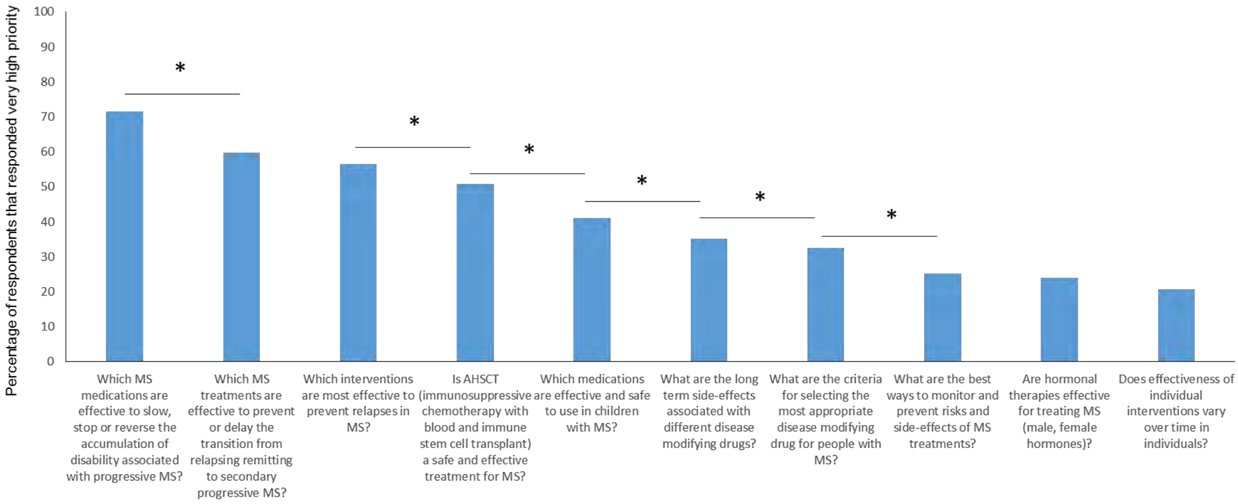
Predicting when a person may transition from relapsing remitting MS to secondary progressive MS was rated as a higher priority by people with MS (34.1% selected this as a 'very high priority') when compared to people with a close connection to MS (27.9%) and those with a professional connection to MS (9.2%). People with primary progressive MS did not see this topic as a high priority (12%) compared to people with relapsing remitting (36.4%) and secondary progressive MS (34.8%).

Predicting the side effects of treatment was rated equally by all groups other than those who were living well with MS who rated it as a lower priority.

3.7. WITHIN THE FIELD OF BETTER TREATING MS (RELAPSES AND PROGRESSION)

This field of research was rated as the second highest priority overall. Within this field, more people rated the question of ‘Which MS medications are effective to slow, stop or reverse the accumulation of disability associated with progressive MS?’ as a very high priority than any of the other research questions within this field of research. This was followed by ‘Which treatments are effective to prevent or delay the transition from relapsing remitting MS to secondary progressive MS?’ and ‘Which inventions are the most effective to prevent relapses?’. These questions were followed in priority by ‘Is AHSCT (immunosuppressive chemotherapy with blood and immune cell transplant) a safe and effective treatment for MS?’, ‘Which medications are effective and safe to use in children with MS?’, ‘What are the long term side-effects associated with different disease modifying drugs?’, and ‘What are the criteria for selecting the most appropriate disease modifying drugs for people with MS?’. The research questions rated equally as the lowest priority related to monitoring side effects, hormonal therapies for MS and effectiveness of therapies over time (Fig. 14).

*Figure 14 Please indicate the level of priority you feel that each research topic should be given within the field of better treating MS (relapses and progression). * denotes statistically significant difference in the priority placed on items connected by the lines.*



When looking at the top rated research question of ‘Which MS medications are effective to slow, stop or reverse the accumulation of disability associated with progressive MS?’, there was less support from the professionals (55.4%) compared with those affected by MS (73%). People with different types of MS (relapsing remitting MS, secondary progressive MS, primary progressive MS) rated this question as an equally high priority. However, when looking at the severity of MS, support for this research question did increase in a step-wise fashion as disease severity increased from well (65.6%) to mild (69.5%), moderate (75.8%) and severe (80.3%).

People with mild MS (62.8%) were more interested in the research question of ‘Which inventions are the most effective at preventing relapses?’ compared with 54% of people with moderate disease and 51% of people with severe disease. People with relapsing remitting MS (61.6%) also placed a higher priority on this question compared with people with secondary progressive (50%) and primary progressive MS (28.6%).

Fewer people with a professional connection to MS (32.3%) rated the question of ‘the efficacy and safety of AHSCT’ as a very high priority than people with MS (52.9%) and people with a close connection to MS (49.3%). Amongst people with MS there was no significant difference between disease types. However, 58% of people with MS who were moderately or severely affected rated this question as a 'very high priority' compared with 46.8% of those who are mildly affected.

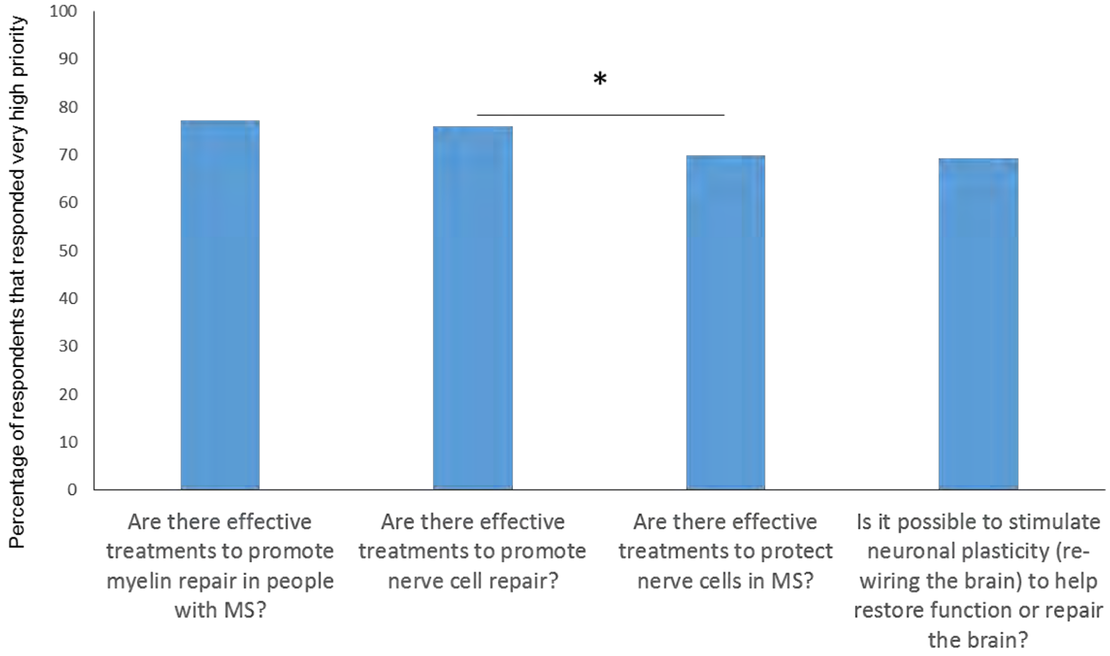
The question of 'What are the long term side-effects associated with different disease modifying drugs?' was seen as a higher priority by those with MS (38.5%), compared to those with a close connection (27.8%) or a professional connection to MS (21.5%). Amongst those with MS, people with relapsing remitting MS (40.3%) and people living well with MS (45.1%) were more interested in this question than those with primary progressive MS (28.6%) or severe disease (33.8%).

3.8. WITHIN THE FIELD FINDING A CURE FOR MS VIA REPAIR AND REGENERATION OF CELLS

This field of research was rated as the highest overall priority. Within this field, the specific research questions were all rated as a very high priority by more than 70% of the survey respondents.

Rated as an equally high priority, with no statistically significant difference between them, are the questions of 'Are there effective treatments to promote myelin repair in people with MS?' and 'Are there effective treatments to promote nerve cell repair?'. This was followed by 'Are there effective treatments to protect nerve cells in MS?' and 'Is it possible to stimulate neuronal plasticity (re-wiring the brain) to help restore function or repair the brain?'.

*Figure 15 Please indicate the level of priority you feel that each research topic should be given within the field a cure for MS via repair and regeneration of cells * denotes statistically significant difference in the priority placed on items connected by the line.*



Finding treatments to promote myelin repair was rated as the highest priority by those with MS (80%) compared to those with a close (70.8%) or professional connection to MS (69.2%). Amongst the people with MS, more of those who are well (84.4%) and those who are severely affected (86.6%) rated it as a very high priority compared with those who are mildly (74.1%) or moderately (80.1%) affected by their MS. There was equal support for this research question when analysed by type of MS (relapsing remitting MS, secondary progressive MS, primary progressive MS).

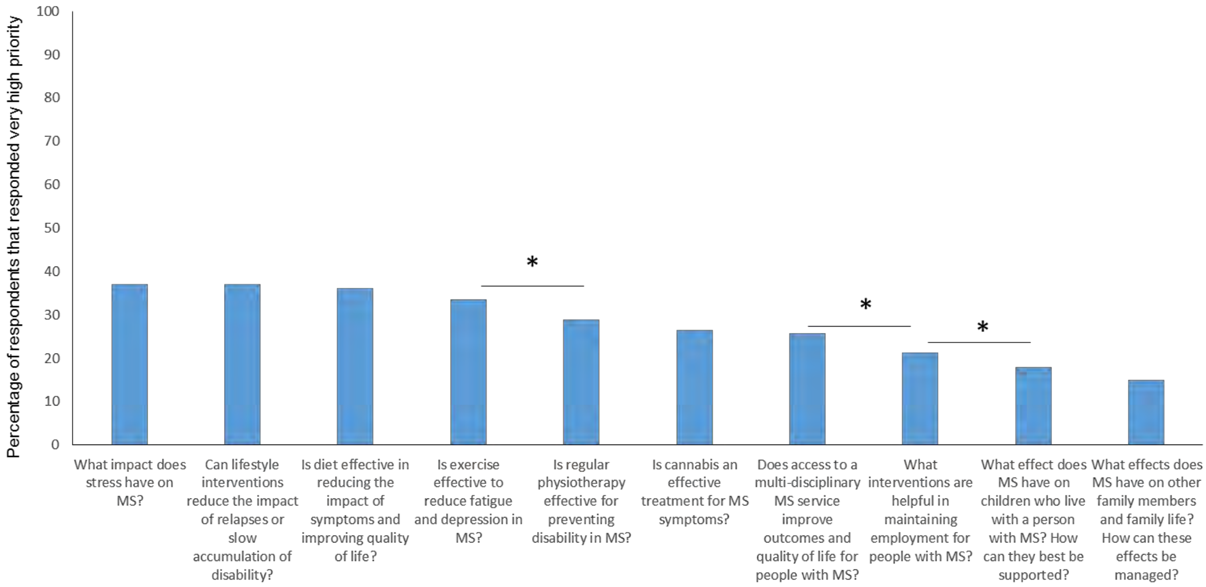
The research question of promoting nerve cell repair was more commonly rated as a 'very high priority' by people with MS (78.4%) and a close connection to MS (74%) than people with a professional connection to MS (61.5%). Amongst people with MS, those who are severely affected rated it higher (85.3%) than those who were are well (75.4%) or mildly affected (76.2%). People with secondary progressive MS (87.3%) also rated it as a higher priority than people with relapsing remitting (76.3%) or primary progressive MS (71.4%).

3.9. WITHIN THE FIELD OF MS MANAGEMENT AND CARE (SYMPTOMS, REHABILITATION, SUPPORT)

While overall this field of research was rated as a lower priority than the other fields of research it is important to understand which aspects of MS management and care and which symptoms are seen as the highest priorities for research.

Of the specific research questions that were presented within the field of MS Management and Care (Symptoms, rehabilitation and support), research to understand the impact of stress on MS is rated as a very high priority by the most people. This is followed closely by 'Can lifestyle interventions reduce the impact of MS?', 'Is diet effective in reducing the impact of MS? and 'Is exercise effective to reduce fatigue and depression?'. There was no statistically significant difference between the number of people who rated these three questions as 'very high priority'. After these three, came the question 'Is regular physiotherapy effective in preventing disabilities'?' and then 'Is cannabis an effective treatment for symptoms?', 'Does access to multi-disciplinary services improve outcomes and quality of life in MS?' and 'What interventions are helpful in maintaining employment?'. The least number of people rated as a 'very high priority' the research questions of 'What effect does MS have on the children who live with a person with MS?' and 'What effect does MS have on other family members and family life?' (Fig. 16).

*Figure 16 Please indicate the level of priority you feel that EACH research topic should be given within the field of MS Management and Care (Symptoms, Rehabilitation, Support) - * denotes statistically significant difference in the priority placed on it*



People with MS (39.9%), regardless of disease type, were more supportive of research into stress compared with those with a close connection (30.1%) or a professional connection to MS (27.7%). However, people with MS who were well (26.2%) gave it the lowest rating compared with people who are mildly (44.7%), moderately (43.1%) or severely affected by their MS (37.6%) (Fig. 17).

Research into the lifestyle interventions that might help with the management of MS was rated as a higher priority by people with relapsing remitting MS (39.5%) compared to secondary progressive MS and primary progressive MS (both 27%), and those who were well or mildly affected felt this area of research was a higher priority than those more severely affected (Fig. 17).

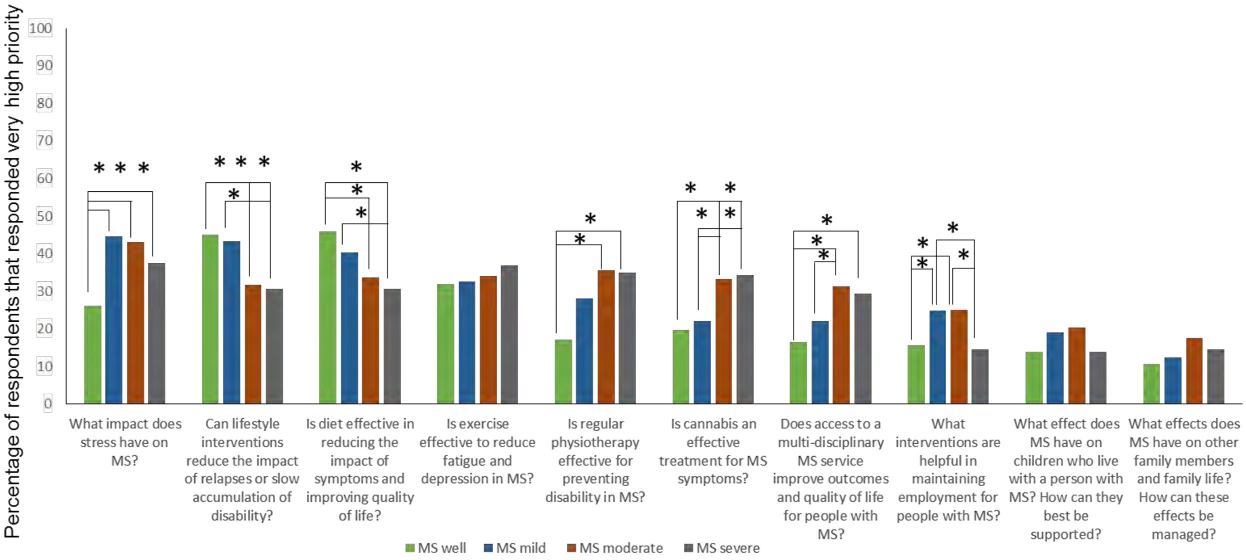
Research into dietary factors that might reduce the impact of symptoms and improve quality of life was rated as more important by people who are more mildly affected by their MS with a stepwise decrease in support for this type of research as the severity of MS increases (Fig. 17).

Conversely, research into the benefits of regular physiotherapy was seen as a higher priority by those with severe disease compared to those with more mild disease (Fig. 17).

Support for research into the role that cannabis might play in managing MS symptoms was similar across disease types (between 27 and 30%) and between people with MS and those with a close connection (27%). 17% of those with a professional connection to MS felt this was a priority but this was not statistically significantly different to those affected by MS. However, amongst people with MS research into cannabis was seen as a higher priority by those with severe or moderate disease compare to people who were mildly affected or well (Fig. 17).

Research into the benefits of multidisciplinary MS services was rated approximately equally as a ‘very high priority by between 23 and 29% of respondents across all groups and all disease types, although those with more mild disease did not view it as such a high priority compared to those more severely affected (Fig. 17). Research into interventions to maintain employment were seen as a higher priority by people with MS who were mildly and moderately affected by MS when compared to those who are well or severely affected (Fig. 17).

*Figure 17 Percentage of people with MS with different levels of disease severity who rated research questions within the field of MS Management and Care as a 'very high priority' * denotes statistically significant difference in the priority placed on items connected by the line.*



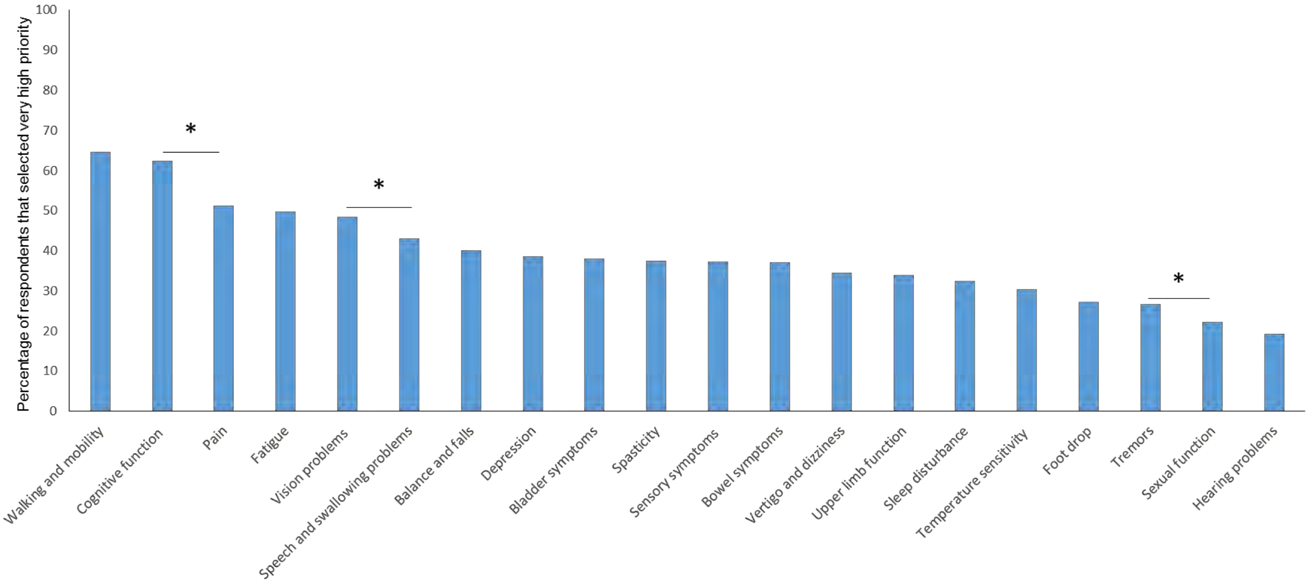
3.9.1. Symptoms

We also asked the survey respondents what priority should be placed on research into treating or managing the specific symptoms of MS (Fig. 18).

The top rated symptoms seen as the highest priority for research were:

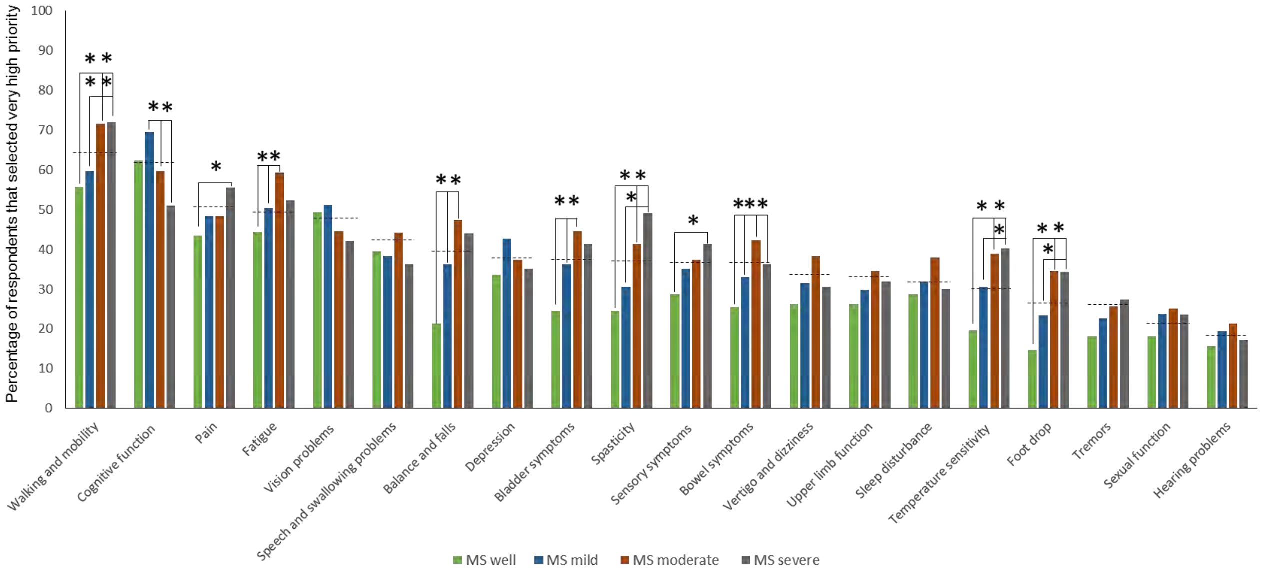
1. Walking and mobility;
2. Cognitive function;
3. Pain and fatigue (rated equally important);
4. Vision;
5. Speech and swallowing.

*Figure 18 Please indicate the priority that you feel should be placed on research into treating or managing each of the following symptoms * denotes statistically significant difference in the priority placed on items connected by the line.*



When we looked at the priority placed on research into the management of each symptom according to the degree to which people with MS are impacted by their disease, we saw that for the majority of symptoms, research into the symptom was seen as a higher priority as severity of disease increased (Fig. 19). Significant exceptions to this were seen with the symptoms of cognitive function, which were seen as a higher priority by those with mild disease compared to those living well and those with moderate or severe disease. Pain was seen as a significantly higher priority by those with severe disease.

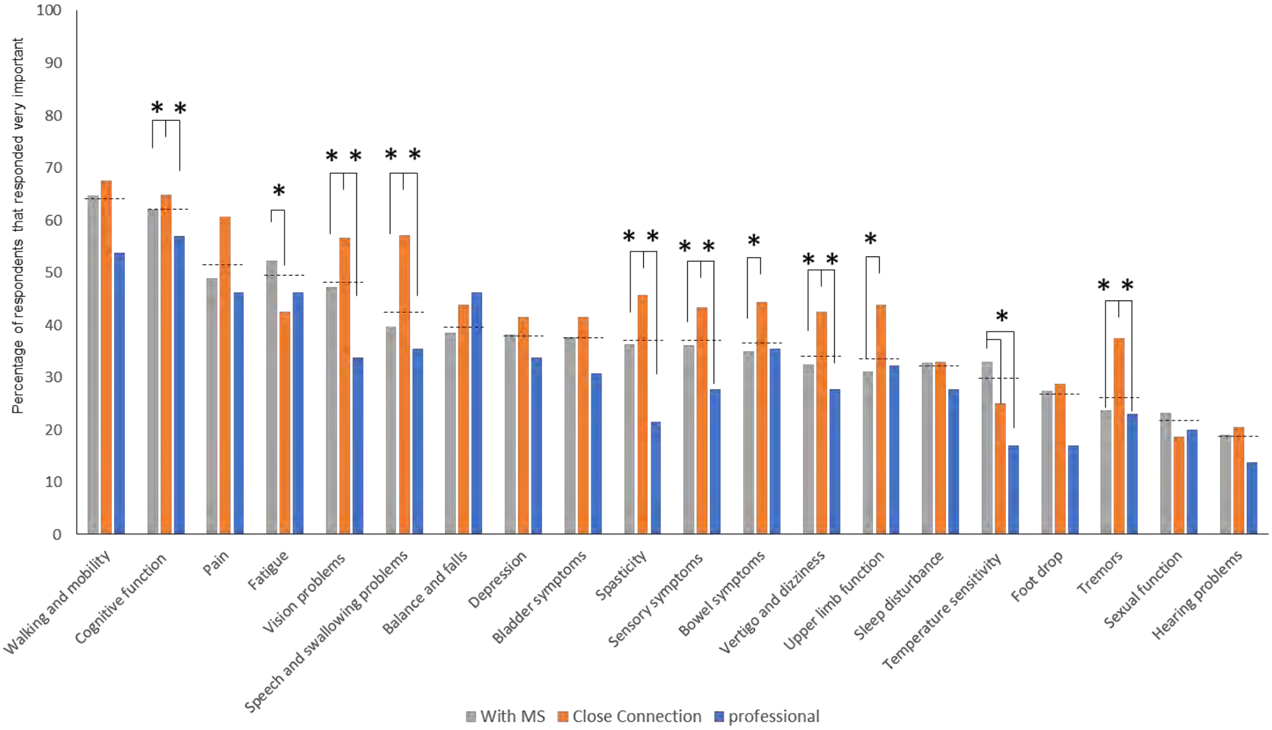
*Figure 19 The percentage of people with MS with different levels of severity who rated research into specific symptoms as a 'very high priority' * denotes statistically significant difference in the priority placed on items connected by the line, dotted lines indicate the average rating of all survey respondents*



When looking at the priority placed on research into specific symptoms by connection to MS (Fig. 20), it was interesting to note that people with a professional connection to MS rated all symptoms as a lower priority for research than people with MS or people with a close connection to MS.

Also of interest is the higher priority placed on research into certain symptoms by people with a close connection to MS when compared to people with MS themselves (Fig. 20). This was most notable for cognitive function, pain, vision, speech and swallowing, spasticity, sensory symptoms, bowel symptoms, vertigo/dizziness, upper limb function and tremors.

*Figure 20 Percentage of respondents who rated research into specific symptoms as a 'very high priority' according to their connection to MS * denotes statistically significant difference in the priority placed on items connected by the line, dotted lines indicate the average rating of all survey respondents*



Respondents were also provided with an open-text field to note any symptom that they felt had not been included in the list of symptoms provided in the survey. There were 56 responses which mentioned specific symptoms, however, no significant theme emerged as a symptom missed from the survey. The majority (44) of the symptoms mentioned could be classified under the broader categories already listed, including 11 specific sensory symptoms and 10 specific cognitive functions. There were also several mental health related symptoms mentioned (4), including anxiety and fear, which were not adequately captured by the mental health category we provided of ‘depression’. A further 8 symptoms were mentioned by only either one or two individuals and included migraine, dry eyes, breathing or heart related symptoms, nausea, and Raynaud’s syndrome.

3.10. ‘DID WE MISS ANYTHING?’

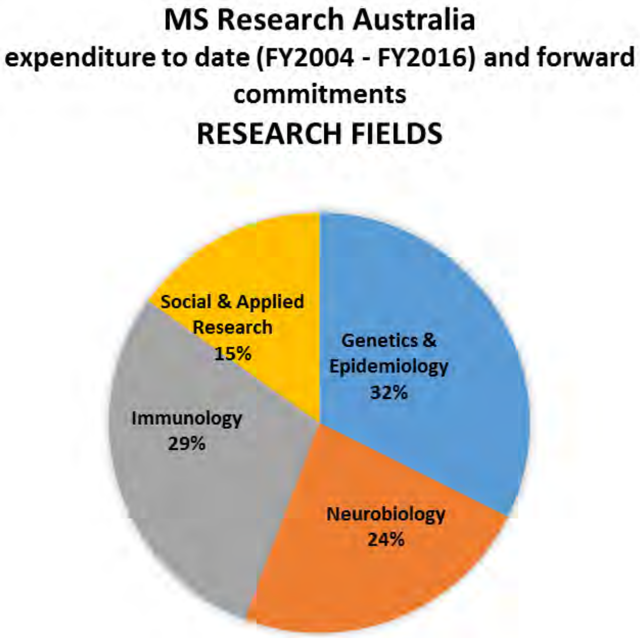
We provided an open text field at the end of the research part of survey for respondents to identify any research questions that they felt we may have missed in the rest of the survey. 94 respondents entered new information in this field, however, there was no consistent theme that emerged within those responses. The vast majority of these responses fell into the categories of research that were identified as priorities elsewhere within the survey. This included six responses regarding research into progressive forms of MS (which is covered by the top priority identified in the research goal of ’Better treat MS’ to ‘Slow, stop, reverse the accumulation of disability’). Nine respondents also mentioned stem cells and of these three directly referenced autologous haematopoietic stem cell transplant (AHSCT), which was the fourth ranked research question within the ’Better treat MS‘ category. Six of those who mentioned ‘stem cells’, referred to other types of stem cell therapies which are incorporated into the 'Neurobiology' field of research and the top ranked priority of 'A cure for MS through repair and regeneration of cells'. Topics that were not covered in other areas of the survey, and were identified by more than one participant, included chronic cerebrospinal venous insufficiency (CCSVI) or cardiovascular issues (6 people) and the relationship of gut health and gut bacteria to MS (5 people).

4. HOW DOES MS RESEARCH AUSTRALIA MEASURE UP?

How do the MS community's MS research priorities compare with MS Research Australia's current strategy and funding allocations?

Since inception, MS Research Australia has maintained a broad approach to MS research which has aimed at building capacity for MS research in Australia, supporting Australia's strengths and addressing the broad focus required for research into a complex disease that involves the immune system, nervous system, genes and environment, and has wide-ranging impacts in terms of symptoms and support needs.

The pie charts below illustrate how MS Research Australia's research expenditure has been apportioned across the overall research goals of a 'A cure for MS via repair or regeneration of cells', 'Identifying the triggers for MS' and 'Developing better treatments'. Also shown is the expenditure across the different fields of research. These funding categories represent funding allocated both through the investigator-driven grants programs and our support for major national and international collaborative research 'platforms' (International Progressive MS Alliance, PrevANZ Vitamin D MS Prevention Trial, Australian MS Longitudinal Study, ANZgene MS Genetics Consortium, AHSCT Registry, MS Research Australia Brain Bank, Clinical Trials Network, NSW MS Research Network).



Biomedical research funding (past and current) has been significant in the areas of epidemiology and genetics, vitamin D and UV radiation, EBV, immunology, neurobiology and myelin repair. These are all areas of significant strength within the Australian MS research community. Therefore, our significant investment in these areas is in keeping with our strategy from the outset to support Australian strengths and complement global endeavours.

While research into the MS community's top priority - 'A cure for MS via repair or regeneration of cells' - accounts for 11% of MS Research Australia expenditure, looking at the funding for the field of neurobiology shows that nearly 25% of overall expenditure has been focussed on understanding how the nervous system is affected in MS and mechanisms of nerve damage and repair and myelin repair. This fundamental neuroscience research is the crucial first step towards developing testable interventions to enhance myelin repair, neuroprotection and nerve repair and reflects the current stage of this research globally. However, there is a clear imperative to accelerate the translation of this discovery science into pre-clinical and clinical research.

The category of 'Developing better treatments for MS' incorporates both treating relapses and progression, and improving MS management and care (symptoms, rehabilitation, support). The allocation of research funds to 'Improving MS management and care' can be better seen when looking at funding distribution across the different fields of MS research, with social and applied research receiving 15% of the total past and ongoing funding. This level of funding would appear to be in keeping with the MS community's lower prioritisation of this category of research, however, an adjustment in the areas of research funded within this field may be required to align more closely with community's priorities (see below for more detail).

Within the category of 'Developing better treatments for MS (relapses and progression)', survey respondents demonstrated a clear desire for more focus on the identification and development of 'treatments to slow, stop or reverse the accumulation of disability associated with progressive MS' and 'preventing the transition from relapsing remitting MS to secondary progressive MS'. 'Preventing relapses' was rated third. A great deal of the research funded to date in the fields of immunology, genetics and neurobiology has seen us well advanced along the path to identifying new ways to address these problems. Greater effort is needed to accelerate translation of these discoveries into pre-clinical and clinical research. Quite rightly, there is a great desire within the MS community to address the enormous unmet need for treatments for progressive MS. MS Research Australia's investment and collaboration within the International Progressive MS Alliance will contribute significantly to this goal, however, increased focus on supporting Australia's significant strengths in this area is also warranted.

The research to understand the safety and efficacy of AHSCT for MS was also identified as a relatively high priority within the field of 'Developing better treatments for MS'. MS Research Australia has made significant efforts to review and communicate the data on this to date and undertaken a range of collaborative advocacy activities with MS Australia and the medical community to increase access to the treatment for those who need. However, this must be combined with ongoing collection of robust data on the safety, efficacy and most appropriate use of the therapy and this is ongoing through the MS Research Australia-supported Australian AHSCT Registry. Efforts to strengthen and enhance the activities of the Registry will be important as will further consideration of all avenues to promote the understanding of and access to this form of treatment for those in whom other treatments have failed or are not suitable.

Strategies to prevent MS have been identified through the category of 'Identifying the triggers for MS' as well as to a certain extent, begun to be tested through research in the category of

‘Developing Better Treatments’, which incorporates our very significant total commitment of $4.1 million to complete the PrevANZ vitamin D MS prevention trial (results due 2018).

The translation of the findings relating to the risk factors for MS from epidemiological and genetic studies that have been supported by MS Research Australia over the last decade, including from ANZgene and AusImmune have led to a number of studies to test whether intervention in the areas vitamin D and UV radiation risk factors can prevent MS. The PrevANZ vitamin D MS prevention clinical trial (supported by MS Research Australia) and the PhoCIS UVB light therapy trial (NHMRC funded) are currently underway. Epidemiological findings linking EBV infection as a risk factor for MS (AusImmune) and studies that reveal the interactions of EBV with the immune system in MS (numerous MS Research Australia investigator-led research grants) have also led towards the testing of a treatment that targets EBV in a Phase I adoptive immunotherapy clinical trial. This trial is being conducted by the Queensland Institute for Medical Research and is funded through a partnership between MS Research Australia and the MS Society of Queensland. AusImmune’s findings linking smoking to the risk of MS onset and progression have also been incorporated into international consensus advice on cessation of smoking for people with MS and their families.

Clinical trials

With respect to the very high priority placed on clinical trials by the survey respondents, it is important to note that of 54 currently ongoing grants and platforms, eight are clinical trials (this includes the two mentioned above):

- PrevANZ - vitamin D MS prevention trial - major investment to translate MS Research Australia-funded epidemiological findings;
- Phase I adoptive immunotherapy trial against EBV– translating more than a decade of research into EBV biology in MS;
- Five clinical trials targeting symptom management
    - 3x walking and mobility
    - 1x cognition
    - 1x heat sensitivity and exercise;
- MS Research Australia Clinical Trials Network – supporting access to trials for people with MS and supporting the development of trials by commercial and non-commercial investigators and trial sponsors.

However, there is a clear gap, in that the high priority placed on both clinical trials and a cure for MS via repair and regeneration of cells, has not yet been realised in terms of pre-clinical and clinical research into myelin and nerve protection and repair. This is in part, related to this research still being largely in the ‘discovery' phase, but also to the high cost of pre-clinical and clinical research. A strategic approach may be required to accelerate this research along the translational pathway, and to begin developing the necessary funding streams for clinical trials. In parallel to this it will also be important to continue to develop the necessary tools and biomarkers that can be used in clinical trials to accurately track progression of disease and repair of myelin and hence measure whether experimental medications are working.

Rehabilitation, symptoms and support

The allied health clinical trials above address two of the top priority symptoms, walking and mobility and cognition, as well as temperature sensitivity (which came lower down the list of symptoms prioritised for research).

Looking at the research that MS Research Australia has funded in the past and is currently funding in the area of 'Improving MS management and care' it is clear that there has been a significant focus on walking and mobility, with more grants funded in this area than others. Employment support has also received significant attention, driven in large part by the important data generated by the Australian MS Longitudinal Study (AMSLS) on the big disparity in employment participation between people with MS and the wider population. This focus on employment, however, appears to have paid dividends, as a soon to be published paper from the AMSLS shows a significant improvement in employment retention for people with MS over the last four years. Other social and applied research grants have been awarded, in small numbers, in the areas of cognition, continence, rehabilitation, psychological support, fatigue and information needs.

This indicates that, despite a good match with the MS community's priority on walking and mobility, increased attention is needed on the other top priority symptoms of cognition, pain, fatigue, vision and speech and swallowing.

The survey also identified the higher prioritisation of interventions relating to stress, lifestyle, diet and exercise in the management of MS. Studies such as AusImmune and the AMSLS have been crucial in identify the role that these factors play in the risk of developing MS. However, a greater focus is now required on translating this information into robust studies to test whether and how lifestyle interventions can contribute to reducing the impact of MS.

Some investigation may be required to understand the different priority placed on research into certain symptoms by people affected by MS and people with a professional connection to MS. It is possible that this is because health professionals are aware of a range of interventions and methods to manage many of these symptoms, whereas people with MS or those with a close connection may not be aware, or may not receive referrals or access to these services. This would indicate that greater effort needs to be made to raise awareness of the symptom management interventions available and ensure that people with MS and their families get connected to these services. However, it also possible that the interventions that are available are being broadly utilised by people with MS, but still do not provide satisfactory solutions.

What next?

MS Research Australia will be considering all of the results of this survey within our strategic planning, research governance and grant-making processes. The results will also be widely disseminated to stakeholders in the MS community including researchers, health professionals and our colleagues in MS Australia and the state MS societies.

5. Comparison to MS Society UK Research Priorities

Having based some of our survey questions on the UK MS Society's priority setting process, it is interesting to compare the results of our survey to the priorities identified by the UK MS community.

Although our survey did ultimately differ in structure to the MS Society UK's priority setting process, there are some common themes. The UK top priority (see box) matches one of the Australian MS community's top three priorities for the overarching goals of MS research 'to better treat MS (relapses and progression)' and within that research field, the UKs top priority of 'Which treatments are effective to slow, stop or reverse the accumulation of disability associated with MS?' was also Australia's top ranked research question.

Also in our top three was prevention, which came number 2 in the UK priorities. 'A cure for MS via repair or regeneration' a question unique to the Australian survey, to a certain extent also matches the UK priority to stop or reverse accumulation of disability.

In relation to symptom management strategies to be prioritised for research, the UK also ranked fatigue, mobility, cognition and pain as the top 4 symptom-related priorities within their top 10 overall research priorities.

The 4th ranked priority in the UK's top 10, 'How can people with MS be best supported to self-manage their condition?', while being arguably broader, is also aligned with the high priority placed by our survey respondents on the factors relating to MS that can potentially be managed by themselves, including stress, lifestyle and diet.

MS Society UK - TOP 10 PRIORITIES (2012)

1. *Which treatments are effective to slow, stop or reverse the accumulation of disability associated with MS?*
2. *How can MS be prevented?*
3. *Which treatments are effective for fatigue in people with MS?*
4. *How can people with MS be best supported to self-manage their condition?*
5. *Does early treatment with aggressive disease modifying drugs improve the prognosis for people with MS?*
6. *Is Vitamin D supplementation an effective disease modifying treatment for MS?*
7. *Which treatments are effective to improve mobility for people with MS?*
8. *Which treatments are effective to improve cognition in people with MS?*
9. *Which treatments are effective for pain in people with MS?*
10. *Is physiotherapy effective in reducing disability in people with MS?*

6. ACKNOWLEDGEMENTS

MS Research Australia would like to acknowledge the enormous input of Mr Mike Hemingway, MS Research Australia Board member and person with MS, into the development and testing of the survey.

We thank Ms Candace Garam, National Australia Bank, who provided expert pro bono assistance in setting up the online survey.

We are very grateful to the group of people affected by MS and MS Research Australia, MS Australia and state MS society staff and board members who assisted in testing the survey and providing valuable feedback prior to implementation of the survey.

We are enormously grateful to Dr Hamish Campbell and Dr Julia Morahan, MS Research Australia, for their considerable work in collating and statistically analysing the survey results.

We thank the MS Society UK and the MS Society of Canada for their assistance and advice, and for sharing the surveys and methodologies used in their own priority setting activities.

Thank you to Associate Professor Ingrid van der Mei, Menzies Institute for Medical Research, Tasmania, for independent statistical analysis comparing the demographic profile of people with MS who responded to this survey with the Australian MS Longitudinal Study cohort.

And most importantly, thank you to the entire Australian MS community for embracing this process and taking the time to, carefully and thoughtfully, complete the survey.

7. References

1. Taylor BV, Palmer A, Simpson S Jr, Lucas R; NZMSPS study group, Simmons RD, Mason D, Pearson J, Clarke G, Sabel C, Willoughby E, Richardson A, Abernethy D. Assessing possible selection bias in a national voluntary MS longitudinal study in Australia. Mult Scler. 2013 Oct;19(12):1627-31. doi: 10.1177/1352458513481511. Epub 2013 Mar 25. PubMed PMID: 23530001.

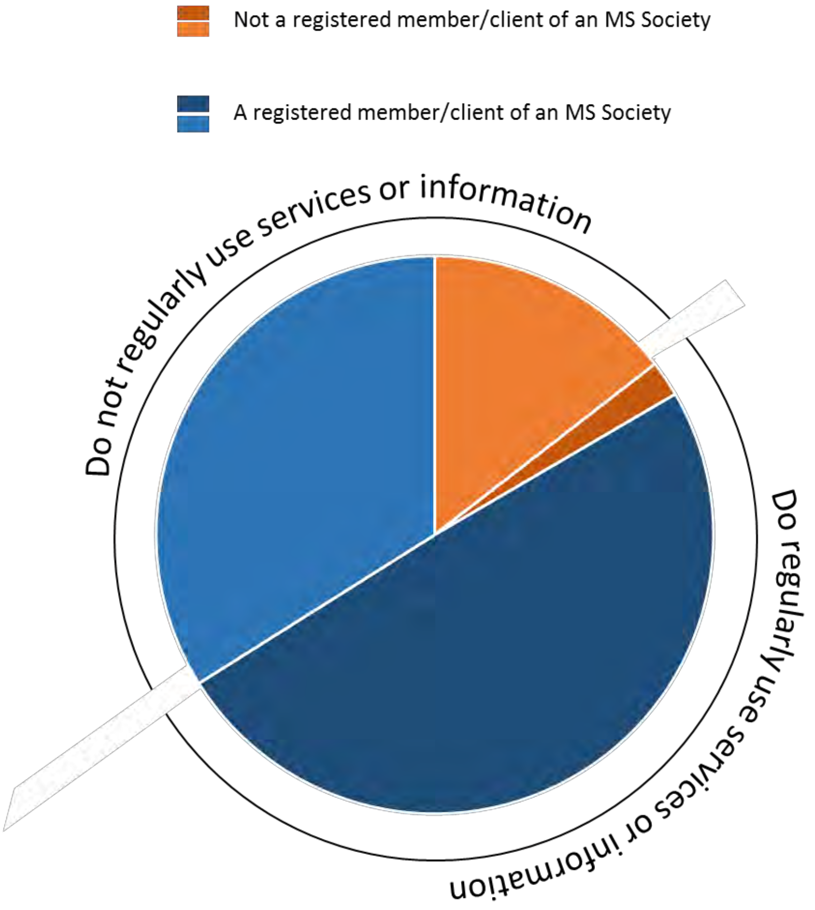
APPENDIX 1 - How do people with MS interact with MS organisations in Australia?

86% of people with MS who responded to the survey identify as a registered member or client of a state MS society (Fig.21 - shown in blue shades in the pie chart). It is important to note that the term ‘member’ and ‘client’ mean different things in different states, therefore this question simply captures all people who identify as being registered/affiliated with the MS organisation as a client and/or as an official member of a member-based organisation.

51.6% of all people with MS who responded to the survey say they regularly use services or information provided by an MS society (dark blue/dark orange), 48.4% do not (light blue/light orange).

Of the people with MS who identify as member/clients of MS societies, 59.3% regularly use services or information provided by an MS society. 40.7% say that they do not regularly use services or information provided by a state-based MS society (Fig.21).

Figure 21 Proportion of people with MS who are registered members and/or clients of state MS societies and those who regularly use services or information provided by an MS society



There is a broad distribution of ages of people with MS who regularly use MS society services and information, but in general they are slightly older than the overall population of people with MS who responded to the survey (Fig. 22). However, they are slightly younger than the participants in the Australian MS Longitudinal Study (AMSLS). The severity of disease in the people with MS who regularly use services and information provided by MS societies is also broadly distributed from those who are very well through to those with significant levels of disability and/or symptoms, however, there is a shift towards the more severely affected end of the spectrum compared with the overall population of people with MS who responded to the survey (Fig. 23).

Figure 22 Age distribution of people with MS who regularly use MS society services and information compared to the overall population of people with MS who responded to the survey and to the participants in the Australian MS Longitudinal Study

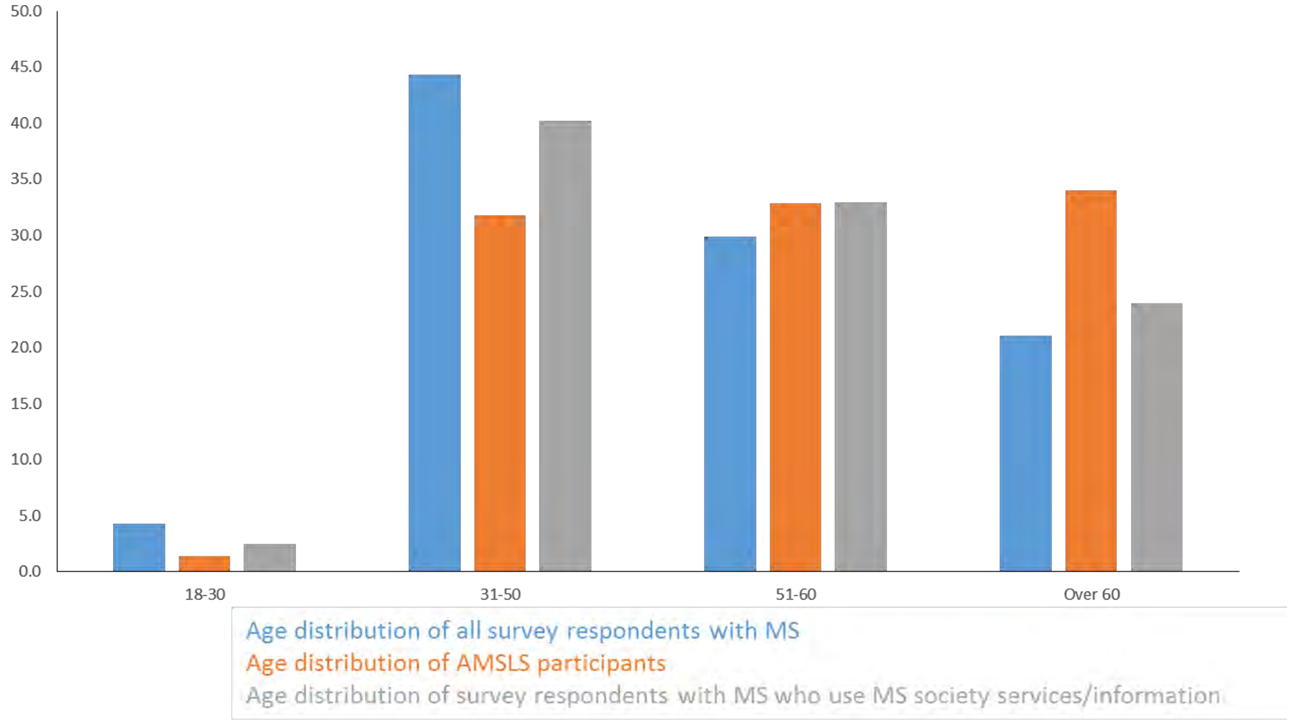
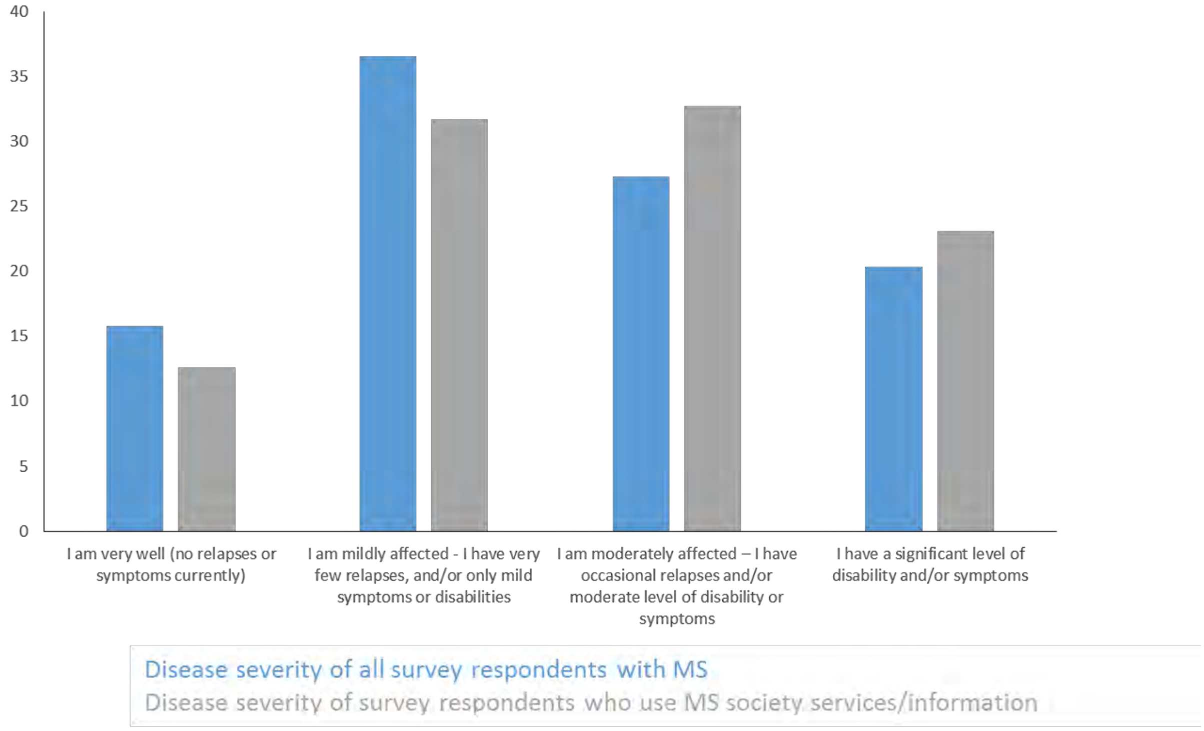


Figure 23 Disease severity of survey respondents with MS who regularly use MS society services/information compared to the overall population of people with MS who responded to the survey



MS Research Australia – Consultation on Research Strategy and Research Priorities

Thank you for taking the time to complete this survey.

MS Research Australia is seeking feedback on our current and future research strategy. We would like to understand which of the many different areas of MS research are considered important by people directly and indirectly affected by MS, as well as health professionals and researchers.

MS Research Australia is a national organisation which aims to accelerate research activity in areas where Australian scientists can have the greatest impact on worldwide MS research to improve outcomes for people with MS. We work in close partnership with and encourage collaboration between a number of Australia's top universities and medical research institutes. We have a very rigorous process to allocate funding to the strongest projects and researchers that have the greatest chance of making an impact for people with MS. Our current research strategy and funding allocations are guided by a robust research governance process headed by leading research experts in the MS field (you can learn more about our research governance and funding process here).

It is a priority for MS Research Australia that the views of the Australian MS community help to guide our research strategy into the future.

In this survey we will ask you to provide feedback on the main 'streams' of research that make up MS Research Australia's overall research strategy, as well as some more detailed, specific areas of research.

We greatly appreciate you taking the time to complete this survey. The survey should take approximately 10-15 minutes to complete.

You will only be able to complete the survey once, but if you need to take a break you will be able to leave and return to the survey to pick up where you left off and/or edit responses on previous pages until you have clicked the 'Done' button.

The survey is anonymous, your name will not be collected. All personal demographic information collected at the end of this survey will be grouped and used only for the purpose of analysing the survey results and cannot be linked to you as an individual.

Feedback on our existing strategy

Question 1
MS Research Australia's overall goals are to better diagnose and treat MS, to predict and prevent MS and to promote cell repair and regeneration.

* Please read the following goals and rank them in order from 1 to 6 (where 1 is the most important to you and 6 is the least important). Select the number 1 for your first choice, number 2 for your second choice and so on until you have used all numbers from 1 to 6, and used each number only once:

☐ Improving the diagnosis of MS
☐ Predicting an individual's disease course (prognosis)
☐ Better treating MS (preventing relapses and disease progression)
☐ Preventing MS
☐ Improving MS management and care (symptoms, rehabilitation and support)
☐ Finding a cure for MS via repair and regeneration of cells

Question 2
MS Research Australia supports research in five key streams to achieve the overall goals to better diagnose and treat MS, to predict and prevent MS and to promote cell repair and regeneration. Four of these streams aim to help us to understand the biology and processes underlying the disease with the goal of identifying treatments, reducing side-effects and working towards prevention and a cure. The fifth area helps us to understand how people living with MS may be best supported to improve rehabilitation, manage symptoms and improve quality of life.

* Please indicate how important you feel EACH of these research streams is to you. You do not need to rank them relative to each other.

	Very important	Important	Fairly important	Not very important	Not important at all	Don't know
Genetics and epidemiology (understanding genetic and environmental risk factors, identifying triggers and causes of MS)	○	○	○	○	○	○
Neurobiology (understanding how the nervous system is affected in MS, mechanisms of nerve damage and repair)	○	○	○	○	○	○
Immunology and virology (understanding the role of the immune system in MS, how viruses may be involved in the disease process, how treatments might modify the immune response in MS)	○	○	○	○	○	○
Clinical trials (supporting clinical research to translate research discoveries into treatments and interventions for people with MS)	○	○	○	○	○	○
Social and applied research (understanding the social, economic, and quality of life impacts of MS, interventions such as rehabilitation, symptom management, physiotherapy and psychology)	○	○	○	○	○	○

Basic/Translational/Clinical

Question 3
The research that MS Research Australia currently funds covers the full spectrum of research from the laboratory bench to clinical studies - the types of research along this spectrum also have different timeframes in which the results of the research can be expected to have an impact on people living with MS.

* Please tell us how much priority should be placed on the different types of research within this spectrum. You do not need to rank them relative to each other, simply assign a level of priority to each one.

	Very high priority	High priority	Medium priority	Low priority	Not a priority	Don't know
'Basic' laboratory-based research to understand the cause and biology of MS – likely to have an impact on people with MS in the longer term (10 years or more)	○	○	○	○	○	○
'Translational' research that may develop into a clinical application within 5 years or less	○	○	○	○	○	○
'Clinical' studies and clinical trials that are likely to have an immediate impact once the study is completed	○	○	○	○	○	○

Questions about specific fields of MS research

Listed on the following pages are some specific areas of MS research for which we don't yet have the answers. We have grouped these specific research topics into broad categories of MS research - prevention, diagnosis, prognosis, treatment, repair, and symptom management. Please indicate the level of priority you feel that EACH research topic should be given using the scale shown below. You do not need to rank them relative to each other.

1. **Very high priority**
2. **High priority**
3. **Medium priority**
4. **Low priority**
5. **Not a priority**

Preventing MS

* **Question 4**
Please indicate the level of priority you feel that EACH research topic should be given within the field of preventing MS. You do not need to rank them relative to each other.

	Very high priority	High priority	Medium priority	Low priority	Not a priority	Don't know
Can MS be predicted in individuals?	○	○	○	○	○	○
How can MS be prevented?	○	○	○	○	○	○
Can MS be prevented in relatives of people with MS? (Family members have a slightly increased risk of MS compared with the general population)	○	○	○	○	○	○
Can vitamin D prevent MS?	○	○	○	○	○	○
Would vaccination against Epstein Barr Virus (EBV) prevent MS? (Previous infection with EBV is a known risk factor for MS)	○	○	○	○	○	○
Is it possible to eradicate EBV and 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?	○	○	○	○	○	○

Diagnosing MS

* **Question 5**

Please indicate the level of priority you feel that EACH research topic should be given within the field of diagnosing MS. You do not need to rank them relative to each other.

	Very high priority	High priority	Medium priority	Low priority	Not a priority	Don't know
How can we diagnose MS earlier (e.g. before a second relapse or MRI event)?	○	○	○	○	○	○
Can an accurate diagnosis of primary progressive MS be made?	○	○	○	○	○	○
Is there variation around Australia in the way that MS is diagnosed and treated?	○	○	○	○	○	○
Can we accurately diagnose the change from relapsing remitting to secondary progressive MS?	○	○	○	○	○	○

Prognosis of MS

* **Question 6**

Please indicate the level of priority you feel that EACH research topic should be given within the field of prognosis for MS. You do not need to rank them relative to each other.

	Very high priority	High priority	Medium priority	Low priority	Not a priority	Don't know
Is it possible to predict how severe a person's disease will be or how fast they will progress?	○	○	○	○	○	○
Is it possible to predict when a person may transition from relapsing remitting MS to secondary progressive MS?	○	○	○	○	○	○
What is the best way to measure progression in people with MS?	○	○	○	○	○	○
Is it possible to predict whether a person will respond to a particular MS medication (reduced relapses/progression)?	○	○	○	○	○	○
Is it possible to predict whether a person will experience side-effects/adverse events in response to a particular MS medication?	○	○	○	○	○	○
What effect does pregnancy have on the long-term progression of MS?	○	○	○	○	○	○
Do other medical conditions influence the prognosis of MS?	○	○	○	○	○	○
Are there any environmental or lifestyle risk factors that affect the long term progression of MS?	○	○	○	○	○	○

Treating MS (relapses and progression)

* **Question 7**

Please indicate the level of priority you feel that EACH research topic should be given within the field of better treating MS (relapses and progression). You do not need to rank them relative to each other.

	Very high priority	High priority	Medium priority	Low priority	Not a priority	Don't know
What are the long term side-effects associated with different disease modifying drugs?	○	○	○	○	○	○
Which interventions are most effective to prevent relapses in MS?	○	○	○	○	○	○
Does effectiveness of individual interventions vary over time in individuals?	○	○	○	○	○	○
Which MS treatments are effective to prevent or delay the transition from relapsing remitting to secondary progressive MS?	○	○	○	○	○	○
Which MS medications are effective to slow, stop or reverse the accumulation of disability associated with progressive MS?	○	○	○	○	○	○
Are hormonal therapies effective for treating MS (male, female hormones)?	○	○	○	○	○	○
What are the best ways to monitor and prevent risks and side-effects of MS treatments?	○	○	○	○	○	○
What are the criteria for selecting the most appropriate disease modifying drug for people with MS?	○	○	○	○	○	○

	Very high priority	High priority	Medium priority	Low priority	Not a priority	Don't know
Which medications are effective and safe to use in children with MS?	○	○	○	○	○	○
Is AHSCT (immunosuppressive chemotherapy with blood and immune stem cell transplant) a safe and effective treatment for MS?	○	○	○	○	○	○

A cure for MS via repair and regeneration?

* **Question 8**

Please indicate the level of priority you feel that EACH research topic should be given within the field finding a cure for MS via repair and regeneration. You do not need to rank them relative to each other.

	Very high priority	High priority	Medium priority	Low priority	Not a priority	Don't know
Are there effective treatments to promote myelin repair in people with MS?	○	○	○	○	○	○
Are there effective treatments to protect nerve cells in MS?	○	○	○	○	○	○
Are there effective treatments to promote nerve cell repair?	○	○	○	○	○	○
Is it possible to stimulate neuronal plasticity (re-wiring the brain) to help restore function or repair the brain?	○	○	○	○	○	○

MS Management and Care – Symptoms, Rehabilitation and Support

* **Question 9**

Please indicate the level of priority you feel that EACH research topic should be given within the field of MS management and care (symptoms, rehabilitation, support). You do not need to rank them relative to each other.

	Very high priority	High priority	Medium priority	Low priority	Not a priority	Don't know
Can lifestyle interventions reduce the impact of relapses or slow accumulation of disability?	○	○	○	○	○	○
Is diet effective in reducing the impact of symptoms and improving quality of life?	○	○	○	○	○	○
What effects does MS have on other family members and family life? How can these effects be managed?	○	○	○	○	○	○
What effect does MS have on children who live with a person with MS? How can they best be supported?	○	○	○	○	○	○
What interventions are helpful in maintaining employment for people with MS?	○	○	○	○	○	○
What impact does stress have on MS?	○	○	○	○	○	○
Does access to a multi-disciplinary MS service improve outcomes and quality of life for people with MS?	○	○	○	○	○	○
Is exercise effective to reduce fatigue and depression in MS?	○	○	○	○	○	○
Is cannabis an effective treatment for MS symptoms?	○	○	○	○	○	○
Is regular physiotherapy effective for preventing disability in MS?	○	○	○	○	○	○

The Symptoms of MS

Question 10
MS can affect people in very different ways and can cause a variety of different symptoms. Not everyone will experience all of these symptoms, but below is a list of symptoms that can occur in MS. Please indicate the priority that you feel should be placed on research into treating or managing EACH OF the following symptoms.

* Please indicate the priority that you feel should be placed on research into treating or managing EACH OF the following symptoms. You do not need to rank them relative to each other.

	Very high priority	High priority	Medium priority	Low priority	Not a priority	Don't know
Balance and falls	○	○	○	○	○	○
Bladder symptoms	○	○	○	○	○	○
Bowel symptoms	○	○	○	○	○	○
Cognitive function (thinking, memory, information processing, decision making)	○	○	○	○	○	○
Depression	○	○	○	○	○	○
Fatigue	○	○	○	○	○	○
Foot drop	○	○	○	○	○	○
Hearing problems (Including tinnitus)	○	○	○	○	○	○
Pain	○	○	○	○	○	○
Sensory symptoms (e.g. burning, tingling, itching, freezing)	○	○	○	○	○	○
Sexual function	○	○	○	○	○	○
Sleep disturbance	○	○	○	○	○	○
Spasticity	○	○	○	○	○	○
Speech and swallowing problems	○	○	○	○	○	○
Temperature sensitivity (either heat or cold)	○	○	○	○	○	○
Tremors	○	○	○	○	○	○
Upper limb function	○	○	○	○	○	○
Vertigo and dizziness	○	○	○	○	○	○
Vision problems (e.g. optic neuritis, blurred vision, double vision)	○	○	○	○	○	○
Walking and mobility	○	○	○	○	○	○

Question 11

Is there any other symptom of MS, not described here, that you feel requires research to improve understanding and treatment of that symptom?

☐

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Did we miss something important?

Question 12

Please tell us if you feel there is a crucial research question that should be prioritised that has not been covered in the previous questions.

And now some questions about you

Please tell us what is your connection to MS

* Do you have MS (or suspected MS, e.g. clinically isolated syndrome)?

○ Yes

○ No

What is your connection to MS?

* Do you have a family member or friend that has MS?

○ Yes

○ No

And finally some questions about you

What is your professional role? (please select all that apply)

- ☐ Researcher
- ☐ Nurse - MS Specialist Nurse
- ☐ Nurse - Other (please describe below)
- ☐ Doctor - Neurologist
- ☐ Doctor - Rehabilitation
- ☐ Doctor - General practitioner
- ☐ Doctor - Other (please specify below)
- ☐ Allied Health Professional (please specify below)
- ☐ Pharmacist
- ☐ Social worker
- ☐ Health Service Manager
- ☐ Care/Services Manager
- ☐ Care Assistant
- ☐ Complementary Therapist
- ☐ Staff within an MS organisation
- ☐ Other Professional (please specify below)
- ☐ Other (please specify)

What is your connection to MS?

* Are you an unpaid/informal carer for someone with MS?

○ Yes

○ No

What is your connection to MS?

* Are you a paid carer for someone with MS?

○ Yes

○ No

What is your connection to MS?

Do you have a professional connection to MS - for example because you are a health or allied health professional, or researcher?

○ Yes

○ No

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What is your connection to MS?

Please tell us about your interest in MS

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And finally some questions about you

* What type of MS do you have?

- ○ Clinically Isolated Syndrome (CIS)
- ○ Relapsing remitting MS
- ○ Secondary Progressive MS
- ○ Primary Progressive MS
- ○ I don’t know
- ○ Other (please specify)

☐

* How long ago were you diagnosed?

- ○ Less than a year
- ○ 1-4 years
- ○ 5-10 years
- ○ 11-19 years
- ○ More than 20 years
- ○ I don’t know

* How are you affected by your MS? *(select the one that most closely matches your circumstances)*

- ○ I am very well (no relapses or symptoms currently)
- ○ I am mildly affected - I have very few relapses, and/or only mild symptoms or disabilities
- ○ I am moderately affected – I have occasional relapses and/or moderate level of disability or symptoms
- ○ I have a significant level of disability and/or symptoms

And finally some questions about you

* Are you a registered member/client of your state MS society?*(MS Society of Tasmania, MS-ACT/NSW/VIC, MS Society of WA, MS Society of Queensland, MS Society of SA/NT)*

○ Yes

○ No

* Do you regularly use services and/or information provided by a state MS society?

○ Yes

○ No

And finally some questions about you

* What is your gender?

○ Male

○ Female

○ Other

○ Prefer not to say

* What is your age?

○ Under 18

○ 18-30

○ 31-50

○ 51-60

○ Over 60

○ Prefer not to say

* Are you an Australian resident?

○ Yes

○ No

* Do you live in a...

○ Major metropolitan centre

○ Regional centre

○ Rural area

○ Remote area

And finally some questions about you

* Do you volunteer for a MS society or local MS support group?*(e.g. peer support, advocate, ambassador, events)*

○ Yes

○ No

* Do you fundraise for your state MS Society*(e.g. MS society of WA, MS society of Queensland, MS society of Tasmania, MS-ACT/NSW/VIC, MS Society of SA/NT)?*

○ Yes

○ No

○ Prefer not to say

* Do you fundraise for MS Research Australia?

○ Yes

○ No

○ Prefer not to say

Thank you!

Thank you for completing this survey.