

A ROADMAP FOR CONSUMER ENGAGEMENT



RESEARCH
ADVOCACY
CURE

OBJECTIVE

Our mission is to empower people with MS to live well through:

1. Research to treat, prevent and cure multiple sclerosis (MS)
2. Advocacy to drive change & Education to improve awareness and outcomes
3. Governance and operations that is consistent with our mission and values

This Roadmap is aligned to the MS Australia **Strategic Plan 2022-2026** and seeks to ensure that people with the lived experience of MS, other neurological diseases and chronic neurological conditions, their families, friends and carers, (herein called 'consumers') are at the centre of all we do.

This roadmap will inform how we collaborate with our consumers and underpins our commitment to evidence-driven consumer engagement.

WHY IS THIS IMPORTANT?

Consumer Engagement has always been part of MS Australia's strategic agenda and commitment. We understand that we are stronger together, and we support the MS community's mantra of 'Nothing about us without us'. We remain committed to creating a better future for people with MS, their families and carers and believe in the importance of partnering with consumers throughout their journey.

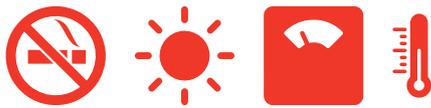
As the national peak, we empower researchers to pursue ways to treat, prevent and cure MS, seek sustained and systemic policy change via advocacy, and act as the champion for Australia's community of consumers.

We wouldn't be able to do what we do without the help of our MS Member Organisations and our MS community. Therefore, we believe it is important to formally integrate consumer engagement into our research, advocacy, governance, and operations through this roadmap.

This roadmap outlines our organisational commitment as we build our capacity towards successful and more effective consumer engagement. We want to promote meaningful consumer engagement to influence and improve health outcomes of all people living with MS, their family and carers.

THE PREVALENCE OF MS

The prevalence of MS in Australia has increased from **103.7 per 100,000 people in 2017** to **131.1 per 100,000 people in 2021**. This increase in prevalence is most likely due to changes in exposure to known MS risk factors.



Global experts believe that addressing the impact of **smoking, Vitamin D deficiency, obesity and glandular fever** could prevent 60% of MS cases.



62% of people with MS are using a disease modifying therapy*, **an increase of 35%** since 2010.

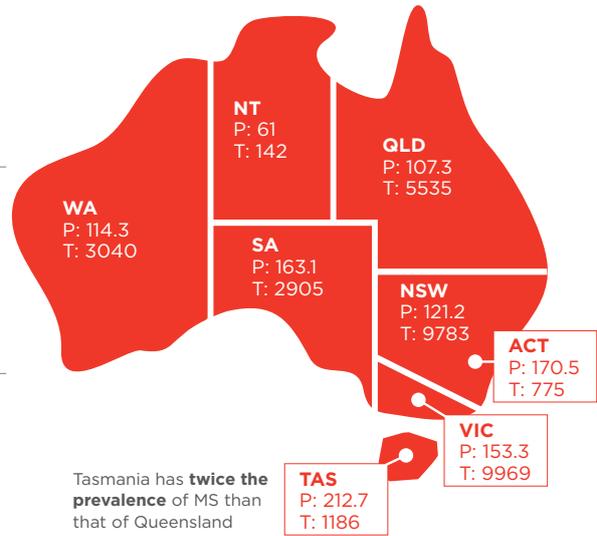
*A drug designed to reduce the number and severity of relapses and slow or halt the progression of their MS



If there was a vaccine against the Epstein-Barr virus* **90% of MS cases might be prevented.**

*the virus that causes glandular fever

The **further** away from the equator people live the **higher the prevalence** of MS.



Prevalence (P) of MS per 100,000 people and total number (T) of people with MS

GENERAL FACTS ABOUT MULTIPLE SCLEROSIS



More than 33,300 Australians live with MS



Over 2.8 million people are living with MS worldwide



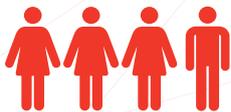
1-2 Australians are diagnosed with MS every day



Average age of diagnosis is between 20-40 years



MS affects more young adults than any other acquired chronic neurological disease



3 out of 4 Australians diagnosed with MS are women

FORMS OF MS AT DIAGNOSIS

85% RELAPSING REMITTING MS (RRMS)

12% PRIMARY PROGRESSIVE MS (PPMS)

3% UNKNOWN MS DISEASE TYPE

Many people diagnosed with RRMS will eventually develop secondary progressive MS (SPMS).

COMMON SYMPTOMS OF MS

The symptoms of MS can be both visible and invisible to others, are unpredictable and vary from person to person and from time to time in the same person.



WHAT IS CONSUMER ENGAGEMENT?

Consumers are broadly defined as those diagnosed, their families, carers and communities who have lived experience of MS or other neurological diseases.

Type of consumer	Perspective
Patients	People who seek and receive health care, having lived experience of a health condition such as MS and other neurological conditions and have a range of experiences within the health service system.
Consumers	People who seek and receive disability, aged care and community services, having lived experience of functional impairments or disabilities and barriers to access as a result of a health condition such as MS or other neurological conditions and are varied experiences with navigating community and disability service systems. They therefore have lived experience of service delivery issues, navigational and coordination requirements, accessibility and barriers within varied service areas.
Carers	Family members, friends and loved ones of those who live with a health condition, functional impairments or disability and therefore have lived experience of being in carer role. Carers often provide day-to-day supports and care, assist in navigating various service systems on behalf or with those they care for or to seek support for themselves to sustain their caring responsibilities.
Consumer Representatives or Advocates	People with lived experience of being patients, carers or consumers who are nominated by MS Australia to represent the views of people living with MS on behalf of the organisation. This cohort provide their support to MS Australia on a volunteer capacity and may contribute to our governance areas such as a consumer representative on our Board or work within our Lived Experience Panel or MS Advocates groups. Consumer Representatives could also represent the view of the MS Community on external stakeholder groups or committees, representing the views of a certain group or condition.
Member Organisations	Member organisations (as set out in Section 4 of MS Australia's Constitution) provide direct service delivery and supports to our MS community and therefore have various opportunities to collate consumer views, experiences, needs, perspectives, anecdotes and case studies and identify gaps that will inform planning, priorities, resource allocation and activities.
General Public	All people within Australia who brings a broader perspective and various levels of understanding of multiple sclerosis and general service system navigation and issues that might be shared with those who have lived experience of MS.

Table 1 Different consumer perspectives (adapted from Kelson et al., 2012; Greenhalgh, 2017, NHMRC 2018)

Consumers might be:

- current, past, or potential users of support and services through our member organisations
- users of information or educational resources
- influencers in policy settings, advocacy information or active participants in our advocacy efforts
- people with an active interest in research processes and outcomes
- part of our governance activities and structure
- within our community who have an interest to progress our goals given their connection with someone (directly or indirectly) who has a diagnosis of MS or a neurological disease.

Within our MS community, we often reiterate that everyone experiences MS differently, so every perspective is unique. Consumers can experience a wide range of symptoms and can be affected differently at various stages in their life.

Consumers are also diverse in age, gender, cultural background, and other demographics that inform their lived experiences. This may include how long they have lived with a MS diagnosis, how much support they need, or which barriers are preventing accessibility and inclusion. It is therefore impossible for one person to identify what matters most or inform outcomes or outputs that affects more than 33,335 people living with MS in Australia.

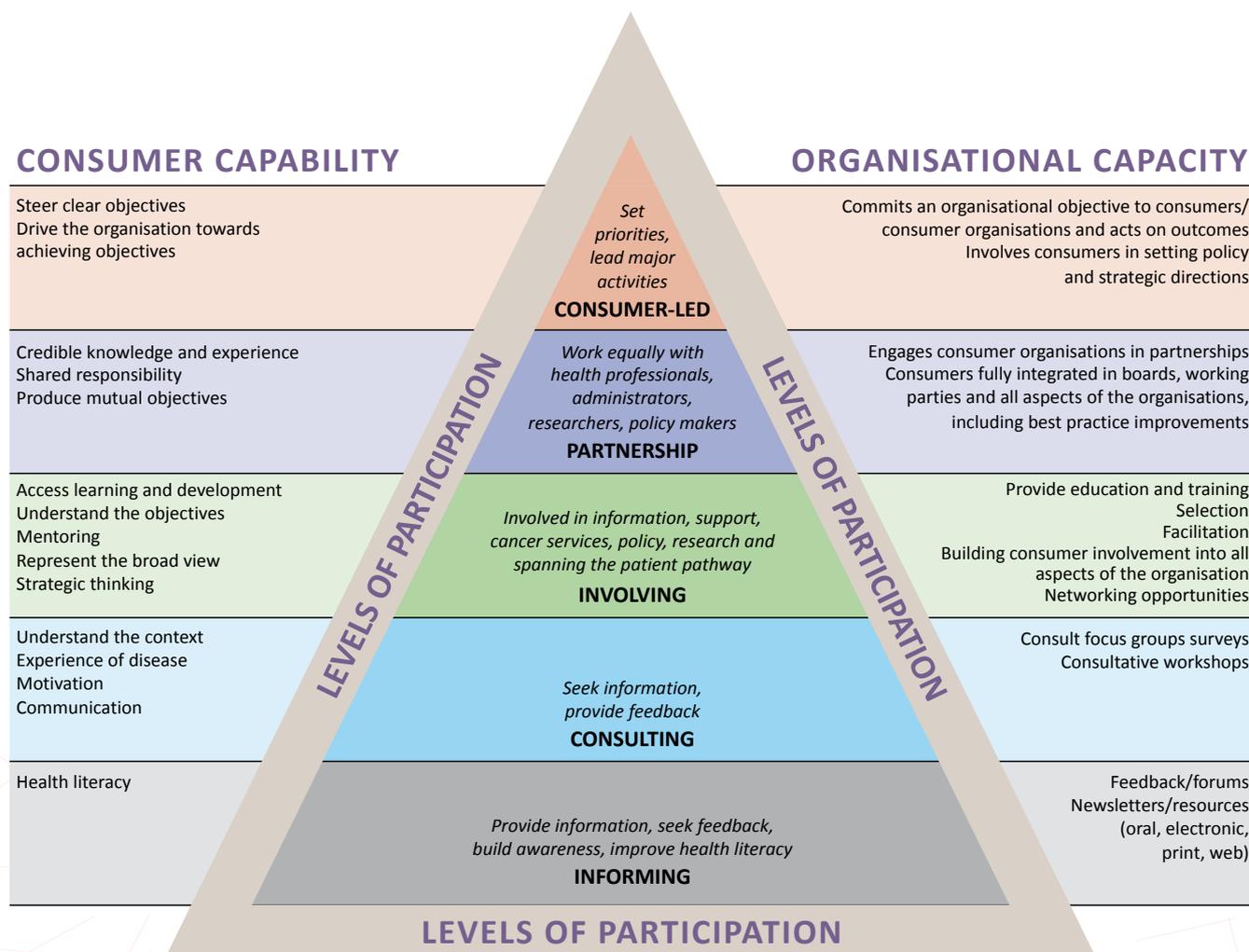
This roadmap aims to achieve a commitment to engage with a diverse and wide audience to inform our work within MS Australia.

We can define **'consumer engagement'** within MS Australia as the active involvement of consumers at various stages to help shape decisions, outputs, and outcomes. By actively working with our research, communications and advocacy teams, consumers will influence our research practices, advocacy and policy direction, education and information. This engagement will achieve the best possible outcomes for those living with MS, now and in the future.

This foundation Roadmap will be values driven, particularly promoting our value of being **consumer-centred**, as it involves asking consumers what matters to them most and integrating their preferences, needs and values in everything we do.

HOW WILL WE ENGAGE?

Consumer involvement or engagement could interchangeably be used alongside terminology like 'consultation', 'partnership' and 'co-production', 'co-creation' or 'collaboration'. Within this spectrum of engagement, the levels of engagement will depend on the task, topic, planning process, consumer capability and organisational capacity.



Reference: Reproduced with permission from Cancer Australia and Cancer Voices Australia (2011), pg. 9

MS Australia has adopted a set of principles to support an effective engagement model, that include:

Principle	Definition
Consumer Rights	<ul style="list-style-type: none"> Those affected by our organisation’s governance, research, advocacy, education, and information provision have the right to be consulted and influence priorities and outcomes.
Consumer-centred	<ul style="list-style-type: none"> Consumer voices are essential, bringing a perspective steeped in lived experience. They have expert knowledge and understanding of the disease, and its impacts. MS Australia aims to develop meaningful engagement processes that embrace the values and needs of our consumers wherever they are on their journey.
Diversity & Inclusion	<ul style="list-style-type: none"> MS Australia will ensure that consumer engagement opportunities will be accessible, equitable and inclusive, with flexibility and a range of options for consumer engagement.
Purposeful	<ul style="list-style-type: none"> MS Australia commits to purposeful engagement by establishing a shared vision about goals and any respective roles. We will stay committed to the task and to having a clear, transparent expectation and understanding of the task, activities, and outcomes we want to achieve together. We will communicate complete information and updates with our consumers in ways that are affirming, accessible and useful.
Partnership	<ul style="list-style-type: none"> Engagement will be based on a partnership approach and mutual respect. Working relationships will be built on transparent and accountable processes.
Advocacy & Support	<ul style="list-style-type: none"> Consumers are provided with the support they need to engage meaningfully.
Capacity Building	<ul style="list-style-type: none"> MS Australia will provide opportunities for consumers to develop their capacity, abilities, and skills in the engagement process; always providing access to information and support; whilst simultaneously building capability of staff and the organisation in consumer engagement.
Continuous Improvement	<ul style="list-style-type: none"> Consumer engagement is regularly reviewed and evaluated to drive continuous improvement. Consumer engagement will always include measuring and evaluation, providing everyone involved with opportunities to learn and grow. MS Australia will communicate how consumer input has influenced outcomes. Evaluation will be incorporated from the onset of any engagement process and dissemination of outcomes will be shared with consumers.
Dignity & Respect	<ul style="list-style-type: none"> All levels of consumer engagement will be based on mutual respect, value and dignity. We will listen to and honour consumer perspectives and choices. Our consumers’ knowledge, values, beliefs and cultural backgrounds will be incorporated into the planning and delivery of our work.
Evidenced-based	<ul style="list-style-type: none"> Through engagement, we generate evidence to improve our benefits to the MS community. We act on feedback and show our consumers that their opinion matters.

HOW WILL WE IMPLEMENT THIS ROADMAP?

<p style="text-align: center;">①</p> <p style="text-align: center;">Research to treat, prevent and cure MS</p>	<p style="text-align: center;">②</p> <p style="text-align: center;">Advocacy to drive change & Education to improve awareness and outcomes</p>	<p style="text-align: center;">③</p> <p style="text-align: center;">Governance and operations that is consistent with our mission and values</p>
<p>Destination:</p> <p>Ensure consumer voice is embedded in research priorities, activity, strategy and governance, and funding allocation.</p>	<p>Destination:</p> <ul style="list-style-type: none"> • Advocating with and for those living with MS, other neurological diseases and/ or other chronic neurological conditions including serving as the national voice • Ensure consumers' voice is embedded into education and awareness campaigns and activities. 	<p>Destination:</p> <p>Ensure consumer engagement is embedded in our workplace, reflected in our policies, people and culture framework and demonstrated in consumer representation in our various governance functions.</p>
<p>Fund innovative, high-quality research according to the research priorities identified by our community.</p> <ul style="list-style-type: none"> • Continue to involve consumers in informing our research strategy through the Research and Advocacy Priorities Survey and other methodologies, helping to shape MS Australia's future strategic direction. 	<p>Advocate for increased funding of research that aligns to the research priorities of the MS community.</p> <ul style="list-style-type: none"> • Six point plan involves working with a consultant to improve access to MRFF funding. • Strategic focus for CEO and Head of Research on NHMRC funding and working with international partners. 	<p>Ensure a flexible, safe, respectful and adaptive workplace, that is easily accessible and responsive to the needs of stakeholders.</p> <ul style="list-style-type: none"> • Continuous improvement on workplace processes and policies • Ongoing training, learning and development via training and development plan(s) • Access to supports and resources for staff as part of our people and culture framework. • Creating data set – reporting, compliance dashboard and risk framework
<p>Recognise that people with MS and those affected by MS have unique experiences and separate needs that are captured through a robust evidence base.</p> <ul style="list-style-type: none"> • Resourcing consumer capacity building to ensure consumers understand their role in the research program as well as understand the research. 	<p>Recognise that people with MS and those affected by MS have unique experiences and separate needs that are captured through a robust evidence base.</p> <ul style="list-style-type: none"> • Work with the LEEP and National Advocates program to ensure that we are continually capturing this. 	<p>Develop and embed a people and culture framework that embodies the mission, vision and values of the organisation.</p> <ul style="list-style-type: none"> • Development plans that are values based • Values and performance based board evaluation • Imbed into risk framework • Implement a performance development cycle (Board, employees, volunteers) • Accreditation towards carer+ organisation status

<p>Fund innovative collaborative opportunities for clinicians, researchers and people with MS to work together.</p> <ul style="list-style-type: none"> MS Australia strongly encourages engagement of consumers in research co-design and the research process through our investigator-led funding schemes. MS Australia's grant applications ask applicants to describe how they have engaged consumers in the development of their research proposal. 	<p>Ensure our advocacy agenda is informed by our consumer and carer community.</p> <ul style="list-style-type: none"> Ensure policy positions recognise the diversity of needs and aspirations of all people with MS 	<p>Provide training and workshop opportunities across the organisation that build organisational capacity around consumer engagement, methods and strategies and lived experience.</p> <ul style="list-style-type: none"> Develop toolkit to support this roadmap to increase organisational and volunteer capacity
<p>Facilitate national collaborative research platforms according to the research priorities identified by our community.</p> <ul style="list-style-type: none"> Steering committees of our national collaborative platforms involve consumers. These steering committees have regular meetings, coordinated by MS Australia, and have regular email contact. 	<p>Enhance our well-established National Advocates program.</p> <ul style="list-style-type: none"> Project to reassess and re-establish the National Advocates program is underway 	<p>Collaborate closely with Member Organisations on issues relevant to people with MS, those who live with other neurological conditions, carers, family and friends</p> <ul style="list-style-type: none"> Service Agreements with MO's to reflect shared initiatives and priorities Utilise governance and operational processes to collaborate and develop shared initiatives Through the Carer Strategy, map needs and collaboration opportunities with MO's
<p>Ensure that the Research Management Council's (RMC) Governance framework is one of continuous quality improvement & Fund research through our rigorous, expert reviewed funding assessment model:</p> <ul style="list-style-type: none"> The RMC consists of researchers, clinicians and people living with MS who recommend researchers and projects to be funded. MS Australia's grant applications ask applicants to describe how they have engaged consumers in the development of their research proposal. Involvement of consumers in the development of research proposals for grant applications along with researchers, clinicians and MS Australia (e.g. MRFF). Consumers have been part of the working group in the development of these proposals, as well as chief investigators and associate investigators on these applications. Many meetings are involved in the development of these research proposals. 	<p>Ensure consumers are embedded in information, education, updates, awareness campaigns and programs</p> <ul style="list-style-type: none"> Adopt a process for dissemination of information to inform consumers and carers how their participation influences governance, research, policy and advocacy Clearly present MS information and education, research updates and advocacy information that are accessible and relevant to the entire MS community Grow our position as the leading, trusted source of MS information and education Develop educational and awareness-raising programs and material that provides information, tools and resources for the MS community Utilise the most relevant digital communications channels to ensure accessibility and inclusion for all people with MS, carers, family and friends Consult with people with MS, their carers, family and friends as active participants in education and awareness programs 	<p>Design and implement a whole-of-organisation Carer Strategy</p> <ul style="list-style-type: none"> Align human resource and policy frameworks

<p>Assist with the implementation of MS Australia's Carers strategy:</p> <ul style="list-style-type: none"> • Assist the Australian MS Longitudinal Study (AMSLS), one of MS Australia's collaborative research platforms, and a partnership between MS Australia and the Menzies Institute for Medical Research, University of Tasmania, in developing a carers and support people arm. • Providing a body of evidence that could improve research translation & inform resource development to improve the Quality of Life (QoL) of carers & support health and wellbeing in MS. 	<p>Collaborate closely with Member Organisations on issues relevant to people with MS, carers, family and friends</p>	<p>Ensure that the voice and lived experience of consumers are embedded in all fundraising activities</p> <ul style="list-style-type: none"> • MS Australia sign-off on all fundraising strategies where agreed • Industry, corporate and major donor programs link in with lived experience experts
	<p>Collaborate closely with the Neurological Alliance of Australia on issues relevant to the broader neurological and neuromuscular community</p>	<p>Adopt a process for dissemination of information to inform consumers and carers how their participation influences governance, research, policy and advocacy</p> <ul style="list-style-type: none"> • Annual report, website, newsletters and reports reflect information dissemination processes

ABOUT MS AUSTRALIA

Research | Advocacy | Cure

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

We are the largest Australian not-for-profit organisation dedicated to funding, coordinating, educating and advocating for MS research as part of the worldwide effort to solve MS.

Our sincere belief is that we can find ways to prevent and cure MS. Not only eradicating new diagnoses but enabling symptoms to be treated for those living with MS. Our ultimate, singular goal is to enable a world without MS.

Our influence is broad, as the expert, trusted national voice on MS to government and media, and respected supporter of MS medical research in Australia.

We wouldn't be able to do what we do without the help of our MS Member Organisations and you, our community. With a collective dedication to funding and progressing vital MS research and advocacy, we can together enhance and enrich our mutual work and help bring a louder voice and dynamism to the MS cause.

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