

Tasmanian Multiple Sclerosis Priority Setting Partnership (MS-PSP) Workshop - 2 May 2024



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ACKNOWLEDGEMENTS

Acknowledgement of Country

We acknowledge the palawa/pakana of lutruwita, the traditional owners of the land upon which we live and work. We pay respects to Elders past and present as the knowledge holders and sharers. We honour their strong culture and knowledges as vital to the self-determination, wellbeing and resilience of their communities. We stand for a future that profoundly respects and acknowledges Aboriginal perspectives, culture, language, and history.

Acknowledgement of the lived experience of MS

We acknowledge and pay respect to people with lived experience of MS and those family members, supporters and carers affected by the diagnosis of a loved one.

We recognise the vital importance of health and medical research into MS being informed and led by lived experience expertise to ensure it is impactful and relevant to the needs of people living with MS.

Other Acknowledgements

We would like to express our sincerest gratitude to all the consumer and community members and researchers who supported and attended the Menzies Institute for Medical Research, Multiple Sclerosis Research Flagship's, Priority Setting Partnership (MS-PSP); your time, energy and contributions are all greatly appreciated.

Lastly, we would like to thank the MS Priority Setting Partnership (MS-PSP) Steering Committee for their diligent work in planning the workshop, and the Menzies and Western Australia Health Translation Network (WAHTN) staff for their support in successfully facilitating the workshop.



MENZIES, MS RESEARCH FLAGSHIP

Background

The Multiple Sclerosis (MS) Research Flagship is a Flagship program of the University of Tasmania and was established from a long history of MS research at the Menzies Institute for Medical Research (Menzies).

Our vision is to reduce the impact of MS on individuals and the community.

Our mission is to perform high-quality, interdisciplinary, consumer driven research on the causes, treatment and prevention of MS through an integrated pipeline of research.

Essential to our vision and mission is the active involvement of and partnership with consumers and the community. We are committed to continually learning from the MS community to improve our research, ensuring meaningful outcomes for the benefit of the Tasmanian community and beyond.

Context

The Multiple Sclerosis Priority Setting Partnership (MS-PSP) workshop was developed to address one of the key strategic goals of the Flagship. Specifically, to conduct a consumer priority setting exercise for the MS Research Flagship researchers and Tasmanian consumers.

The outputs from the MS-PSP workshop will be used by researchers to inform decisions on future priority areas for MS research. It will provide evidence of consumer involvement in research priority setting, ensuring that the research strategy and direction is being informed by lived experience expertise, and remains relevant to the needs of the MS community. This will ultimately lead to greater investment in MS research that achieves greater impact.



MENZIES, MS RESEARCH FLAGSHIP

MS Research Flagship team

Our team has proudly been at the forefront of research advancement in MS for more than thirty years, utilising the unique concentration of people living with MS and MS research in Tasmania.

Among the breadth of work undertaken by the Flagship, there are five main pillars of research. Clinical Research, Brain Health, Epidemiology and Digital Health, Health Economics, and Genomics. There is a dedicated Consumer and Community Reference Committee (C&CRC) who are involved throughout the research cycle and supported by a Consumer and Community Involvement (CCI) manager. Along with the Steering Committee (SC) and Scientific Advisory Committee (SAC), they form the Flagship's governance structure, supported by the Senior Program Manager.

As of June 2024, the MS Research Flagship's current research awards are worth more than \$28 million, supporting a team of more than 60 research fellows, students, professional staff and collaborators working directly on MS projects that aim to achieve our vision. Together with our critical governance committees and partners, we are one of the largest MS teams in Australia, with more than 90 members.



MS PRIORITY SETTING PARTNERSHIP (MS-PSP)

Scope

In early 2024, the MS Research Flagship met with the WAHTN Consumer and Community Involvement program (CCIProgram) to discuss the development of Tasmania-specific MS research priorities, informed by people with lived experience of MS and Menzies MS researchers.

The scope of the workshop was outlined in the MS-PSP protocol, which received ethics approval from the University of Tasmania, Human Research Ethics Committee (H0030613) on 23 April 2024. The aim of the MS-PSP workshop was to identify unanswered questions about multiple sclerosis and agree the top 10 priorities that are the most important for MS researchers in Tasmania to address. The MS-PSP draws on the highest priorities already identified by the MS community as part of MS Australia's priority setting survey, 2021 and the Pathways to cures for multiple sclerosis: a research roadmap, 2022.

The **objectives** of the MS-PSP were to:

- work with people living with MS, carers, clinicians and researchers to confirm a list of twenty uncertainties about MS.
- to agree by consensus a top-10 list of MS research priorities.
- to publish the process and results of the MS-PSP.
- to take forward the results to research advocacy and commissioning bodies to be considered for funding.

The **scope** of the MS-PSP is defined as:

1. Finding a cure for MS.
2. Preventing MS.
3. Better treatments for MS.
4. Improving the diagnosis of MS.
5. Improving the management and care of MS.
6. Predicting an individual's disease course (MS prognosis).

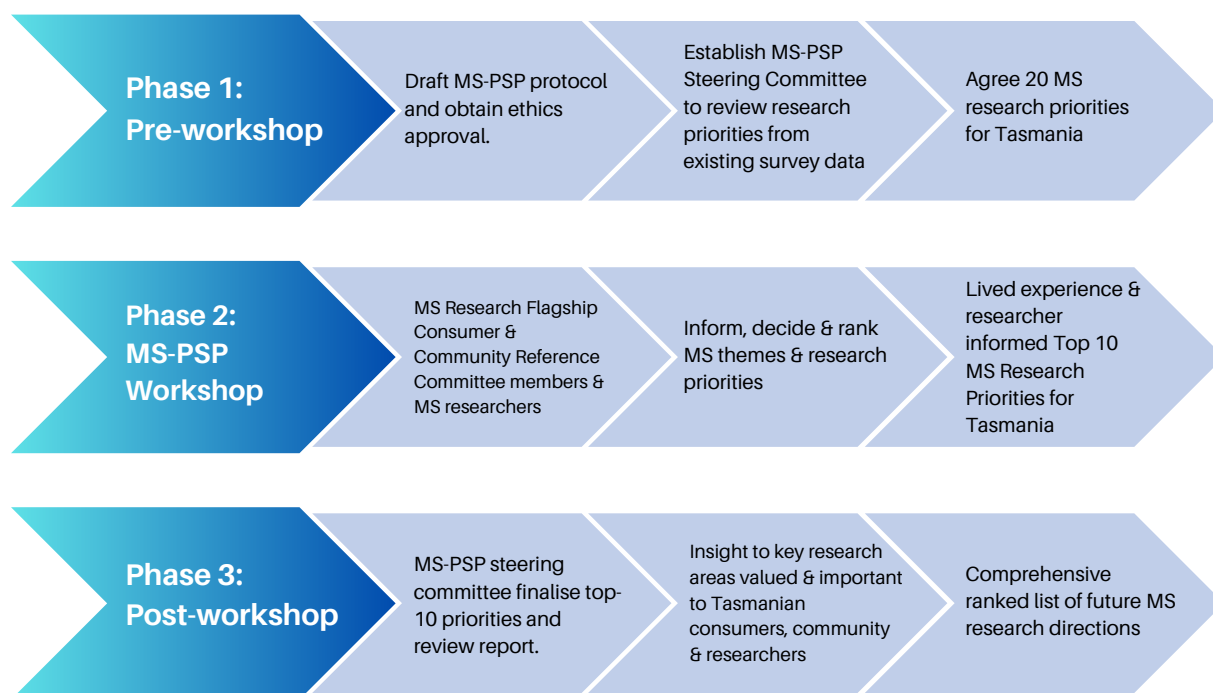
The MS-PSP will **exclude** from its scope:

- Research questions that already have an answer.
- Research questions which are beyond the capabilities of the Menzies Institute for Medical Research.
- MS Australia survey questions on MS symptoms, research streams, types of research or advocacy.

STRUCTURE & PROCESS

The MS Priority Setting Partnership (MS-PSP) was conducted in three separate phases, with Phase 1 consisting of the pre-workshop protocol development and agreement on the 20 unanswered MS research priorities from existing national and international surveys. These were taken forward to the MS-PSP workshop. Phase 2 being the in-person, full-day priority setting partnership workshop to identify the top-10 MS research priorities for Tasmania. Phase 3, the post workshop finalising of the report and wording of the priorities for determining future research directions (Figure 1).

Figure 1: Overview of the MS Priority Setting Partnership process



PHASE 1 - PRE-WORKSHOP IDENTIFICATION OF RESEARCH PRIORITIES

National and international MS priorities

The James Lind Alliance methodology was employed as the framework for the development of a set of Tasmania-specific MS research priorities and themes. A number of alterations to the process included.

- use of pre-existing data and survey responses from MS-specific national and international surveys; and
- researchers from the MS Research Flagship participating in the priority setting partnership workshop alongside consumers and clinicians.

1. **2021 MS Australia Survey**, using a James Lind Alliance approach. Three thousand people were surveyed, with a survey completion rate of 75%, 2,258 people completed the survey. Recipients were identified as;

- 69% person living with MS
- 21% person affected by MS
- 3% professional
- 8% other.

The Report identified 41 topics/research priorities with categories consisting of;

- Finding a cure for MS via the repair and regeneration of cells - 4 topics
- Preventing MS - 7 topics
- Better treating MS - 10 topics
- Improving the diagnosis of MS - 4 topics
- Improving MS management and care - 8 topics
- Predicting an individual's disease course - 8 topics.

2. The second data source comprised responses from the **2022 National MS Society survey**. This process involved consensus building, a Scientific Advisory Committee, and National Board of Directors and Task Force, with representation from USA, UK and Canada. Identification of knowledge gaps and research priorities was achieved with a survey of 300 people with MS. The outcomes were endorsed by 22 leading MS organisations including MS Australia and included **14 recommendations and research priorities under three broad themes**;

- Stopping the MS disease process - 4 topics
- Restoring lost function by reversing damage and symptoms - 4 topics
- Ending MS through prevention – 6 topics

Agreeing the 20 unanswered priorities

A set of 20 key research priorities were required for the MS-PSP workshop. To accomplish this a MS-PSP Steering Committee was formed, comprising two lead MS researchers, a lead MS clinician and the Chair and Deputy Chair of the MS Research Flagship's Consumer and Community Reference Committee (C&CRC).

The Steering Committee performed the following tasks;

- Review the protocol, and >50 existing MS priorities.
- Agree the scope and identify research priorities to be excluded;
 - Research questions that already have an answer
 - Research questions which are beyond the capabilities of the Menzies Institute for Medical research
 - MS Australia survey questions on MS symptoms, research streams, types of research or advocacy.
- Development and approval of the final 20 MS research priorities for use in the MS-PSP workshop
- Refine the wording of the 20 priorities for consistency and ease of use.

The final set of 20 MS research priorities for use at the MS-PSPS workshop are shown below.

TWENTY RESEARCH PRIORITIES

Table 1: Pre-workshop 20 MS research priorities

	MS research priority
A.	How can we promote myelin repair in people with MS?
B.	How can we repair the brain to restore function?
C.	Can we develop effective treatments to protect nerve cells in MS?
D.	What are the mechanisms involved in brain repair and regeneration?
E.	What outcome measures detect regeneration and/or functional recovery?
F.	What are the risk factors necessary and sufficient to cause MS, and when do they act over the life course?
G.	What are the early biological changes that lead to initiation of MS?
H.	How can we identify people at high risk for developing MS?
I.	What interventions could prevent onset of MS in the high- risk population?
J.	What public health interventions could reduce or eliminate MS risk? eg EBV vaccination
K.	Can we find or develop medication to slow, stop or reverse the accumulation of MS disability?
L.	Can we develop effective treatments (drug or non-drug) to promote myelin repair in people with MS?
M.	Can we develop precision medicine strategies to select the best therapy for an individual?
N.	What tools can we develop to make an accurate and early diagnosis of primary progressive MS?
O.	How can we use our understanding of the early biological mechanisms to drive earlier diagnosis of MS?
P.	How can we identify and validate biological markers of disease to improve diagnosis and rapidly measure disease progression?
Q.	Can we determine how stress impacts MS?
R.	What are the most effective supports for people with MS to best self-manage their condition?
S.	How can we conduct effective clinical trials to evaluate rehabilitation and wellness interventions?
T.	What are the environmental of lifestyle risk factors that affect the long term progression of MS?

PHASE 2

MS Priority Setting Partnership (MS-PSP) workshop

The full day in person MS-PSP workshop was delivered on 2nd May 2024 at The Old Woolstore Apartment Hotel, Merino Room, Hobart, Tasmania. A total of 30 participants were in attendance; 11 individuals/carers with a lived experience of MS who are current members of the MS Research Flagship Consumer and Community Reference Committee (C&CRC), together with 12 researchers from the MS Research Flagship. Additionally in attendance were 4 independent facilitators from Menzies, 1 member of the media and communications team. The workshop was independently facilitated by the Head of the WAHTN CCiProgram, Deb Langridge, with assistance from Natasha Stevens, the Senior Program Manager, MS Research Flagship.



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SESSION 1

How did we get here? Research priorities and themes.

The first session of the workshop provided an overview of Phase 1 and the process involved in accessing national and international research priorities and survey responses from the two data sources.

The process of agreeing the pre-workshop 20 key research priorities was also explained, including Steering Committee representatives, scope and criteria.

Of note, each of the attendees received the 20 pre-workshop research priorities in advance to ensure they were aware of the key themes and confident to actively participate in the initial sessions of the workshop.

An overview of the workshop and research prioritisation steps was given to all attendees, discussing objectives for the remainder of the in-person event. The Flagship was invited to provide background information and context regarding the importance of the event and what next steps look like following the findings from the workshop. Ultimately, by the end of the workshop, the consumers and researchers in attendance were to use the twenty identified priorities, together with any new priorities identified, and then rank the top-10 key research priorities for Tasmania and the MS Research Flagship.



SESSION 2

Presentation and discussion of unranked 20 research priorities

This session allowed attendees to discuss the twenty key priorities as condensed and collated by the MS-PSP Steering Committee.

This session provided the first opportunity for attendees to engage and discuss each of the key priorities in table groups. Each table was tasked with discussing the following questions to see if any priorities could be edited, combined, OR if anything additional should be considered:

- What do you think about the identified key priorities?
- Are you in agreement?
- Can you identify any areas that may be missing?
- Are there any themes/priorities that can be combined?
- Are you happy with the wording used to capture each theme or priority?



SESSION 3

Finalising top 20 research priorities for Tasmania

Feedback from the tables was condensed and presented to the larger group. Additional themes were discussed and where agreement was reached, added to the final list of research priorities to be condensed and then ranked. The following revised 26 themes were identified and agreed upon by those in attendance.

Table 2: Final MS research themes and priorities

Please note the new themes are in bold

	MS research priority or theme
A.	How can we promote myelin repair in people with MS?
B.	How can we repair the brain to restore function?
C.	Can we develop effective treatments to protect nerve cells in MS?
D.	What are the mechanisms involved in brain repair and regeneration?
E.	What outcome measures detect regeneration and/or functional recovery?
F.	What are the risk factors necessary and sufficient to cause MS, and when do they act over the life course?
G.	What are the early biological changes that lead to initiation of MS?
H.	How can we identify people at high risk for developing MS?
I.	What interventions could prevent onset of MS in the high- risk population?
J.	What public health interventions could reduce or eliminate MS risk? eg EBV vaccination
K.	Can we find or develop medication to slow, stop or reverse the accumulation of MS disability?
L.	Can we develop effective treatments (drug or non-drug) to promote myelin repair in people with MS?
M.	Can we develop precision medicine strategies to select the best therapy for an individual?
N.	What tools can we use or develop to make an accurate and early diagnosis of primary progressive MS?
O.	How can we use our understanding of the early biological mechanisms to drive earlier diagnosis of MS?
P.	How can we identify and validate biological markers of disease to improve diagnosis and rapidly measure disease progression?
Q.	Can we determine how stress impacts MS?
R.	What are the most effective supports for people with MS to best self-manage their condition?
S.	How can we conduct effective clinical trials to evaluate rehabilitation and wellness interventions?
T.	What are the environmental of lifestyle risk factors that affect the long term progression of MS?

U.	What is the mechanism driving the difference in outcomes between people diagnosed earlier and later in life?
V.	How do we understand how societal characteristics (age, gender, ethnicity, postcode) shape people's experience of MS and access to appropriate supports?
W.	How can end of life care for people with MS/carers be improved?
X.	Why are females more likely to get MS and how do female hormones affect MS throughout the lifespan?
Y.	What are the biological interactions between MS and mental health? And/or symptoms?
Z.	Health, societal and economic impacts for people living with MS, their carers and supporters?



SESSION 4 & 5

Reduction, ranking & presentation of top 10 key priorities

Table groups were asked to perform a number of tasks to collectively;

- Condense the final 20 themes to a top 10
- Provide feedback to the group on their table decision making
- Discuss and rank the final top 10 from 1 to 10 with respect to the most important (1) through least important (10) research priority.

Following in depth discussions, debate, and sharing of lived experiences, the final list of priorities was determined using a dotmocracy process whereby attendees ranked the final 10 key themes into the following research priorities for the MS Research Flagship. The MS-PSP steering committee made minor modifications to the final wording of the top-10.

Table 3: Top 10 ranked MS research priorities for Tasmania

1.	How can we promote myelin repair in people with MS? With inclusion of sub topics; <ul style="list-style-type: none">• How can we repair brain function?• Can we develop effective treatments to protect nerve cells in MS?• What are the mechanisms involved in brain repair and regeneration?• Can we develop effective drug treatments (drug or no-drug) to promote myelin repair in people with MS?
2.	Why are females more likely to get MS and how do female hormones affect MS throughout the lifespan?
3.	How do we understand the social characteristics (age, gender, ethnicity, postcode) that shape people's experience of MS and their access to appropriate supports?
4.	What outcome measures detect regeneration and/or functional recovery? With inclusion of sub topics; <ul style="list-style-type: none">• What tools can we use or develop to make an accurate and early diagnosis of primary or progressive MS?• How can we identify and validate biological markers of disease to improve diagnosis and rapidly measure disease progression?
5.	What are the most effective supports for people with MS to facilitate MS self-management.
6.	What are the risk factors that are necessary and sufficient to cause MS, and when do they act over the life course?
7.	What are the early biological changes that lead to initiation of MS? With inclusion of sub topics; <ul style="list-style-type: none">• How can we use our understanding of the early biological mechanisms to drive earlier diagnosis of MS?• What are the mechanisms driving the different outcomes between people diagnosed earlier and later in life?
8.	How can we identify people at high risk of developing MS? With sub topic; <ul style="list-style-type: none">• What (cost effective) interventions could prevent MS onset in high-risk populations?
9.	What links MS, mental health and other MS symptoms?
10.	What are the health, societal, and economic impacts for people living with MS, their carers and supporters?

NEXT STEPS

The final session involved discussion about next steps and use of the Top 10 MS research priorities for Tasmania. These lived experience and researcher informed research priorities being a first for Tasmania will be used in a number of strategic and impactful ways including;

- Reporting and promotion to the MS Research Flagship, Menzies Institute, the broader MS community of people with a lived experience of MS, and also to the national and international advocacy and research sectors.
- Informing research and grants will be a key element of the priorities to both guide what to research, together with providing evidence of how consumer and community members have been involved in supporting the prioritisation and ideation of research topics and projects. This will be a valuable element of all future research grant proposals.
- Informed decision-making regarding resourcing and support of research and further enquiry of the themes and topics highlighted in the top 10 research priorities for Tasmania will be aided by this information.
- Strategic planning of targeted research, projects, support and initiatives can be inclusive of these top 10 research priorities. Whether pertaining to the strategic direction of the MS Research Flagship, Menzies, University of Tasmania, or partners and collaborators, these lived experience and researcher-informed priorities can assist in directing the future roadmap of MS research both in Tasmania and nationally.

The CCIProgram enjoyed the opportunity to continue their ongoing support of the MS Research Flagship and the opportunity to connect with the remarkable people with lived experience of MS, and the MS researchers at the Menzies. The exemplar practice of involving people with lived experience in research at the MS Research Flagship and the adoption and commitment to consumer and community involvement in research by the research team continues to be an ongoing strength further demonstrated by the development of these 10 MS research priorities for Tasmania.



ABOUT THE WORKSHOP FACILITATOR

Consumer and Community Involvement Program

The Consumer and Community Involvement Program (CCIPProgram) is an enabling platform of the Western Australian Health Translation Network (WAHTN). The CCIPProgram actively supports partner universities, health and medical research institutes, health service providers and non-Government organisations to bring together consumers and people with lived experience and connect them with health and medical researchers. The success of the CCIPProgram comes through building and maintaining strong relationships with WAHTN and Partner Organisations.

Consumers and community members are an integral part of the research process, allowing for greater transparency, openness and accountability leading to research which is more relevant and impactful to the community. Our aim is for consumer and community involvement to be standard practice in all health research in Western Australia. As such, our services, resources and training programs have been developed to support consumers and community members being involved at all stages of the research cycle.

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