

CASE STUDY



The Multiple Sclerosis Research Flagship Consumer and Community Reference Committee

Multiple Sclerosis Research Flagship, Menzies Institute for Medical Research

The mission of the [Multiple Sclerosis \(MS\) Research Flagship](#) (“the Flagship”) at the Menzies Institute for Medical Research (“the Menzies”) is to reduce the impact of MS on individuals and the community. The Flagship conducts research on the causes, treatment, and prevention of MS, with consumers involved at every stage.

In 2019, the Flagship established a Consumer and Community Reference Committee (C&CRC). In 2019–2020, the Flagship received funding from the Australian Government Department of Health, Disability and Ageing under the Medical Research Future Fund (MRFF) for a 5-year Emerging Priorities and Consumer Driven Research Initiative grant. The C&CRC started with seven members with lived experience of MS. By 2024, this had expanded to 18 members. The C&CRC provided 1,980 hours of consumer and community involvement between 2019 and 2024, coordinated by the Flagship’s consumer and community involvement manager.

C&CRC members were involved in all research activities conducted by the Flagship, including:

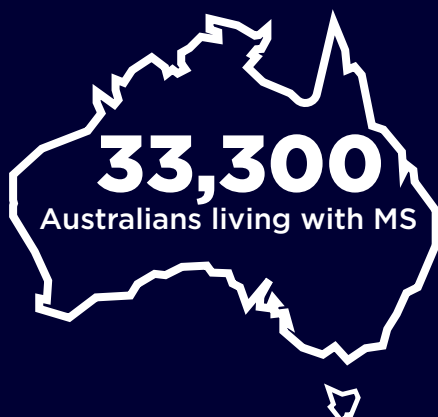
- identifying research topics that matter most to people with MS
- collaborating as co-investigators on grants and co-authors on publications
- reviewing public facing research materials and plain language summaries

- partnering with laboratory scientists to create a shared understanding of MS and the research significance
- providing their lived experience and advocating for people affected by MS.
- contributing to program governance and strategic oversight.

The outcomes of the 2019–2020 MRFF research grant and how consumers were involved were shared with the MS community at an event called *Research with Connections* held in June 2024. It was attended by 130 people, 80% of whom were consumers. The presentations are available here: [MS Research Flagship - YouTube](#).

Beyond the 2019–2020 MRFF grant, the vital work of the C&CRC continues with funding from the National Health and Medical Research Council (NHMRC) Centre of Research Excellence, MRFF, MS Australia, the Menzies and philanthropic funding. C&CRC members are paid for their contributions and provided with ongoing training and development.

In 2021, the Flagship led the development of consumer and community involvement policy for the Menzies, including agreed values and principles of involvement. A workshop involving equal numbers of researchers and health consumers helped identify the barriers and enablers of involvement. The workshop resulted in a consumer and community involvement strategy that is used across the Menzies. The Menzies employed a consumer and community involvement coordinator and a consumer advisory group (M-CIRCLE) to implement the strategy and evaluate its



> 2.8 million
people living with MS
worldwide

Understanding Multiple Sclerosis courses

Some of the Flagship's most impactful work is the suite of [online courses](#) designed to provide free, accessible information to people living with MS, their families, carers and health professionals.

People living with MS co-designed, developed, participated in and tested the courses alongside researchers. They identified priority areas for people living with MS, including biology, pathology, symptoms, diagnosis, risk factors, disease management, and living with MS. The Understanding MS course was launched in 2019. Since then, it has received multiple international awards and achieved global reach and impact.

People who complete the "Understanding MS" course show a significant improvement in their MS knowledge, health literacy, and confidence communicating. Importantly, people with MS who complete the course report increased self-efficacy (their belief in their ability to complete tasks and achieve goals). The success of the Understanding MS course also led to the co-design of complementary courses:

- Mental Health and MS
- Deciding about Disease Modifying Therapies for MS
- Ageing Well with MS.

The Menzies researchers have also developed similar online courses for Stroke, Motor Neuron disease, and Parkinson's disease. Funding for the MS courses was provided by the Menzies, MS Plus, MS Australia, MRFF and MS International Federation with support from the Wicking Dementia Research and Education Centre.

What is multiple sclerosis?

Multiple sclerosis is a disease that causes damage to the protective covering of nerves called the **myelin sheath**. When the myelin sheath is damaged, it breaks down leading to loss of nerve cells and support cells and scar tissue formation; known as sclerosis. Sclerosis prevents normal flow of electrical impulses along the nerves, resulting in clinical symptoms including problems with vision, fatigue, pain, sleep, cognition, and difficulty walking. The symptoms and their severity vary widely between people living with MS. Because people experience MS differently, it's essential they are involved in MS research to ensure it reflects the diversity of their needs and experiences. In turn, this enhances the reach and accessibility of the research and relevance and impact of findings.

Top Tips for researchers and research institutions

- Start early and allow plenty of time for genuine consumer and community involvement.
- Building trusting relationships and shared understanding is key.
- Be clear about the commitment, what's involved, the outcomes you're aiming to achieve, and the level of reimbursement and support offered.
- A consumer and community involvement request form can help seek expressions of interest and start the conversation, with further development of a plan done in consultation with your consumers.
- Invest in consumer and community involvement and plain language training for researchers and consumers.
- A consumer and community involvement coordinator or manager that balances the needs of the consumer with the needs of the research is vital. They also provide a safe space for reflection and feedback.
- Listen as much as you speak.
- Provide feedback to consumers regularly and acknowledge the contributions they've made.
- Institute leadership and support is critical.

Understanding MS course:



Launched in

2019



More than

60,000

enrolments
from **187** countries



Average completion rate

40%
with
5/5

star rating on Class Central

Of people who have completed the course (as of September 2024):

94% rate the course quality as high

97% would recommend it to others

88% agree the course could improve quality of life

94% improved MS knowledge

98% expressed satisfaction with the learning experience