Evaluation of the MS Australia Research Program: Performance, Impact and Strategic Alignment

An independent review of research programs, outcomes and future directions

March 2026

Research Program Review Committee:

- Dr Tony Willis (Chair)
- Professor William Carroll
- Dr Sarah Flaim
- Professor David Tscharke
- Dr Pamela Valentine

Table of Contents

Glossary of Acronyms and Key Terms

Term / Acronym	Definition
AHSCT Registry	Autologous Haemopoietic Stem Cell Transplant Registry – A national registry systematically collecting safety and efficacy data on stem cell transplant outcomes in MS.
AMSLS	Australian MS Longitudinal Study – One of the world's longest-running longitudinal lived-experience studies, capturing more than 20 years of data on the impacts of MS on Australians.
ANZgene	Australia and New Zealand MS Genetics Consortium – A collaborative genetics research consortium identifying MS risk and severity genes and contributing to international genetic discovery efforts.
ARC	Australian Research Council – Australian Government research funding body.
Brain Bank (MS Australia Brain Bank)	A national resource providing high-quality post-mortem brain and spinal cord tissue to researchers.
EBV Platform	Epstein–Barr Virus and MS Platform – A national platform coordinating research into the role of Epstein–Barr Virus in the cause and progression of MS.
IMSGC	International MS Genetics Consortium – A global collaborative network advancing discovery of MS susceptibility and severity genes. Australian participation occurs through ANZgene and related initiatives.
InforMS	Digital Patient-Reported Outcomes Platform – A secure digital platform capturing real-time patient-reported outcomes and experiences. Enables more personalised care and provides research-ready datasets.
IPMSA	International Progressive MS Alliance – A worldwide alliance accelerating therapies for progressive MS.
LEEP	Lived Experience Expert Panel – Advisory panel comprising people with lived MS experience.
Medical Research Future Fund (MRFF)	Australian Government medical research funding program.
MSA	MS Australia
MS Brain Health Initiative	An international initiative promoting earlier diagnosis, optimised treatment and improved long-term outcomes through evidence-based brain health strategies in MS.
MSBase	An international, investigator-led registry collecting clinical data on MS to improve treatment strategies, monitor long-term outcomes and support collaborative research.
MSIF	MS International Federation – The global umbrella organisation uniting national MS societies.
PLATYPUS	Progressive MS Adaptive Platform Trial – An Australian-led adaptive clinical trial evaluating multiple therapies for progressive MS.

PrevANZ	Vitamin D Prevention Trial – A clinical trial testing whether vitamin D supplementation can reduce the risk of developing MS in high-risk individuals.
PwMS	People with MS – Individuals living with multiple sclerosis; central beneficiaries of MS Australia's research investment.
Research Program Review Committee (RPRC)	Independent committee appointed by the MS Australia Board to conduct the evaluation of the Research Program.

Context and Purpose: Lived Experience and Research

MS Australia's core strategic purpose is to support people living with MS. Its research program exists because individuals and families affected by MS have consistently called for better treatments, earlier diagnosis, improved quality of life, and ultimately prevention and cure. Over decades, the program has been shaped through partnership between people with lived experience, researchers, clinicians, donors and national and international collaborators.

For people living with MS, research is not abstract. It influences access to therapies, informs decisions about care, shapes understanding of disease progression, and offers hope for prevention. Research also provides opportunities for participation through surveys, advisory roles and clinical trials, ensuring that research priorities remain grounded in real-world experience and community need.

For researchers and clinicians, MS Australia's investment has provided stability, credibility and a national platform for collaboration. Investigator-led grants have sustained research capability and seeded discovery. National platforms have reduced duplication, strengthened clinical trial readiness, built critical data and infrastructure, and enabled translation. International partnerships have accelerated and amplified MS Australia's investments, connecting Australian researchers and people living with MS to global initiatives and expanding both scientific influence and access to emerging knowledge.

Research sits at the heart of MS Australia's mission, reflecting a clear and enduring commitment to people living with MS. This review builds on that strength, examining how the organisation can steward its resources responsibly, strengthen areas of greatest impact, modernise governance where appropriate, and ensure that each investment — direct or leveraged — delivers meaningful outcomes for the community it serves.

The report's findings and recommendations should therefore be read as an affirmation of partnership between lived experience and research, and as a roadmap to ensure that MS Australia's research investment continues to evolve, remain credible, and deliver benefit in an increasingly resource-constrained environment.

Executive Summary

MS Australia (MSA) commissioned this independent review following recommendations from the 2023 Willis Report to ensure the organisation's Research Program remains fit for purpose, strategically aligned, transparent, and capable of meeting the evolving needs of people with MS and the MS research community.

Across the program, the review identifies opportunities to accelerate discovery and translation while amplifying the impact of existing and leveraged investments, particularly through coordination, and partnership.

The review seeks to ensure that MSA's research program remains strong, sustainable and impactful in a rapidly changing global research environment. At a time when research funding is increasingly constrained and science itself is contested in some settings, MSA's commitment to research remains unwavering. The purpose of this review is to recommend how MSA might steward limited resources responsibly, strengthen areas of greatest impact, and ensure their research program continues to

deliver outcomes for people living with MS in Australia while maintaining national and international leadership.

The review aligns with the Terms of Reference approved by the Board in August 2024, which require assessment of:

1. the operation and outcomes of major research activities
2. alignment with the MS Australia Strategic Plan 2022–2026
3. effectiveness, efficiency and equity in research investment
4. opportunities to strengthen coordination, impact measurement and partnerships
5. recommendations to improve future governance and investment.

A mixed-methods approach was adopted, incorporating information and analyses provided by the review Secretariat, performance and financial analyses, survey data, structured stakeholder interviews, and a seven-point assessment matrix. All programs were evaluated against common criteria, with independent scoring and cross-validation by panel members.

Overall Assessment

The review concludes that the MSA Research Program is a nationally significant and high-performing portfolio, delivering substantial scientific outputs, national infrastructure, consumer-relevant insights, and strong global engagement. Across domains, the program demonstrates solid alignment with the MS Australia Strategic Plan and with the needs and expectations of researchers, clinicians, people with MS, and international partners.

Importantly, the review identifies opportunities to rebalance, modernise and future-proof the program, particularly as expenditure moves from a recent peak of $7.5M in 2024—reflecting time-limited additional investment—towards a projected $4.5M by 2030. This pattern reflects the lumpy nature of research funding rather than a planned disinvestment in research, which remains a core strategic commitment of MS Australia. Several platforms now require transition or consolidation, while emerging priorities—such as prevention, early detection, progressive MS, and improved translation pathways—require sustained investment.

The findings and recommendations set out in this report respond directly to the Terms of Reference and provide a coherent framework for future decision-making.

Findings Against the Terms of Reference

Operation and Outcomes of Major Research Activities

Investigator-Led Grants Program

The grants program remains a cornerstone of MSA's research investment, consistently endorsed across interviews and supported by strong performance data. It provides best practice peer review; delivers high rates of publication, collaboration and follow-on funding; and is crucial for maintaining research workforce capability in a constrained national funding environment.

However, demand substantially exceeds available resources, and stakeholders signalled a preference for fewer, more fully funded grants.

National Collaborative Research Platforms

MS Australia's research platforms have emerged through multiple pathways, including investigator- and clinician-led initiatives as well as organisation-initiated investments to address contemporary opportunities and challenges. Given the diverse origin of each of these national platforms and their

commencement they show high variability in maturity, purpose and performance, but several are strongly aligned with strategic needs and deliver clear benefits:

- **High-performing platforms**: AMSLS, Clinical Trials Platform, PLATYPUS, EBV in MS
- **Strategic infrastructure**: Brain Bank, AMSLS, ANZgene
- **Emerging/early-stage**: InforMS, EBV platform (post-MRFF)

On the other hand, PrevANZ has been completed and the results published and the urgent need for the AHSCT Registry is reducing due to changes in the availability and early use of highly effective therapies. ANZgene activity is lessening, though ongoing collaborations with the International MS Genetics Consortium remain an important legacy. As programs mature, they require careful review and structured transition, and while each will have its own pathway, a general policy is needed.

International Platforms

The IPMSA, Global Prevention & Early Detection Platform and the MSIF demonstrate strong global leverage, influence and alignment with MSA's long-term research vision. For relatively modest national investment, these platforms address research gaps that require a coordinated global approach, unlock substantial financial and intellectual leverage, expand access to international expertise and consumer networks, and accelerate progress toward shared research objectives.

For Australians living with MS, these global investments support earlier access to cutting-edge knowledge, accelerate the translation of international findings into local clinical practice, reduce duplication of effort, and ensure Australian researchers and consumers help shape – rather than simply adopt – global research priorities.

While their direct impacts for Australian consumers require clearer communication, their strategic value is high.

Strategic Alignment

The Research Program Review Committee (RPRC) employed an assessment framework that shows that alignment with MSA's strategic priorities is generally strong, particularly for platforms addressing:

- progressive MS
- prevention and early detection
- clinical trial readiness
- epidemiology and real-world outcomes
- global collaboration.

High-scoring platforms such as PLATYPUS, AMSCTP and AMSLS clearly advance the Strategic Plan's commitments to translation, prevention, and improving quality of life. Variation in alignment across other initiatives—including the Brain Bank, Policy Alliances and the MS Brain Health Initiative—reflects differences in program and platform origins, maturity, and the clarity of pathways to impact, rather than a lack of underlying value.

Effectiveness, Efficiency and Equity

Effectiveness

The portfolio generates substantial scientific output, but impact narratives are inconsistent, particularly for infrastructure and discovery platforms where contributions are indirect or long-term. More systematic impact reporting would strengthen visibility for consumers and funders, and better capture downstream influence.

Clearer articulation of how investments contribute to real-world benefits – such as shorter diagnostic pathways, better trial readiness, improved understanding of disease progression, or the long-term pursuit of prevention – would support stronger trust and engagement from people living with MS and the broader community.

Efficiency
Governance and administrative processes are strongest in the Investigator-Led Program, whereas broader platform governance is highly variable. Consolidation of clinical trials infrastructure, rationalisation of mature platforms, and improved reporting structures would materially strengthen efficiency.

Equity
Participation remains concentrated in a small number of institutions. Early-career researcher support is valued but inconsistently linked to broader capacity-building strategies. Stronger mechanisms are needed to broaden institutional participation and ensure equity across the research ecosystem.

Coordination, Measurement and Partnerships
The review identifies substantial opportunities to enhance coordination across platforms—particularly clinical trials, digital platforms, epidemiology infrastructure and global partnerships. The current portfolio has grown organically, with some duplication and inconsistent reporting.

In addition, leveraged funding and in-kind contributions are significantly under-reported, hampering full valuation of MSA's investment impact. A light-touch mechanism for capturing leverage is recommended.

Partnership opportunities remain strong, especially with MRFF-funded initiatives, global prevention research, progressive MS alliances and emerging AI/device translation pathways.

Recommendations

The recommendations in the full report directly address the ToR requirement for actionable, future-focused advice. They fall into three groups: immediate priorities, medium- to long-term improvements, and scenario-based guidance for different funding settings. In this Executive Summary, recommendations are presented in a consolidated, thematic form to provide a strategic overview, with the full detailed list—including scenario-specific variations—set out in the main report.

(1) Immediate (2026–2027)
- **Strengthen communication and impact reporting**
  Improve clarity, consistency, and visibility of research impact for people living with MS in Australia.
- **Consolidate national clinical trials infrastructure**
  Integrate existing trials platforms and networks to reduce duplication and strengthen national readiness.
- **Apply lifecycle-based transition for mature platforms**
  Implement structured transition or exits for platforms where MS Australia's strategic role, or the value of the platform has diminished.
- **Reshape investigator-led funding with attention to balance**
  Adjust grant structures to balance administrative burden, grant size, and success rates,

including higher-value incubator grants and strengthened NHMRC Investigator or Ideas Grant top-ups.
- **Embed structured lived-experience involvement**
Introduce proportionate, fit-for-purpose lived-experience engagement across platforms.

(2) Medium- to Long-Term (2027–2030)

- **Establish rolling platform lifecycle reviews**
Implement a three-year review cycle assessing maturity, performance, and alignment.
- **Sustain investment in high-performing platforms**
Prioritise continued investment in platforms demonstrating strong impact and strategic alignment.
- **Strengthen national coordination and governance**
Standardise governance and reporting while preserving scientific independence.
- **Build capability in prevention and early detection**
Invest in biomarkers, EBV mechanisms, and digital epidemiology through partnerships.
- **Capture leveraged funding and institutional contributions**
Systematically document co-investment and funding leverage.

(3) Funding Scenarios

Scenario-based guidance is provided to support prioritisation under reduced, stable and expanded funding environments, ensuring the recommendations are operationally adaptable.

Conclusion

The MSA Research Program is delivering significant scientific, clinical, collaborative and strategic value. The organisation has built an ecosystem that is widely respected and central to national progress in MS research. In an environment where public confidence in science can no longer be taken for granted, MSA's commitment to credible, consumer-relevant research plays an important role in maintaining trust, countering misinformation, and ensuring that evidence continues to inform care, policy and individual decision-making.

Importantly, beyond scientific output, the program is contributing to outcomes that matter directly to people living with MS in Australia, including improved clinical trial access, earlier identification of disease progression, strengthened pathways to prevention and early detection, and increased opportunities for individuals to participate meaningfully in research that shapes future care.

The findings of this review highlight specified opportunities to modernise governance, strengthen communication, rebalance investment and more clearly articulate and support the robust engagement of lived experience across the research lifecycle.

Taken together, the recommendations provide a clear, evidence-based roadmap for ensuring that MSA's investment continues to grow in impact—shaping future research, accelerating translation and positioning the organisation to lead Australia's next decade of progress toward prevention, earlier diagnosis, better treatments, and ultimately, a cure.

1 Introduction

1.1 Purpose of the Review

This review was commissioned by the Board of MS Australia (MSA) following the recommendation made in the *Report on MS Australia Research Support* (Willis, November 2023), which advised a comprehensive, independent review of the organisation's Research Program. Willis (2023) identified opportunities to clarify program objectives, strengthen governance and coordination, and better demonstrate the impact of MSA's research investments.

In commissioning this review, the MSA Board seeks to understand how MS Australia's research investments can be structured to accelerate progress towards outcomes and amplify the value of each dollar invested. In this context, the Board seeks to assess the performance, relevance and future direction of the research program, and to ensure it remains fit for purpose in a complex and evolving global research landscape. With finite resources and increasing expectations for impact, careful stewardship and strategic focus are essential. Importantly, the program under review is a strong and respected one, having delivered significant scientific, clinical and collaborative value over time.

Viewed in this way, the review should be read as an affirmation of MS Australia's ongoing commitment to research, rather than a signal of retrenchment or disinvestment. The findings identify opportunities to strengthen communication, modernise governance, and rebalance investment in ways that sustain capability, enhance impact, and position MS Australia to continue exercising leadership nationally and globally.

The intent is to ensure the research program continues to evolve, remains credible, and delivers outcomes that matter most to people living with MS.

The review supports the objectives of the *MS Australia Strategic Plan 2022–2026*, which defines the organisation's mission to *empower people with MS to live well through research, advocacy and education*. It is consistent with national and global strategies for advancing research excellence and translation, including MSA's own *A Roadmap to Defeat MS in Australia (2021)* and its participation in international alliances.

The review's objectives are to:

- Evaluate the effectiveness, efficiency and strategic coherence of MSA's research investment
- Assess how well the MSA Research Program reflects and responds to the priorities expressed by the MS community in the *2025 Research Priorities Survey* and through stakeholder consultations
- Provide actionable recommendations to strengthen future investment, governance, research coordination and communication, collaboration and reporting.

The intended outcome is an evidence-informed report that offers a clear framework for future funding decisions and research partnerships and strengthens MSA's position as the national leader in research support for the MS community.

1.2 Terms of Reference

The *Terms of Reference* (ToR), approved by the MSA Board in August 2024, define the scope, methodology and deliverables for this review. The full Terms of Reference are available on request. An outline of key elements is below:

- Examine the operation and outcomes of the organisation's major research activities, including the Investigator-Led Grants Program, the suite of Collaborative Research Platforms, and initiatives supporting clinical trials and translation
- Assess strategic alignment between the MSA Research Program, the *MS Australia Strategic Plan 2022–2026*, and the organisation's mission to accelerate research toward prevention, better treatments and a cure for MS
- Evaluate effectiveness, efficiency and equity in the allocation and management of research funding
- Identify opportunities to improve coordination, impact measurement, and partnerships nationally and internationally.

The review's deliverables comprise:

- A written report setting out findings, analysis and recommendations
- A presentation of the key findings and recommendations to the MSA Board.

Governance of the review rests with the MSA Board, supported by an independent Chair (Dr Tony Willis) and a Research Program Review Committee (RPRC) with expertise in neurological and applied research, clinical science, lived experience, research management and evaluation.

1.3 Process

The review began in February 2025 and proceeded through five main stages:

1. Initiation and planning – confirmation of the Terms of Reference, establishment of the RPRC Committee, and collation of relevant documentation and data.
2. Data collection – briefings from the Secretariat, review of program materials, and completion of the stakeholder survey and interviews.
3. Assessment – evaluation of key programs and platforms using a seven-point rubric to ensure consistency and objectivity.
4. Analysis – integration of quantitative and qualitative evidence, mapping of findings against the ToR criteria, and identification of cross-cutting themes.
5. Reporting – preparation and refinement of the draft and final reports for submission to the Board.

Governance oversight was maintained through periodic updates to the Board, with the Secretariat providing logistical and data support. The Chair ensured that the review remained independent and evidence based.

Stakeholder engagement was central to the process, with representation from across the Australian MS research community, clinicians, consumer advocates and platform collaborators.

1.4 Confidentiality and Independence

Although supported by a secretariat provided by MSA, the review was conducted independently of MSA's management structures and operational decision-making. All RPRC members declared any

actual or perceived conflicts of interest, and interviewees were likewise asked to identify any relevant interests during the interview stage. Declared interests were considered and managed by Chair and did not influence the RPRC's deliberations or review recommendations.

All information obtained through interviews, surveys and documentation has been treated as confidential and used solely for the purposes of this review. The RPRC affirms that its findings and conclusions are evidence-based, independent and presented without bias or undue influence.

2 Methodology

A mixed-methods approach was adopted, drawing on multiple sources of information, as outlined below:

2.1 Information supplied by MSA

The MSA Secretariat provided detailed descriptions, performance metrics and financial summaries for all major research programs and collaborative platforms, along with case studies of successful MSA-supported researchers. They also supplied a summary of the impact of the Investigator-Led Grants Program, Research Progress Reports, Financial Status Reports and materials on research outcomes. A summary of the key information is provided at **Appendix 1.**

2.2 MSA Research and Advocacy Priorities Survey

The RPRC reviewed the draft MSA Research and Advocacy Priorities Survey to be conducted in 2025 and proposed several additional questions. These were subsequently incorporated into the survey and focused on:

- Investigator-Led Grants Program – New questions asked participants to assess whether current MS Australia grant amounts—within a fixed annual research budget—are adequate and useful for achieving their intended research goals. The questions covered all major funding schemes and used a five-point agreement scale
- National Collaborative Research Platforms – Additional questions invited respondents to indicate their involvement with MSA's National Collaborative Research Platforms and to assess their value, impact, and the efficiency of associated funding. Respondents were also given the opportunity to provide open comments on potential improvements

A summary of survey outcomes is provided at **Appendix 2.**

2.3 Stakeholder interviews

Structured interviews were conducted by members of the RPRC with a broad range of MSA stakeholders—including researchers, clinicians, platform leads, and people with lived experience of MS—to gather qualitative insights into their familiarity with, and assessment of, the performance and impact of the MSA Research Program. A standardised question set (**Appendix 3**) was used across all interviews, organised around four thematic areas: (A) Strategy, Impact and Value; (B) Delivery, Structure and Resources, covering adequacy of funding, stakeholder engagement, and capacity-building contributions; (C) Lived Experience & Inclusion, exploring links between research program activities and improvements in care, quality of life, and community outcomes; and (D) Other Comments, providing an opportunity for interviewees to raise additional insights or emphasise issues of importance.

2.4 Other Reference materials

The RPRC also drew on a range of reference materials to inform its analysis. These included previous evaluations such as the Willis (2023) Report, MS Australia's strategic and operational plans, and documentation associated with the existing research platforms. Where relevant, the RPRC reviewed international frameworks and guidance from comparable organisations, as well as national benchmark documents—including NHMRC and MRFF scoring rubrics, assessment criteria, and good-practice guidance for research funding bodies. Together, these materials provided important context to support and inform the RPRC's judgements.

2.5 Assessment framework

To support consistent and transparent assessment of the MS Australia Research Program, the RPRC developed a structured evaluation matrix to integrate the qualitative assessments of inputs outlined above into a quantitative structure. Structured around the elements of the MSA Research Program that underpinned the stakeholder interviews, each element of the portfolio was assessed against a common set of criteria, including Strategic alignment & System Capacity; Translation & Implementation; Value for money & Leverage; Global Positioning; Stakeholder Value – Researchers & Clinicians; Impact for People with MS; Lived Experience Involvement; Feasibility & Risk; and Future Use. Evidence from financial analyses, performance reports, survey data and stakeholder interviews was synthesised and scored using a seven-point scale. Committee members rated each program independently, and mean scores ± standard errors were calculated. These scores informed the RPRC's collective judgements in preparing the report. Further details of the assessment matrix are provided in **Appendix 4**.

2.6 Quality assurance

Findings were cross validated among RPRC members throughout the data collection, analysis, and report drafting stages. MSA's Lived Experience Expert Panel (LEEP) [1] reviewed a preliminary draft of the report to ensure appropriate inclusion of the lived experience perspective, given its strategic importance to MS Australia. Feedback from the LEEP was incorporated into this version of the report. The Chair assumed responsibility for coordinating the final report, with all RPRC members contributing to its preparation and verifying the accuracy and balance of the findings.

2.7 Limitations

Some variability in data availability and stakeholder response rates is acknowledged. These limitations are identified in relevant sections of the report and considered in interpreting the findings.

The methodology for this review was informed by the principles of the Medical Research Future Fund Monitoring, Evaluation and Learning Strategy, which promotes systematic, transparent, and evidence-based approaches to assessing performance and impact.

3 Investigator-Led Grants Program

The Investigator-Led Grants Program is one of the core functions of MS Australia. Addressing the unmet need to better understand multiple sclerosis, its disabling potential, and the imperative to prevent progression through effective treatment at all stages of the disease remains central to MS Australia's purpose. While highly effective disease-modifying therapies have reduced relapse

---

[1] https://www.msaustralia.org.au/leep/

activity, they have not eliminated progression, long-term disability, or the need for prevention-focused research. As care requirements evolve with the introduction of these therapies, the continuing rationale for MS Australia and its member organisations is to support and fund the research needed to address this unmet need and to ensure that people with multiple sclerosis are informed of, and have access to, effective treatments.

Consistent with the objectives outlined in the Introduction, this section assesses whether the MSA Research Program remains fit for purpose, strategically aligned, transparent and capable of meeting the evolving needs of PwMS and the wider research community.

A summary of the Investigator-Led grant program is below.

Table 1. Summary of Investigator-Led Grant Schemes

- **Project Grants**:   ≤3 years; $50–200K per annum
- **Incubator Grants**:   ≤12 months; ≤$25K
- **Postdoctoral Fellowships:**   ≤3 years; $40K-$100K per annum
- **Senior Research Fellowships**:   ≤5 years; ≤$130K per annum
- **Paired Fellowships:**   ≤3 years; ≤$250K per annum
- **Postgraduate Scholarships**:   ≤3 years; ≤$40K per annum
- **Travel Awards (Ian Ballard)**:   8 weeks (≤12 months validity); ≤$25K
- **Targeted Call Project Grants**:   Details specified in call.

3.1 Program Demand and Funding Patterns

Project Grants and Incubator Grants remain the most frequently sought schemes and are highly valued for enabling research aligned with MSA's strategic aims. Fellowships (Postdoctoral and Senior Research) and Scholarships contribute to research capacity building. In 2024, requests for Project Grants and Postdoctoral Fellowships totalled **$12.73 million**, representing **94.7%** of all funding requested. Of the **$5.8 million** awarded, **94%** was allocated to these two schemes.

Figure 1 shows the distribution of MSA-funded grants in 2024. **Figure 1a** illustrates that most of the total funding was directed to Project Grants and Postdoctoral Fellowships, reflecting the higher value of these awards. This aligns with the long-standing funding weightings applied by the Research Management Council. **Figure 1b**, the second pie chart, shows that the number of funded grants was divided almost equally among Project Grants, Postdoctoral Fellowships and Incubator Grants.

3.2 Program Performance

A more detailed assessment of outcomes highlights the strong performance of key schemes in the Investigator-Led Grant program. In summary:

- Most projects have been or will be presented at national or international conferences
- More than 50% have been published or submitted for publication
- Over one-quarter have attracted additional research funding
- More than 40% have led to new collaborations, including many international partnerships
- Several projects have contributed to major advances through ANZgene and the IMSGC, including identification of the MS severity mutation (rs10191329)
- Biomarker identification, MS model development and new research assays have been achieved
- One patent application has been filed.
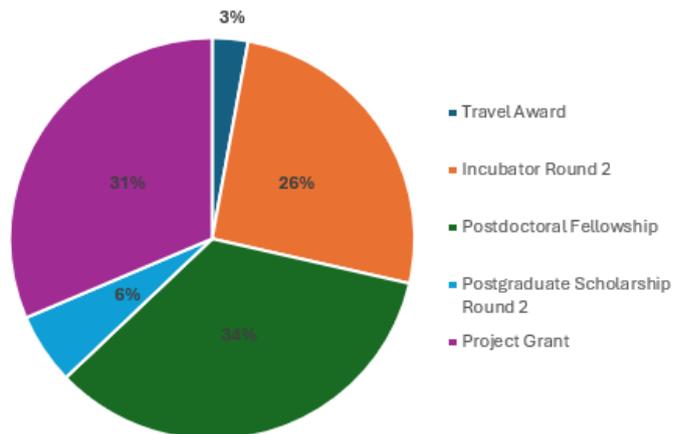
Three case studies illustrate the importance of sustained support. For example:

- **A/Prof Justin Rubio (Florey Institute)** – contributed to identifying genetic variants linked to MS severity and evidence for increased axonal mutation burden in MS
- **Dr Chenyu Wang (Brain and Mind Centre, Sydney)** – developed an AI-assisted MRI program for detecting lesion evolution and brain volume change, now FDA approved
- **Dr Jessica Fletcher** – identified key mechanisms linking remyelination to protection against axonal loss and disability progression

Collectively, these examples demonstrate the value of consistent, multi-year support in enabling impactful research.

3.3 Insights arising from interviews

Overall, the Investigator-Led Program received strong endorsement, particularly compared with other elements of the MSA Research Program. Stakeholders emphasised:

- The pivotal role of MSA in shaping Australia's MS research ecosystem
- The importance of communicating research progress to the MS community
- Support for the breadth of the program, with views shaped by the interviewees' exposure to particular grant types
- Desire from some for more substantial funding per researcher in contrast to earlier approaches of spreading smaller amounts more widely.

4 Collaborative Research Platforms

MSA supports research through a program of national platforms and international platforms. The following sections outline key elements of these platforms.

4.1 National Platforms

The National Collaborative Research Platforms were adopted or established by the MSA Board to address strategic priorities or fill identified gaps in Australia's MS research ecosystem. Their common purpose is to provide coordinated national effort—reducing duplication, accelerating progress, and enabling broad access for researchers to shared resources, data, and biospecimens. The platforms vary in age and maturity, with some long-standing infrastructure initiatives and others created more recently to meet emerging needs. Each platform is contracted, funded, and resourced at a level appropriate to its function, and operates under governance arrangements that include embedded lived-experience input and annual reporting. There are currently nine National Collaborative Research Platforms, as outlined below:

- **ANZgene** - a coordinated MS genetics consortium established to overcome fragmented research and has since built a large biobank and delivered major discoveries. It now operates largely self-sufficiently with modest MSA support and continues to collaborate internationally through the International MS Genetics Consortium.
- **Australian MS Clinical Trial Network and Platform**: The Australian MS Clinical Trials Network and Platform streamline national clinical trial activity, improving access, coordination, and trial readiness. It incorporates patient education and centralised expertise and is highly valued for reducing duplication and accelerating translation.
- **PLATYPUS Clinical Trial** - PLATYPUS is an adaptive clinical trial designed to rapidly evaluate repurposed treatments for progressive MS, addressing a major unmet need. With strong initial investment, it aims to expand candidate therapies and integrate emerging scientific insights.
- **Australian MS Longitudinal Study (AMSLS)** – This is a national longitudinal study capturing real-world lived-experience data essential for policy, advocacy, and service design. It is highly regarded and fully funded by MSA, with future growth focused on data linkage and early-stage disease capture.
- **InforMS** - is a digital health platform enabling people with MS to track symptoms, integrate wearable data, and share information with clinicians for improved care. Early in its lifecycle, it intends to play a major role in future research and digital engagement.
- **Autologous Haemopoietic Stem Cell Transplant (AHSCT) Registry** - The AHSCT Registry systematically tracks long-term outcomes of AHSCT treatment for MS to support informed

clinical decision-making. Now reaching maturity, it is expected to operate largely independently with minimal ongoing MSA funding.

- **Epstein-Barr Virus (EBV) and MS Platform** - The EBV and MS Platform advances research into the causal link between EBV and MS, leveraging a significant MRFF investment secured through MSA's advocacy. It is strategically important and aims to drive biomarker development and future EBV-targeted prevention or therapeutic trials.
- **MS Australia Brain Bank**: The MS Australia Brain Bank provides high-quality, well-characterised MS brain and spinal tissue to researchers, addressing a critical gap in pathology research. It is widely used and strategically important, though its impact is less visible to the MS community.
- **PrevANZ Vitamin D MS Prevention Trial** - PrevANZ tested whether vitamin D supplementation could prevent MS and now functions as a data-sharing platform after finding no protective effect. It remains scientifically useful but requires no further major investment.

4.2 International Platforms

The International Collaborative Research Platforms have been established by the MSA Board to advance strategic priorities that require coordinated global effort. While collectively extending MSA's international influence and collaboration, these platforms differ in purpose, governance and funding model, ranging from membership-based coordination bodies to co-funded global research platforms addressing specific research gaps. There are currently four International Collaborative Research Platforms, as outlined below, noting that the International MS Genetics Consortium has been addressed in the preceding section:

- **MS International Federation (MSIF)** – this is the global network of MS organisations supporting research, advocacy, and equity, with MSA contributing data and membership dues. It plays a significant role internationally, including supporting global resources like the Atlas of MS.
- **International Progressive MS Alliance (IPMSA)** - The IPMSA is a major global collaboration addressing progressive MS by directing high-impact multinational research with funding at levels and duration beyond most national organisations means and in which lived-experience leadership is strongly incorporated. MSA is a managing and contributing member.
- **Global Research Strategy Group (Pathways to Cures)** - The Global Research Strategy Group coordinates international research priorities across the Stop, Restore, and End pathways outlined in the Pathways to Cures Roadmap. Its work highlighted the gap in prevention and early detection, prompting development of a new global platform.
- **Global Prevention and Early Detection Platform** - This platform, co-led by MSA and MS Canada, aims to advance global MS prevention and early detection research, supported by a five-year MSA investment. It focuses on risk factors, EBV mechanisms, and long-term global cohort development.

MSBase is a large, internationally recognised MS clinical registry that plays an important role in generating evidence on disease course and treatment effectiveness. While MSBase is not a formal MSA platform, its relationship with MSA is strong and operational, with MSBase leaders actively contributing to multiple committees and collaborative activities. MSBase is also the underlying data resource for multiple MSA Investigator-led grants. The registry represents a significant Australian-led contribution to global cohort development and provides an important example of how informal but well-aligned partnerships can deliver substantial scientific and clinical value.

4.3   Analysis of Platforms

The following section provides a high-level analysis of the national and international research platforms. It summarises cross-cutting themes and patterns in alignment, performance, cost-effectiveness, collaboration potential, and future funding considerations across the full platform portfolio.

Alignment with Strategic Priorities

Across both national and international platforms, alignment with MSA's strategic priorities is strong and consistent. Virtually all platforms align with at least two priorities, and many align with four or five. A clear pattern emerges: national platforms tend to align strongly with direct research outputs, quality of life, and translation, while international platforms emphasise global collaboration, capacity-building, and accelerating breakthroughs through collective effort.

High-performing platforms such as AMSLS, the Australian MS Clinical Trials Network and Platform, PLATYPUS, and the EBV in MS Platform demonstrate alignment across prevention, treatment, quality of life, and translation. International platforms such as MSIF and IPMSA strongly reflect the priorities of collaboration, workforce capacity, and global coordination. Overall, alignment is strong but varies by the platform's lifecycle—mature platforms often show alignment with long-term capacity building, whereas newer platforms tend to align with emerging scientific priorities such as EBV, prevention, and early detection.

Platform-Specific Analysis

A set of distinct functional categories emerges across the platform portfolio.

National platforms range from long-standing infrastructure (AMSLS, MS Australia Brain Bank) and registries (AHSCT) to high-impact clinical research enablers (Australian MS Clinical Trials Network and Platform), major strategic trials (PLATYPUS), and focused scientific initiatives (EBV in MS Platform, PrevANZ). Their maturity varies significantly: AMSLS (23 years) and the MS Australia Brain Bank (17 years) have been operating for some time, while digital platforms like InforMS are still early in development. Several platforms (ANZgene, AHSCT Registry, PrevANZ) are now mature or largely self-sustaining, with diminishing need for intensive MSA coordination. Others (PLATYPUS, EBV in MS Platform) represent strategic renewal, focused on progressive MS treatments, prevention, and fundamental disease mechanisms.

International platforms form a complementary layer focused on global alignment, scientific coordination, and shared research agendas. MSIF functions as an international network and information hub; IPMSA is a major driver of progressive MS research; the Global Research Strategy Group (Pathways to Cures) shapes the global research roadmap; and the Global Prevention and Early Detection Platform represents an emerging long-horizon investment aligned with identified global gaps.

Together, these platforms form a broad ecosystem that supports discovery, translation, infrastructure, lived-experience insights, and global collaboration.

Cost-Effectiveness

The portfolio shows wide variation in cost and leverage, with several platforms delivering substantial value for relatively modest investment. ANZgene, for example, operates on low direct funding while sustaining a large biobank and international collaborations. The AHSCT Registry similarly requires limited ongoing investment, and PrevANZ now functions primarily as a data asset with low continuing cost. High-investment platforms such as PLATYPUS and AMSLS provide significant

strategic and translational impact, with PLATYPUS representing the Australian extension of a major international clinical trial and AMSLS providing a unique longitudinal evidence base.

Digital infrastructure (InforMS) and tissue infrastructure (MS Australia Brain Bank) involve higher ongoing operational costs but are either being developed (InforMS) or are well-established (Brain Bank) as important long-term assets. International platforms also vary: MSIF membership dues are relatively low, whereas IPMSA requires a substantial annual contribution but returns benefits through major research investment. In general, MSA achieves strong leverage where platforms access co-funding or international investment—most notably, the EBV in MS Platform's $10M MRFF-supported research program.

Collaboration Opportunities

Collaboration is a defining feature across all platforms, with multiple opportunities to strengthen integration. Nationally, clinical trials–related activities (PLATYPUS, Australian MS Clinical Trials Network and Platform) could benefit from coordinated governance and shared operational processes to reduce duplication and enhance trial readiness. AMSLS and InforMS present opportunities for deeper integration through data linkage and digital-health expansion. The MS Australia Brain Bank and EBV in MS Platform offer opportunities for integration with global consortia and large research cohorts.

International platforms further extend these opportunities: MSIF supports shared data and advocacy initiatives; IPMSA brings together researchers, people with MS, and industry partners in progressive MS clinical trials; and the Global Research Strategy Group creates alignment across global research roadmaps. The Global Prevention and Early Detection Platform offers early-stage opportunities for long-term international cohort development, EBV-related research, and new models of prevention science.

Future Funding Prospects

Future investment decisions can be guided by lifecycle stage, strategic importance, and demonstrated value. Several national platforms appear ready for transition or reduced funding, including ANZgene, AHSCT Registry, and PrevANZ, which have either achieved core objectives or can operate largely independently. High-priority platforms warranting continued or expanded investment include AMSLS, the Australian MS Clinical Trials Network and Platform, PLATYPUS, and the EBV in MS Platform, all of which align with major unmet needs or strategic opportunities.

Digital and infrastructure platforms such as InforMS and the MS Australia Brain Bank may require ongoing investment contingent on clearer articulation of value, impact communication, and growth trajectories. Among the international platforms, MSIF and IPMSA appear to carry enduring strategic value, while the Global Prevention and Early Detection Platform represent a forward-looking commitment aligned with global research gaps identified through Pathways to Cures. Overall, future funding prospects favour platforms that address major unmet needs (progressive MS, prevention, lived-experience data), provide national coordination, or leverage significant external investment.

5 Portfolio Funding Balance

5.1 Funding Models and Levels

Across the Investigator-Led Grants Program and the National and International Collaborative Research Platform there is a wide range of funding models, funding levels and amounts of leverage. At one end there is the Investigator-led Grants Program that at face value is fully funded by MSA with allocations in the order of $4-5m per annum across the program as a whole. Similarly, some of

the National Platforms are fully funded by MSA, e.g. AMSLS (~$1m over 2024-29) and some trials, e.g. historically PrevANZ and currently PLATYPUS ($1m MSA and $3m MSWA). At the other end, MSA provides modest in-kind support only to the EBV in MS Platform that aims to boost collaboration across several consortia funded by a total of $10m in MRFF funds. In the middle are National Platforms such as InforMS where there are contributions from MSA in cash and in-kind to support a project funded by the NHMRC, that also has local institutional contributions.

In leveraged funding initiatives such as those supported through MRFF and similar mechanisms, MSA has played a major lobbying, convening, and coordination role, while grant applications themselves have been developed and led by researchers and funds are not held directly by MSA. This facilitative role is a significant strength of the program and warrants clearer recognition, as it enables alignment across projects, reduces fragmentation, and supports outcomes that would be difficult to achieve through isolated investments alone.

The spending on International Collaborative Research Platforms is leveraged almost by definition, but while the MSA contribution is added to a much larger international pool, the amount that comes back to support MS research in Australia and Australians with MS is more complex to assess. Participation in some International Programs (e.g. Global Research Strategy Group - Pathways to Cures) require in-kind support through the participation of MSA staff, and this engagement opens new opportunities. By contrast, the Prevention and Early Detection Program, is supported by an initial investment of $2.5M in cash from MS Australia and $5M from MS Canada, with additional international partners expected to join through future MOUs, increasing both financial and strategic leverage over time. Levels of support, funding models and leverage are summarised for the National and International Platforms below:

National Programs

Program	Funding Model	MSA Amount	Dates	Leverage
ANZgene	Partial funding + in-kind strategic oversight	$50,996	2024	
Australian MS Clinical Trials Network	An internal activity of MSA	In kind through MSA salaries	Ongoing since 2010	
AMSCTP (Platform Trials)	Co-funding and leveraged grants	PLATYPUS: $1M; MSA in-kind $282K	Trials commenced in 2025; in-kind support over 5 years	Supported trials: PLATYPUS: MSWA $3M; STOP-MS & FIRMS-EBV: $3M each (MRFF)
AMSLS	Fully funded by MS Australia	$1,000,191	2024–2029	
AHSCT Registry	Data collection and analysis funded by MSA	$144,000	2024–2026	
EBV in MS Platform	Support from MSA for externally funded projects	In kind through MSA salaries	Platform launched 2024	Supports $10M external funding (MRFF)
InforMS Digital Platform	Co-funding: NHMRC + MS	$400K cash + $280K in-kind	Current funding to Sept 2026	NHMRC, $703,705; UTAS

	Australia cash/in-kind			in-kind with a salary 2025-26
MS Australia Brain Bank	MS Australia cash +	$180,330.15	Sept 2024 – Jan 2026	In-kind USyd and RPAH
PrevANZ Vitamin D Trial	Initially fully funded by MS Australia	$4.7M initial trial funding	Trial completed; ongoing data-sharing platform	None

International Programs

Program	Funding Model	Amount	Dates	Leverage
MS International Federation	Membership contribution	GBP 46,435 (based on 2024)	Ongoing	No specific funds for research
International Progressive MS Alliance	Co-funded global research collaboration	$464K	2013–2025	Local funding of €923K; €60m committed globally
Global Research Strategy Group (Pathways to Cures)	In-kind support	Not specified	2022–2024	No specific funds; has led to collaborative projects.
Prevention and Early Detection Platform	Co-funding	$2.5m	2024–2029	$5m (MS Canada)

International programs serve two complementary purposes: advancing outcomes more rapidly through global collaboration and expanding opportunity for Australian researchers by providing access to larger international funding pools, expertise, and infrastructure. At the same time, MS Australia must balance its contribution to global efforts with donor expectations that research investment delivers tangible benefit for Australian researchers and for people living with MS in Australia. Making this balance explicit helps clarify the strategic intent of international engagement and provides a basis for assessing its ongoing value. This in turn will build confidence and drive advocacy for these platforms, and new opportunities to engage internationally as they arise.

In this context, continued participation in international platforms should be informed by the broader benefits of global collaboration, as well as the extent to which Australian researchers are able to participate meaningfully and secure funding.

It is important to recognise that even platforms that receive significant direct funding in cash from MSA typically receive institutional in-kind support not captured in the table above by way of infrastructure and salaries of senior researchers. Further, the Investigator-Led Grants are nearly all best described as "grants-in-aid". This means that in addition to leveraging infrastructure and senior researcher salaries, and in some cases salary gaps, most projects are supplemented with other funding from research groups. It would be worthwhile for MSA to capture these additional leveraged funds for a complete picture of the extra funding that flow into MS research in Australia due to the activities they fund.

5.2 Funding Recommendations

There are four areas where the current funding of the Investigator-Led Grants Program and the Research Platforms by MSA merits further consideration: 1) Fully capturing costs and leverage; 2) consolidation to reduce potential duplication and complication; 3) a forward-looking approach to funding; 4) seeking new co-funding opportunities.

Fully capturing costs and leverage

Across the information available to the RPRC, the full in-kind spend by MSA is not captured. It maybe that in these cases, the support given is too small a slice of salary to be worth the burden of record keeping and accounting. However, a light-touch assessment across all programs would be valuable to ensure that in-kind contributions remain proportionate and are not driven by avoidable inefficiencies.

One area requiring greater clarity is the total cost of delivering the Investigator-Led Programs, which includes MSA resourcing and associated expenses and is currently estimated at $138,000 per annum. Likewise, the leverage of MSA funds in terms of infrastructure, researcher salaries and the filling of funding gaps by research groups and institutions is not captured. This is probably easiest done by providing an opportunity for researchers to estimate these amounts in their financial reports, preferably without requiring formal verification by institutions. The aim here is not to be a strictly accurate accounting exercise, but rather to help MSA estimate the value of this leverage, because these are funds that support MS research in Australia that would cease in the case of any activity that is stopped.

Consolidation

As noted elsewhere, the full range of activities under the MSA Research Program has grown over many years and there are opportunities for consolidation. The most obvious place to start is the clinical trial Platforms. The Australian MS Clinical Trials Network and Platform (along with its trials) and the remaining obligations associated with PrevANZ could come under a single umbrella. Another is the Investigator-led Grants Program with eight programs that, except for the Ian Ballard Travel Award, fall into two categories: researcher salary support and project support. Other funders have moved away from funding researcher salaries without any funds for projects and have more strict rules for applications across programs that are largely overlapping.

Forward-looking funding

The various Research Platforms are at different stages in their lifecycle and the oldest now sit in very different contexts in terms of the important questions in MS research than when they started. Drawing from views across the researcher community, not all have consistent support. Research Platforms such as ANZgene, the AHSCT Registry and PrevANZ are perhaps the most obvious of these. ANZgene because the identification of MS susceptibility genes is slowing now after an immense body of work done by the international community, including Australian researchers through ANZgene. The AHSCT Registry and PrevANZ because high efficacy treatments such as anti-CD20 therapies have been so successful and the spotlight has moved somewhat away from vitamin D.

What is important is that a funding exit strategy is constructed for Research Platforms where the science or treatments have moved on. In the case of the AHSCT Registry an internal review has done this work and concluded that further direct financial contributions by MSA are unlikely to be needed. It is worth noting that considering the life of Platforms needs to be done at the same time as new investments and research opportunities arise. For example, the relationship between EBV and MS remains one of the most exciting MS research directions, but the major funding in this area in

Australia is from a set of MRFF projects that are in their final year or will end soon. MSA has rightly invested to encourage collaboration across these projects, but this Platform will need an injection of new funded projects if it is to remain relevant.

New funding opportunities

The advent of the MRFF has not delivered all that the MS research community might have hoped for, it is however a significant source of funds. The 2022 Multiple Sclerosis Research Grant Opportunity funded under the MRFF Clinical Trials Activity Initiative and Emerging Priorities and Consumer Driven Research Initiative stands out as the largest injection of funds for MS research from the Federal Government. We recognise the advocacy by MSA that led to this opportunity. It will be important to track changes in policies as the MRFF matures and the broader medical research landscape shifts with the release of the forthcoming National Health and Medical Research Strategy 2026-2036. A significant shift in Australian Government funding is underway for projects on the pathway to commercialisation, for example through the MRFF's Medical Research Commercialisation initiative, but also emerging schemes such as Australian's Economic Accelerator Ignite and Innovator. Much of the research that can be done by the MS research community is necessarily discovery in nature and these types of schemes are not relevant, but the application of devices and innovations in AI could well lead to translation. It might be that community groups might be able to contribute in future schemes, so keeping an eye on these developments and looking for opportunities would be wise. Also, projects that assist MS researchers to be competitive for this type of funding are worth considering. Finally, over the years MSA has offered joint funds directly with NHMRC, which is a very effective form of leverage that should be investigated again. An example would be exploring whether there is an opportunity to repurpose Senior Research Fellowships by strengthening the current arrangements with NHMRC on Investigator Grant "top ups". Another is the possibility of co-funding NHMRC Ideas Grants.

6 Program Effectiveness

6.1 Impact of Research Outcomes

Assessing the impact of research requires consideration of all users of a research outcome. Research impacts can range from direct changes in policy or a new treatment, to changes in community attitudes, to more traditional academic measures of the importance of a finding in the field. Often a smaller piece of research can be found to have much broader impact if a full analysis of what secondary or tertiary users of the new information have been able to achieve. Many impacts take years to become apparent, and some are unanticipated at the time the research was done, meaning that it is very difficult to capture the impact of a particular activity through annual or end of project reporting. In many reviews of research outcomes, impact is typically demonstrated through *post hoc* case studies that take significant time and resources to complete. Due to the overlapping nature of MSA funding investments, many impacts have drawn on more than one program or platform, which on the one hand might make the contribution of each difficult to judge, but on the other shows the benefit of funding infrastructure platforms and creative investigator-Led projects.

Having set this definition of research impact, it is not easy to find concrete examples of detailed impacts for all platforms. In some cases, it is because the activity is too new (e.g. EBV in MS). In others, the platform is an enabler of research done by others, e.g. the MS Australia Brain Bank and Australian MS Clinical Trials Platform. For these it could be argued that their impact is the enabling activity itself, but that leaves them without a compelling narrative of success that can be easily understood by MSA supporters and the MS community. Of those with a stronger impact story, PrevANZ stands out: a clinical trial was done that tested whether high dose vitamin D might delay

the onset of clinically defined MS and while the answer was disappointingly "no" in this particular trial, this remains an important outcome adding to an international body of evidence. The finding directly influences recommendations on the use of high dose vitamin D, which is important because taking these high doses is not without health risks. The AMSLS has provided data to back MSA advocacy, for example in the Health Economic Impact of MS in Australia Reports [2]. Key statistics from these studies demonstrate the platform's value in informing advocacy and shaping policy. In 2024, there were 37,756 people living with MS in Australia. The estimated cost of MS to Australian society was just over $3.004 billion in 2024, reflecting a substantial increase over previous years. The mean cost per person living with MS was $79,581. For people living with MS with no disability, the mean cost was $42,688. In contrast, those living with severe MS-related disability incurred a significantly higher mean cost of $135,780.

For the Investigator-Led Grants Program, the summary of impacts includes publications, a patent, development of laboratory models, new grant applications, and collaborations. These are all important indicators of research activity and success; however, they are better understood as markers along the pathway to impact rather than impact itself. MSA has developed three case studies, and it is pertinent to discuss two of them here. Associate Prof Justin Rubio's research exemplifies the benefit of combined use of project and platform (MS Australia Brain Bank) funding from MSA and highlights an important scientific finding. The significant translational potential of the outcome is described, but the result is too new for translation to have started and there is no information on how the outcome has been used by others. By contrast the work of Dr Chenyu Wang, initially funded by an MSA Postdoctoral Fellowship, led to the development of an AI method of MRI analysis that is now available for clinical use.

Several interview participants who were in lived experience groups or from state-based MS organisations noted that they found it difficult to understand for themselves, or to explain to others how MSA-funded research has directly impacted the lives of people with MS. They appreciated that the scientific outcomes may have been well communicated, but they were keen to hear stories from the research that demonstrated something more tangible to them – either benefits or changes for people in their communities. The development of more impact case studies would provide the content for this type of communication.

6.2   Value to MS Research Community

The value of MSA funding and funded platforms to the Australian MS research community is enormous and well-documented. For example, in recent years success rates for NHMRC grants have been in the order of 10 to 13%, where MSA schemes average a success rate of 40%. This provides support for researchers who are passionate about MS research through a robust selection process, but where the only competition is other MS researchers. The value of this funding to individuals is illustrated through the case study of Dr Jessica Fletcher, who was supported as an early career researcher by MSA and who has become a leader in MS research, having been chief investigator on successful grants from NHMRC and ARC. Her focus though these years has been on remyelination, which is identified by the MS community as a research priority.

MSA Research Platforms have an additional benefit in that they provide either 1) resources that would be impossible for a single researcher to amass, like the MS Australia Brain Bank or 2) coordination, like the Australian MS Clinical Trials Platform. Through interviews with researchers, there was not necessarily agreement as to which platform was of the greatest value. A common

---

[2] See, for example, https://www.msaustralia.org.au/amsls/key-findings/

refrain, however, was that one or more of the platforms were essential. Interview participants also suggested practical improvements and pointed to useful resources. A recurring message was the substantial administrative burden involved in multi-site or newly established clinical trials. By reducing the associated workload, MSA Research Platforms can improve access to clinical trials for the Australian MS research community. A stronger and more efficient clinical trials environment increases the attractiveness of Australia as a site for research investment, expands access to trials for Australians with MS, and ultimately supports improved health outcomes.

7 Program Efficiency

7.1 Application and Review Processes

Long-term expenditure data show the overall cost of the MSA Research Program increasing from approximately $0.7 million in 2005 to $3.0 million in 2013, peaking at $7.5 million in 2024, and projected to fall to $4.5 million by 2030. This expenditure trajectory forms an important backdrop for considering future efficiency and investment balance.

7.2 Cost-Effectiveness

Investigator-Led programs

Cost-effectiveness of the Investigator-Led Grants Program is reflected in the outcomes summarised in Section 3.1. All platforms—except for PrevANZ, which has completed its purpose—continue to operate and deliver value. However, assessment of the Investigator-Led Grants Program, indicates opportunities to adjust the number of schemes and the balance of the overall portfolio:

- **Project Grants**: Strong support exists for maintaining this scheme. However, there is a clear trend in views towards fewer, more fully funded projects. To preserve an arm's-length approach to governance, the Research Management Council (RMC) could be invited to outline alternative priority-setting approaches and advise on optimal selection mechanisms.
- **Incubator Grants**: These grants are relatively low-cost and effective. Increasing their value to $30–40K could be considered, even if accompanied by a slight reduction in the number awarded annually.
- **Postdoctoral Fellowships**: These fellowships resemble Project Grants in research scope and contribute significantly to capacity building.
- **Postgraduate Scholarships**: Similar to Incubator Grants, Scholarships should continue and ideally be linked to senior researchers.
- **Senior Research Fellowships and Paired Fellowships**: This scheme appears to require review and potential adjustment to its frequency.
  One possibility is to revise current arrangements associated with the NHMRC Investigator Grant program. Redirecting a greater share of funding toward NHMRC Investigator Grants—potentially by drawing from the Senior Research Fellowship program—could strengthen the pathway for the highest performing MSA-supported researchers to transition to external funding. This would assist researchers who are competitive in the NHMRC Investigator scheme and would, in turn, free resources for other Investigator-Led Grant schemes if appropriate limitations were put on applications to some other MSA grants in the same way that, for example, funders including the ARC and the NHMRC apply to schemes in their programs.
- **Travel Awards:** These awards are modest in financial value but nonetheless require administration and programme management. It may be more cost-effective to consolidate this support into other schemes, such as Project Grants, or alternatively Postdoctoral and

Postgraduate schemes where it would contribute to career development, rather than maintaining a separate award stream.

In considering any changes to investigator-led funding arrangements, a balance must be struck between maintaining an attractive and accessible funding environment for researchers and ensuring schemes remain efficient, sustainable, and capable of delivering impact. In implementing any changes, key considerations include the effects on application success rates, the administrative burden associated with multiple schemes, and the role of smaller grants in supporting early-stage or exploratory research. For example, the Board might examine opportunities to streamline the number of schemes, considering whether incubator grants are set at an appropriate level to support the generation of competitive follow-on funding. However, any implementation must be accompanied by an assessment framework to monitor how any adjustments affect participation and feasibility across the research community.

These considerations are intended to improve the effectiveness of investigator-led funding and accelerate progress, not to reduce support for high-quality research or discourage participation.

Governance and Administration

Managing Research Platform costs within the projected reduction in overall expenditure—from $7.5 million per annum to $4.5 million over four years—will be challenging, particularly alongside calls for improved communication and coordination. Based on the information available to the Committee, the following observations can be made in relation to specific platforms:

- AMSLS: May warrant review, including consideration of its current operations and contractual arrangements with the Menzies Institute for Medical Research, to ensure ongoing value, efficiency, and alignment with future needs.
- InforMS – Digital Platform: Current operations and cost structures are not sufficiently clear. MS Australia would benefit from a targeted review of costs and functionality to better understand the platform's cost–benefit profile and inform future directions.
- AHSCT Registry: Costs to MS Australia are expected to be minimal. Retention of the registry is recommended while AHSCT remains a necessary treatment option.
- ANZgene: Current annual expenditure is budgeted at $48,590, reflecting MS Australia's support for coordination and record-keeping activities.
- AMSCTP: MS Australia's FY26 resourcing commitment is $185,110. While the platform plays an important role in enabling clinical trials, greater clarity regarding the scope and drivers of these costs would assist future planning and assessment of value.
- Brain Bank: FY26 costs are $263,498 and are likely to relate primarily to record-keeping and communication activities, potentially shared with the Brain and Mind Centre. Further clarification of cost allocation, leverage and efficiencies would be beneficial.
- PLATYPUS: The platform is co-funded with MSWA, with MS Australia committing $1 million over five years. Additional operational or in-kind costs borne by MS Australia are not fully specified and would benefit from clearer articulation.
- MSIF: Participation is obligatory, with costs associated with membership and contribution to international coordination and shared global resources.
- International MS Genetics Consortium (IMSGC): No direct cost is incurred by MS Australia. The consortium provides access to international collaboration and data through in-kind participation.
- MS Brain Health Initiative: Supported through an MS Australia Board decision, reflecting strategic alignment with global best practice in MS care and research translation.

- EBV collaborations and EBV in MS Platform: EBV-related initiatives are discussed briefly elsewhere in the report. The EBV in MS Platform currently involves a resourcing cost of $33,600 and leverages MRFF support for the associated research activities. While the platform appears appropriately funded at present, MSA's longer-term financial commitments and the scope of ongoing EBV collaborations would benefit from clearer articulation.

A notable contrast exists between the governance of grants and other platforms. Investigator-Led research grants operate with clear processes, including annual reporting on progress and expenditure. In contrast, many of the other platforms appear to lack comparable levels of transparency, reporting and consistency of process. There is an opportunity to centralise their oversight and management under a unified MSA governance structure with consolidated records.

8   Strategic alignment

Strategic alignment is a critical measure of how well the MSA Research Program reflects the organisation's mission and long-term objectives. It assesses whether funded initiatives contribute to the overarching goals of the *MS Australia Strategic Plan 2022–2026*, including accelerating research toward prevention, improved treatments, and ultimately a cure, while empowering people with MS to live well. This dimension also considers coherence with other national medical research priorities (NHMRC, MRFF) and global strategies such as the International Progressive MS Alliance and MSIF frameworks.

8.1   Alignment with MSA Strategies

The RPRC used the results of the assessment framework (**Appendix 4**) to shape its views on the degree of alignment with MSA strategic objectives and noted that clinical trials and translational platforms achieved the highest alignment with MSA's strategic priorities. The PLATYPUS Platform scored 6.25 for strategic alignment and 48.50 total, reflecting its direct contribution to MSA's priority of addressing progressive MS—a critical unmet need identified in the 2025 Research and Advocacy Priorities Survey. Similarly, the AMSCTP Clinical Trials Platform scored 6.00, reinforcing its role in enabling trial readiness and accelerating therapeutic innovation.

Among research infrastructure and data platforms, the AMSLS – Australian MS Longitudinal Study scored 6.00, highlighting its strategic importance in generating longitudinal data for policy, health economics, and real-world outcomes. Conversely, initiatives such as the MS Australia Brain Bank (score 4.50) and MS Brain Health Initiative (score 4.33) demonstrated weaker alignment, suggesting these programs may require clearer articulation of their strategic contribution or integration into broader research priorities.

Global engagement initiatives showed mixed results. For example, IPMSA scored 5.67, indicating strong alignment with global strategies for progressive MS, while Policy Alliances scored 4.67, reflecting limited direct impact on MS-specific research objectives.

8.2   Responsiveness to Research Needs

Research Platforms that scored highly on translation and implementation—such as PLATYPUS (6.00) and AMSCTP (5.25)—demonstrate responsiveness to community priorities for progressive MS and clinical trial access. Infrastructure programs like AMSLS (5.25) and EBV in MS Platform (5.33) also show adaptability to emerging research needs, particularly in epidemiology and viral triggers. However, the ANZgene Platform scored only 3.75 for translation, indicating a gap in moving genetic

discoveries toward clinical application. Similarly, MS Australia Brain Bank scored 3.50, suggesting limited pathways for immediate translational impact.

9   Equity and Engagement

Equity and engagement are essential dimensions of the MSA Research Program, ensuring that research investments are inclusive, transparent, and responsive to the needs of all stakeholders – including, importantly, people with lived experience of MS. The RPRC considered whether funding and support mechanisms promote equity and engagement including support for diverse institutions, disciplines and geographic regions, equity within the research community itself (including who is supported and able to participate), and whether people with lived experience of MS are involved in shaping research priorities and governance. As outlined in the following sections, the RPRC also considered stakeholder perceptions of fairness, accessibility, and value, as well as the extent to which the MSA Research Program fosters collaboration nationally and internationally.

9.1   Inclusivity in Research Support

Analysis of lived experience involvement reveals significant variability across programs. AMSLS – Australian MS Longitudinal Study scored 4.75, reflecting strong consumer engagement in governance and data interpretation. In contrast, the MS Australia Brain Bank (2.50) and ANZgene (2.67) scored lowest, indicating limited integration of lived experience perspectives in program design and decision-making. These findings suggest a need for targeted strategies to embed consumer co-design in infrastructure and genetics initiatives.

9.2   Stakeholder Perceptions

Stakeholder value for researchers and clinicians was highest for AMSCTP (5.75) and Project Grants (5.50), confirming their perceived relevance and value. Conversely, global engagement initiatives such as MSIF (3.67) and Policy Alliances (3.67) scored lower, suggesting limited direct benefit for domestic stakeholders. Feedback from interviews indicated that while international collaborations are valued for prestige and knowledge exchange, their practical impact on Australian research capacity and clinical practice is less visible. It is important to note, however, that international platforms often deliver their value indirectly—by leveraging global investment, enabling access to large-scale datasets and specialist expertise, and reducing the time and cost required to achieve major discoveries that would be difficult or impractical to pursue nationally.

9.3   Collaboration Opportunities

Programs enabling shared infrastructure and trial readiness—such as AMSCTP and PLATYPUS—were rated highly for collaboration potential, with total scores of 46.75 and 48.50 respectively. These Research Platforms foster multidisciplinary partnerships and position Australia as a leader in progressive MS research. Global positioning scores were strongest for ANZgene (6.00) and EBV in MS Platform (6.00), reflecting integration into international research networks. However, these programs scored lower on impact for people with MS (3.00 and 4.67), indicating that while globally connected, their translational benefits for consumers remain limited.

10 What's Working Well and What Needs Attention

To inform its recommendations, the RPRC sought to identify what is working well within the current MSA Research Program, and what would benefit from improvement.

10.1 What's working well

Strengths of the Investigator-Led Grants Program

The Investigator-Led Grants Program remains a cornerstone of MS Australia's research efforts and is consistently recognised across interviews, survey responses, and Secretariat documentation as one of the organisation's most strategically important mechanisms for advancing MS research. It directly builds Australia's research workforce, contributing to the development of emerging and established investigators and enabling continuity in research careers. Stakeholders repeatedly emphasised the Investigator-Led Grants Program's role in sustaining scientific capability in a highly competitive national funding environment, where success rates for large national schemes such as the NHMRC remain low.

The Investigator-Led Grants Program's use of rigorous, peer-reviewed assessment processes—aligned with Category 1–style funding expectations—reinforces its credibility and fairness. This structure provides confidence to applicants, panel members, and partner institutions that funding decisions are transparent, evidence-based and consistent with best practice. Researchers value the independence of these processes and view the program as a critical complement to the NHMRC, offering an alternative and MS-specific avenue for support that enables research which might otherwise struggle to secure national-category funding due to scale, novelty, or topic specificity.

Collectively, these features ensure that the Investigator-Led Grants Program funds high-quality science while building capacity, fosters collaboration, and supports a national pipeline of MS researchers who contribute to discovery, translational work, and clinical application.

High-Performing Platforms

Several Research Platforms within the MSA Research Program demonstrate particularly strong performance, high strategic value and clear alignment with research and community priorities. International engagement enables MS Australia to accelerate progress through global collaboration and amplify opportunity by giving Australian researchers access to scale, expertise, and funding beyond national limits.

Interviewees, Secretariat documents, and assessment-matrix results all converge on the conclusion that international platforms—including those focused on progressive MS, global prevention initiatives, and global strategy coordination—are high performing and central to Australia's contribution to worldwide MS research. These platforms offer substantial leverage, global visibility, and opportunities for Australian researchers to participate in international discovery efforts that would otherwise be inaccessible.

Across the national suite, multiple platforms stand out. The Australian MS Longitudinal Study (AMSLS), the Australian MS Clinical Trials Platform (including the Clinical Trials Network), PLATYPUS, and the EBV in MS Platform consistently received strong ratings. Stakeholders highlighted their contributions to improving trial readiness, enabling strategic research, generating policy-relevant evidence, and supporting emerging scientific opportunities. Clinical trial infrastructure, in particular, was viewed as essential for ensuring Australian researchers and people with MS can participate in leading-edge studies. Likewise, PLATYPUS was recognised as a major strategic investment addressing an urgent unmet need in progressive MS, with strong community and scientific alignment.

Infrastructure platforms such as AMSLS and the MS Australia Brain Bank also play essential roles, even where their work is less visible to the broader community. The AMSLS underpins national advocacy, health-economic modelling, and long-term policy work, while the MS Australia Brain Bank provides irreplaceable human tissue resources for neuropathology and the person-to-bench arm of the translational research cycle. Although highly valued by researchers, both platforms would benefit from improved communication strategies to ensure their impact and contribution are more widely understood, particularly by people with lived experience of MS.

Together, these high-performing platforms illustrate the diversity and strength of MSA's research investments. They provide critical national infrastructure, deliver globally recognised contributions, and position Australia as a leader in MS research, while supporting a research ecosystem that spans scientific discovery, clinical translation, and lived-experience insights.

10.2 What needs Attention

While the RPRC identified multiple areas of strength across the MSA Research Program, several opportunities for improvement emerged consistently through the assessment matrix findings, supported by qualitative insights from interviews and discussion within the RPR. These issues do not indicate platform failure; rather, they highlight targeted areas where refinement would strengthen visibility, impact, feasibility, and alignment with strategic goals. The themes below represent system-level observations that apply across multiple platforms rather than isolated concerns.

Lived Experience Involvement

Many platforms scored below 3.0 on this criterion (e.g., Brain Bank: 2.50; ANZgene: 2.67; MS Brain Health Initiative: 2.67), indicating limited consumer engagement in governance and research design. The findings suggest that while platforms may be scientifically robust, structured involvement of people with lived experience is underdeveloped. Strengthening this dimension could include more formalised advisory roles, co-design frameworks, and clearer articulation of how lived experience insights shape decision-making. Improved communication of existing contributions would also increase transparency and perceived value.

Translation and Implementation Pathways

Infrastructure programs such as the MS Australia Brain Bank (3.50) and ANZgene (3.75) scored low for translation, highlighting weak links between discovery research and clinical application. The findings point to the need for clearer translational 'maps' to support movement from foundational research to impact and 'implementation'. Strengthened partnerships with clinical networks, and more visible articulation of downstream value, would help accelerate impact. Improved communication as outputs emerge—for example, the relatively recent "severity gene" identification—may also assist in demonstrating progress.

Impact for People with MS

Several global initiatives scored significantly less than 4.0 (e.g., International MS Genetics Consortium: 2.67; MS Brain Health Initiative: 2.67), suggesting limited visibility of benefits for consumers. This likely reflects limited or unsuccessful communication of 'impact', rather than the value of the initiatives themselves. Programs need to demonstrate tangible outcomes and explain their relevance to people living with MS more clearly.

Equity in Participation

Funding remains concentrated within a small number of research institutions, and particular researcher demographics (e.g, senior researchers). These patterns indicate that participation is

uneven across the sector. While funding decisions must continue to be based on research merit and quality, targeted capacity-building and funding mechanisms for underrepresented groups—including early and mid-career researchers, institutions, and regions—would broaden engagement and strengthen national capability. Clearer pathways for entry and progression may also improve retention and equity.

Feasibility and Risk Management

Programs such as PrevANZ (3.00) and the MS Australia Brain Bank (3.50) scored low on feasibility, indicating sustainability and operational risks. In the case of PrevANZ, the score reflects a completed trial rather than an ongoing platform. For critical infrastructure, long-term funding commitments and risk mitigation strategies will be essential to ensure continuity. These findings suggest a need for forward planning, particularly where resourcing, scalability, and long-term maintenance are required to preserve platform value.

Global Positioning vs. Local Impact

Programs such as ANZgene and the EBV in MS Platform demonstrate strong global positioning (6.00), alongside opportunities to strengthen consumer impact (3.00 and 4.67, respectively). This reflects the opportunity to further connect international leadership with clear domestic translational benefit and visibility.

International engagement adds value by supporting timely progress and broadening the benefits of Australian participation, while meeting donor expectations that research investment delivers tangible outcomes for people with MS in Australia. The findings point to the importance of strengthening communication of local relevance and ensuring effective pathways that translate global advances into national outcomes.

Communications

The review identified several areas of public communication requiring improvement to highlight the relevance of the MSA Research Program, strengthen its effectiveness, and more clearly demonstrate impact. These issues relate primarily to how activities and outcomes are conveyed, rather than the performance of the platforms themselves. Key areas requiring attention include:

- Low lived experience involvement
  - Exemplars: MS Australia Brain Bank; ANZgene; MS Brain Initiative
  - Suggested improvements:
    - Greater integration of lived experience perspectives through structured advisory roles
    - Use of co-design frameworks to inform program development
    - Improved communication of the value and contribution of lived experience input
- Low translation
  - Suggested improvements:
    - Strengthening communication as translational outputs emerge
    - Increasing the visibility of how foundational research progresses toward clinical or practical application, e.g. by facilitating the reporting of all MSA funded grants and platforms that contribute to a translational outcome
    - Providing clearer articulation of downstream relevance

Improved communication across these areas, e.g. though the development of more case studies, would support multiple objectives by increasing understanding of platform purpose, clarifying

pathways to impact, and making benefits more visible to people with MS and the broader research community.

Cross-Cutting Observations

Across the areas above, several themes recur: many issues relate to visibility, clarity of purpose, and the degree to which value is communicated or experienced by consumers, more so than to scientific performance. Improvements in co-design, translation pathways, and equity would support the impact of MSA's overall research investment program.

11 Future Focus

This review identified several forward-looking considerations to guide the next phase of the MSA Research Program. The following subsections summarise emerging priorities, opportunities for stronger coordination, and targeted investment areas to enhance impact and sustainability.

11.1 Emerging Priorities

Key priorities identified through the assessment matrix and RPRC discussion include strengthening lived experience involvement across programs scoring below 3.0, improving visibility of translational pathways for infrastructure platforms, and addressing uneven participation across institutions and career stages. There is also scope to ensure that international leadership is more clearly connected to benefits for people living with MS in Australia. These priorities reflect a shift toward greater visibility, co-design, and clearer articulation of impact rather than structural change to the program.

11.2 Partnership and Coordination

Progress will rely on more coordinated approaches where system-level issues span multiple platforms. Strengthening links between discovery-focused infrastructure and clinical implementation would support clearer translation and reduce duplication. Improved internal and external communication would increase visibility of advances and clarify the domestic relevance of international collaborations. Formalising mechanisms for lived experience contribution would also provide greater consistency across programs while maintaining existing strengths. Through this facilitative role, MS Australia enhances the reach and effectiveness of researcher-led activity and supports stronger collaboration, while preserving investigator initiative and scientific leadership.

11.3 Investment Opportunities

Targeted and re-purposed investment could deliver significant benefit in several areas: capacity-building for underrepresented institutions and early-career researchers; long-term sustainability planning, particularly for infrastructure with a low score on feasibility; and resourcing structured consumer involvement rather than relying on voluntary contributions.

Investment in communication—particularly around emerging translational outputs—would also address recurring themes, including impact for people with MS and equity of participation.

12 Recommendations and Future Opportunities

The recommendations below synthesise the RPRC's analysis across the Investigator-Led Grants Program and Research Platforms. They are intended to guide MS Australia's research investment over the coming years by setting clear strategic direction, while allowing flexibility in implementation.

They distinguish between immediate priorities, medium- to long-term improvements, and scenario-based guidance for different funding environments. In several areas, the recommendations signal that a balance must be struck between competing considerations, with examples provided to illustrate options rather than prescribe specific operational models.

12.1 Immediate Recommendations (2026–2027)

1. **Strengthen communication and impact reporting across the research portfolio**
   Improve clarity, consistency, and accessibility of public-facing communication, including regular case studies demonstrating benefit to people living with MS in Australia.
2. **Consolidate national clinical trials infrastructure under a unified framework**
   Integrate the Australian MS Clinical Trials Platform, Clinical Trials Network, PLATYPUS, and residual PrevANZ governance to reduce duplication and strengthen national trial readiness.
3. **Apply lifecycle-based transition or exit for mature platforms**
   Implement structured transition or conclusion for platforms where MS Australia's strategic role has diminished, including ANZgene, the AHSCT Registry, and PrevANZ.
4. **Reshape the Investigator-Led Grants Program with attention to balance and trade-offs**
   Review scheme structure to balance administrative burden, grant size, and success rates—for example through consolidation, increased incubator grant size/value, less frequent fellowships, and strengthened integration with NHMRC schemes.
5. **Embed structured lived-experience involvement across platforms**
   Introduce consistent but proportionate lived-experience engagement models aligned to platform purpose and maturity.

12.2 Medium- to Long-Term Improvements (2027–2030)

6. **Establish a formal platform lifecycle review process**
   Implement a rolling three-year review assessing maturity, performance, cost-effectiveness, and strategic alignment.
7. **Prioritise reinvestment in high-performing and strategically aligned platforms**
   Sustain investment in platforms demonstrating strong impact and alignment, including AMSLS, the Clinical Trials Platform, PLATYPUS, and the EBV in MS Platform.
8. **Strengthen national coordination and governance of the research program**
   Develop consistent governance, roles, and reporting expectations across platforms while preserving scientific independence.
9. **Build national capability in prevention, early detection, and enabling technologies**
   Continue targeted investment in biomarkers, EBV mechanisms, and digital epidemiological tools through national and international partnerships.
10. **Capture and report leveraged funding and in-kind contributions**
    Introduce light-touch mechanisms to document institutional co-investment and grant leverage to support advocacy and value-for-money assessment.

12.3 Recommendations Under Funding Scenarios

The following guidance translates the recommendations above into indicative priorities under different funding conditions. These scenarios are intended to inform strategic decision-making rather than prescribe fixed responses.

Scenario A: Reduced Funding (~$4.5 million)
Priority Actions:

- Protect high-performing platforms (AMSLS, Clinical Trials Platform, PLATYPUS).
- Finalise exits from mature platforms (ANZgene, AHSCT Registry, PrevANZ).
- Streamline investigator-led funding, including less frequent Senior Fellowships and current co-funding with NHMRC (e.g. Investigator Grant top-ups).
- Pause major new commitments except where continuity is critical.
- Enhance communication to maintain supporter confidence.

Scenario B: Stable Funding (~$6.0–6.5 million)
Priority Actions:

- Maintain consolidated clinical trials infrastructure and unified governance.
- Implement platform lifecycle review processes.
- Strengthen alignment with NHMRC through continued and possibly expanded Investigator and possibly other Grant top-up arrangements.
- Continue targeted reinvestment in EBV and prevention research.
- Embed consistent governance and reporting across platforms.

Scenario C: Increased Funding (> $7.5 million)
Priority Actions:

- Expand leadership in prevention and early detection research.
- Increase platform and trial capacity to enhance international competitiveness.
- Invest in digital platforms, including InforMS.
- Strengthen equity and capacity-building for under-represented institutions and early-career researchers.
- Build strategic reserves to stabilise long-horizon platforms such as AMSLS and the MS Australia Brain Bank.

13 Conclusion

MSA's long-standing investment in research has built a nationally significant ecosystem of discovery, translation and collaboration that continues to deliver benefits for people living with MS. The actions proposed in this review aim to sharpen that impact — strengthening governance, refreshing priorities, and ensuring that resources are directed where they will achieve the greatest benefit. With sustained commitment to these recommendations, the impact of MSA's investment will continue to grow, positioning the organisation to lead Australia's next decade of progress toward prevention, better treatments and, ultimately, a cure.

14 Acknowledgments

15 Appendices

Appendix 1. Research Program Review Materials

The Research Program Review Committee drew on a comprehensive body of material provided by MS Australia to inform its assessments and judgements. These resources included financial data, program and platform reports, analyses, performance summaries, and case studies, as outlined below:

1. Investigator-led Research Program

1.1 Investigator-led Research Program RPR Overview
1.2 Investigator-led Research Program Financial Splits for 2024 Grant Rounds
1.3 Investigator-led Research Program Impact Summary (2022-2025)
1.4 Investigator-led Research Program Case Studies
1.5 Research Snapshot 2025
1.6 MSA Grant Funding Agreement Template 2024
1.7 MSA Grant Funding Progress Report Template 2025
1.8 MSA Grant Funding Financial Report Template 2025

2. National Research Platforms

2.1 Australia New Zealand Genetics Consortium

   2.1.1 ANZgene RPR Overview
   2.1.2 ANZgene Charter 2022
   2.1.3 ANZgene Funding Agreement 2024
   2.1.4 ANZgene-RGN Progress Report 2024 Blackburn
   2.1.5 ANZgene-RGN Progress Report 2024 Lin Zhou
   2.1.6 ANZgene-RGN Progress Report 2024 McComish

2.2 Australian MS Clinical Trial Network & Platform

   2.2.1 Australian MS Clinical Trial Network RPR Overview
   2.2.2 Australian MS Clinical Trial Platform RPR Overview
   2.2.3 Australian MS Clinical Trial Platform Steering Committee TOR
   2.2.4 Australian MS Clinical Trial Platform Charter

2.3 Australian MS Longitudinal Study

   2.3.1 AMSLS RPR Overview
   2.3.2 AMSLS Steering Committee TOR 2017 (Update Underway)
   2.3.3 AMSLS Services Agreement 120824
   2.3.4 AMSLS Annual Report 2024

2.4 Autologous Haemopoietic Stem Cell Transplant (AHSCT) Registry

   2.4.1 AHSCT Registry RPR Overview
   2.4.2 AHSCT Registry TOR 2023
   2.4.3 AHSCT Registry Funding Agreement 010324

2.5 EBV and MS Platform

   2.5.1 EBV and MS RPR Overview

2.6 InforMS

   2.6.1 InforMS RPR Overview

Appendix 2: Research and Advocacy Priorities Survey Report 2025

The 2025 Research & Advocacy Priorities Survey was conducted to inform the future strategic direction of MS Australia by identifying research priorities, advocacy focus areas, communication approaches and broader organisational goals.

The Research Program Review Committee included several targeted questions within the survey to inform the Review.

The survey tracks shifts in stakeholder perspectives over time and ensures alignment with the needs and expectations of the MS community. The report highlights strong support for research into repair and regeneration, prevention and better treatments, particularly clinical research with near-term impact, alongside advocacy priorities such as increased research funding, improved access to medications, and strengthening the National Disability Insurance Scheme.

The survey results directly inform MS Australia's research and advocacy strategies.

The full report is available at:

https://www.msaustralia.org.au/wp-content/uploads/priorities-survey-2025-report-final-1.pdf

MSA Research Review - Interview Questions

Purpose: To draw out consistent feedback across research platforms, grant recipients, collaborators, and people with lived experience.

No.	Question
SECTION A: Strategy, Impact & Value	

1	The covering email inviting you to this interview noted that MS Australia invests in four key types of research platforms:
	        • Research Infrastructure & Data Platforms
	        • Investigator-led Research & Funding
	        • Clinical Trials and Translation
	        • Global Engagement & Strategic Initiatives
	Which of these MSA research platforms or platform elements are you most familiar with, and why?

2	Does the unmet need that led to the development of this platform, or platform element, still exist?
3	Does this platform, or element, fill that need and achieve its intended goals and objectives?
4	Are there measurable outcomes that demonstrate success? If so, can you explain them?
5	Do you think the structure of the platform you're most familiar with — or specific elements of it — could be improved?

6	Which of MS Australia's research platforms, or platform elements, is the most important to continue supporting? Explain.
	
	Q5 Notes (see also attachment to the interview preamble)
	The key platforms are:
	    • *Research Infrastructure & data.*
	    • *Investigator-led Research grants*
	    • *Clinical Trials and Translation*
	    • *International (global engagement & strategic initiatives)*

7	From your perspective, what has been the overall impact of the research platform — or specific element — you are most familiar with on multiple sclerosis in Australia?
SECTION B: Delivery, Structure & Resources	
8	To what extent does current funding of this platform, or platform element, address the original gap it was designed to fill? Are there now other funders supporting this work? How could resources be structured to maximize impact?
9	How well does this platform, or element, engage with relevant stakeholders (e.g. researchers, clinicians, people with MS, policymakers, and industry)?
10	How well does this platform, or element, contribute to capacity building in Australian MS research?
SECTION C: Lived Experience & Inclusion	
11	Are you aware of any significant improvements in care, quality of life, or understanding of MS that can be linked to the MS Australia research platform — or specific elements of

	the platform — that you know best? If so, why do you say this? Can you suggest any evidence that supports your view?
12	Can you share examples where research made a tangible difference to your life or to the MS community? ***Q12 Notes:*** • *Best directed to those with lived experience, who can speak to personal or community impact.* • *Others should be asked but may not be able to answer meaningfully.*
SECTION D: Any other comments?	
	Do you have any other comments or suggestions concerning MSA's Research program?

Appendix 4: Decision-Making Framework

Purpose of the Framework

A decision-making framework—a matrix—was developed to provide a structured, transparent and consistent approach to assessing the MS Australia Research Program. It operationalises the Terms of Reference for Review of Research Program by translating evaluation requirements into clearly defined criteria assessed using a standardised seven-point rubric. The matrix serves as a decision-support tool, enabling systematic comparison across diverse program types while preserving space for qualitative judgement and strategic interpretation.

Structure of the Matrix

Rows – Programs and Platforms Assessed

Each row represents a discrete program or research platform within the MS Australia portfolio, including Investigator-led funding streams, National collaborative research platforms, and International partnerships and global initiatives.

Columns – Evaluation Criteria

Each column represents a distinct evaluation criterion derived from the Terms of Reference for Review of Research Program. The matrix included the following core criteria columns:

- Strategic alignment & System Capacity
- Translation & Implementation
- Value for money & Leverage
- Global Positioning
- Stakeholder Value – Researchers & Clinicians
- Impact for People with MS
- Lived Experience Involvement
- Feasibility & Risk
- Future Use

Columns headings were defined and explained, as set out in **Table 1** of this appendix (over page), to ensure consistency of interpretation and scoring across all Research Program Review Committee members.

Scoring Approach

A seven-point rubric was developed to score each program, as set out in **Table 2** of this appendix. The approach employed to score each program and complete the matrix included:

- Criterion-by-criterion assessment: Each program was evaluated independently across all criteria.
- Evidence-informed judgement: RPRC members scored each cell by drawing on financial data, interviews, survey findings, platform reports, governance documents and benchmarking analysis
- Comparative calibration: Scores were calibrated across the full portfolio to ensure consistency in what constituted Strong, Very Strong or Exceptional.

Appendix 4, Table 1

Explanation and application of column headings to support scoring within the matrix.

Column	Description	Why It's Included	Strategic Plan / ToR Reference
Strategic Alignment & System Capacity	Assesses how well the program aligns with MSA's research priorities and strengthens future research capability (e.g., workforce, infrastructure).	Ensures resources support key priorities while also building long-term research capacity.	Strategic Plan – 'Fund innovative, high-quality research'; 'Build the capacity of the research workforce'
Translation & Implementation	Evaluates the likelihood and timeliness of uptake into clinical practice, care, or policy.	Helps identify programs with strong pathways to impact.	Strategic Plan – 'Facilitate translation and implementation of research outcomes'
Value for Money & Leverage	Assesses outcomes relative to cost and the program's ability to attract co-investment or enable future funding.	Ensures MSA funds are used efficiently and can unlock additional value.	ToR §2b; Strategic Plan – 'Maximise funding outcomes'
Global Positioning	Measures how the program aligns with or contributes to international best practice and global collaborations.	Ensures MSA remains globally competitive and connected.	ToR §3
Stakeholder Value – Researchers & Clinicians	Assesses the program's relevance and usefulness to researchers and clinical practitioners.	Recognises the importance of end-user engagement for uptake and relevance.	ToR §2b; §3
Impact for People with MS	Measures likely direct benefits for people with MS – including improved care, treatment options, or quality of life.	Ensures funding decisions are anchored in community benefit.	Strategic Plan – 'Improve quality of life for people with MS'
Lived Experience Involvement	Assesses the extent to which people with MS are meaningfully involved in shaping, governing, or informing the program.	Recognises the value of co-design and accountability to the MS community.	Strategic Plan – 'Ensure the MS community has a strong voice'; ToR §3
Feasibility & Risk	Evaluates deliverability, realism, and risk management of the program.	Ensures programs are implementable and not overpromising or under-resourced.	ToR §2a; §2b

Appendix 4, Table 2

Scoring rubric used to complete matrix.

Criterion	Score Level	Description
Strategic Alignment & System Capacity		
	7 – Exceptional	Aligns fully with MSA research priorities and roadmap.
		Clearly builds national research infrastructure and/or workforce.
		Supports early- and mid-career researchers.
		System-wide value across institutions or regions.
		Sustainable and nationally coordinated.
		Co-developed with MS Australia or based on consultation.
	1 – Poor	No alignment with strategic priorities.
		No contribution to system or workforce.
		Isolated and narrow in scope.
		No pathway for sustained impact.
Translation & Implementation		
	7 – Exceptional	Highly developed, feasible translation plan.
		Partnerships with implementation actors.
		High potential for 1–3 year real-world use.
		Builds on existing successes.
		Includes dissemination and uptake plans.
		Likely to change care or outcomes.
	1 – Poor	No path to implementation.
		Theoretical only.
		No partnerships.
		No dissemination plans.
Value for Money & Leverage		
	7 – Exceptional	High impact per dollar invested.
		Attracts co-funding or aligned grants.
		Enables downstream benefits.
		Scalable with strong budget design.
		Clear return on investment.
	1 – Poor	High cost, minimal outcome.
		No co-investment.
		Not scalable or reproducible.
		Poor resourcing.
Global Positioning		
	7 – Exceptional	Positions Australia as global leader.
		Aligns with international priorities.
		Contributes to global networks.
		Adopts global standards.
		Links to trials or international data.
	1 – Poor	No global relevance or connection.
		Redundant or disconnected.
		No alignment with global benchmarks.
Stakeholder Value – Researchers & Clinicians		
	7 – Exceptional	Highly valued and widely used.
		Facilitates collaboration or clinical integration.
		Supports workforce and practice change.
		Bridges research and care.
		Consistently recommended or cited.
	1 – Poor	No uptake or relevance.
		Poor usability or visibility.
		Not integrated into practice.
Impact for People with MS		
	7 – Exceptional	Addresses major unmet need.
		Improves quality of life or treatment access.
		Benefits many people with MS.
		Impact measurable within project or shortly after.
		Community-prioritised focus.

	1 – Poor	No tangible benefit to people with MS.
		Disconnected from lived experience priorities.
		Highly theoretical.
Lived Experience Involvement		
	7 – Exceptional	People with MS embedded in project.
		Structured and ongoing involvement.
		Diverse and ethical engagement.
		Influences decisions and direction.
	1 – Poor	No involvement of people with MS.
		Tokenistic or afterthought.
		No transparency or influence.
Feasibility & Risk		
	7 – Exceptional	Clear, achievable delivery plan.
		Experienced team and available resources.
		Risks identified and well-managed.
		Realistic budget and timeline.
	1 – Poor	Major flaws or unknowns.
		Unclear team or delivery mechanism.
		No risk mitigation.
		Unrealistic scope.