2026–27 PRE-BUDGET SUBMISSION

About MND Australia

MND Australia is the national peak body of MND State Associations that support those living with, and impacted by, motor neurone disease (MND). Since 1993, we have been the voice for the MND community. MND Australia, together with the MND State Associations, form the only national network focused on improving the lives of all Australians living with MND. Through strong national and international partnerships, we advocate for the needs of those impacted by MND and promote greater understanding of the disease. Our State Associations are:

- MND Western Australia
- MND Victoria/Tasmania
- MND Queensland
- MND New South Wales/Northern Territory/ Australian Capital Territory
- MND South Australia

There are no effective treatments for MND and there is no cure. There are no remissions and progression of MND is usually rapid and relentless, creating high levels of life-limiting disability, regardless of the age at onset. People living with MND have complex, constantly changing needs, which require a wide range of changing supports. Average life expectancy following diagnosis is a scant 27 months.

MND Australia has four key priorities, these are:
Advocacy - We advocate for improvements in treatments and care to ensure people living with MND have the best quality of life possible. We seek to improve the lives of those affected by MND through improvements to federally-funded care, enhanced data infrastructure, access to new treatments and genetic testing, and investment in research.
Information - We provide resources, information and service linkage for people living with MND, their carers and family, as well as for the health professionals and service providers who support them to live well.
Research – We invest millions of dollars annually through our research grants program which supports high-quality research to discover the causes, improve care and find treatments and ultimately a cure for MND.
Connection – We are the nexus between research, services support and lived experience engagement. Our members, the State and Territory MND Associations, provide services and support to the vast majority of people with MND in Australia. Our National MND Lived Experience Network of 165 people living with or impacted by MND provide critical insights to researchers, service professionals and government, facilitating informed policy, practice and care. We are also the custodians of the MiNDAUS Registry, open to all people diagnosed with MND in Australia and with 12 participating clinics.

Further information

MND Australia welcomes the opportunity to provide further information in addition to the information contained in this submission. Please contact Clare Sullivan, CEO of MND Australia, on clare.sullivan@mndaustralia.org.au or 0415 265 262.

What is motor neuron disease (MND)?

Each day in Australia two people are diagnosed with MND and each day two people with MND die.

There is no known cure.

Disease progression is often rapid and relentless, creating a wide range of changing needs and supports.

There are approximately 2,752 Australians living with motor neurone disease (MND) today [1]. Every day in Australia, two people are diagnosed with MND and two people die from the disease. MND is the name given to a group of neurological diseases in which motor neurons – the nerve cells that control the movement of voluntary muscles – progressively weaken and die.

With no nerves to activate muscles, people with MND lose their ability to walk, speak, swallow and ultimately breathe. MND affects each person differently. Initial symptoms, rate and pattern of progression and survival time can all vary widely.

The lifetime risk of MND is about 1 in 300 people by the age of 85. It is estimated that 63% of people living with MND were diagnosed aged 65 and over [1]. There is no single medical test that can confirm diagnosis. The average time from the onset of symptoms to confirmation of diagnosis is 13 months in Australia [1]. Access to a specialised neurologist is key to timely, accurate diagnoses.

Average life expectancy for people living with MND is 27 months from diagnosis. A third of those die within one year and more than half die within two years of diagnosis. In 2023, 781 people with MND died in Australia [2]. In 2025, this number is estimated at 867 Australians [1]. MND State Associations report that their case load is increasing across time, a pattern that is confirmed by recent analyses which indicate cases of MND in Australia will reach over 4,000 by 2050 [1].

Currently there are three pharmaceutical treatments available in Australia for MND. These treatments can slow disease progression, delay functional decline and extend survival times, but currently only two of these treatments are listed on the PBS. None of these treatments are a cure for MND.

Up to 15% of MND cases have a known genetic basis through a well-established family history. However, as we continue to better understand the complex nature of MND, it is becoming clear that genetic changes are a factor in a much higher percentage of cases.

Living with MND

People living with MND can experience a variety of changes in the early stages, such as stumbling or falling, changes in dexterity, slurred speech, trouble swallowing, muscle twitching, or cognitive and behavioural changes. As MND is a degenerative condition, these symptoms will worsen over time. The support and equipment needs of someone living with MND will therefore change, often rapidly.

People living with MND benefit greatly from coordinated, multidisciplinary care, as well as assistive technology [3]. This care team may include a neurologist, care coordinator, allied health assistant, occupational therapist, physiotherapist, orthotist, respiratory specialist, speech pathologist, dietitian, nurse, social worker, psychologist or counsellor, palliative care expertise, an MND association advisor, NDIS support coordinator, and community service providers. Evidence shows that those who attend a multidisciplinary clinic experience extended life expectancy[4].

A large variety of aids and equipment, usually referred to as ‘assistive technology’ (AT) are needed. Common forms of AT include power wheelchairs, hoists, hospital beds, respiratory aides, or eye-gaze technology to communicate. Many people also require home modifications, such as ramps or major bathroom modifications.

The MND State Associations provide wrap-around services and coordinated care, access to specialised equipment, assistance with system navigation and psycho-social supports.

Due to the length of time to receive an MND diagnosis, people living with MND will often have significant disability at the point of diagnosis and require immediate supports. This access to immediate supports is critical.

> MND Australia strongly advocates for more equitable solutions that benefit all people living with MND in Australia. We are concerned about inadequate government funding and support for people diagnosed with MND who are aged 65 and over, as well as broader inequities related to access to specialist healthcare, geographic location, cultural and linguistic diversity, and varying levels of health literacy and capacity among people living with MND, their families and carers.

MND Australia’s Budget Recommendations

MND Australia seeks a budget commitment from the Australian Government to implement the following five initiatives to immediately make a difference to the lives of people living with MND, their families and carers.

1. **Link MND data for national impact, by funding the National Unified MND Database.** *Australian Government investment of $12 million over two years.*

2. **Increase access to quality specialist care and research for all Australians living with MND.** *Australian Government investment of $30 million over three years.*

3. **Establish a fast-track aged care pathway for people living with MND.**

4. **Fund disability supports for older people in the Aged Care system at a comparable level to the NDIS, to ensure people living with MND aged 65 years and over receive the unique supports they need.** *Australian Government investment of $287 million per year.*

5. **Protect future generations by expanding the scope of genetic testing supports to include rebatable genetic counselling and no-cost access to preimplantation genetic testing for *in vitro* fertilisation.**

1

Link MND data for national impact, by funding the National Unified MND Database.

Fragmented and ageing MND databases are holding back potential breakthroughs in MND research and understanding.

There is incredible government and community goodwill towards finding a cure for MND. Over the last 10 years, there has been over $100 million in MND research investments by NHMRC and MRFF research grants, focused on understanding causes, finding a cure and improving care. However, to leverage these investments, there needs to be a way to connect up data that can accelerate research. Without linked data, discrete findings are likely to remain underpowered and underutilised.

> **"What's missing right now, and what could truly change the game, is a national MND database. We can't fight what we don't understand. At the moment, there's no single coordinated system capturing who has been diagnosed, where and why. Data is fragmented between states, clinics and research centres. That means we are missing crucial insights that could save lives. A database would allow us to identify patterns, improve care pathways, and connect researchers who are all working on different parts of the puzzle."**
>
> -Ron Hobden, living with MND, speaking to MP Zali Steggall through assisted technology.

The lack of adequate, useful data is a major barrier to MND research and care. Because the progression of MND happens so rapidly, the current fragmented data environment does not provide an adequate number of records that can be analysed for commonalities or patterns. In Australia, biobanks, clinical and patient registries, and practice management systems related to MND remain fragmented and disconnected, many relying on outdated technology nearing end of life. There is an urgent need for a coordinated, holistic approach to the collection, management and analysis of MND data. This requires a sector-wide MND data strategy to elicit the insights that will improve research, enhance clinical care and community support, and help identify the causes of the disease, potentially supporting prevention strategies.

Increased knowledge and understanding of MND is key to advancing better care and new treatments. However, the current limitations in the collection and availability of Australian MND data places significant constraints on advancements. MND Australia has identified a critical need to build and manage a comprehensive National Unified MND Database as a solution to address the current limitations in knowledge and treatment of MND.

This platform would improve diagnosis, identify potential environmental factors contributing to the onset of disease, accelerate research and clinical trials, and optimise care and support services. Further, it would aid more efficient recruitment for clinical trials, support precision medicine and influence public health policy. This data asset would be available to MND researchers and service providers in Australia, and also support global collaboration and data sharing to foster international research efforts and policy development.

This investment is the top priority for many Australians living with MND, as evidenced by the letter-writing and advocacy campaign that has been organised at the grassroots level, organised by Ron and Annie Hobden (NSW) and Jane Simpson (Victoria). Ron is living with MND, Annie cares for him, and Jane provided care for her now-deceased husband. There has been enthusiastic uptake from the Lived Experience Network.

There is currently limited information exchange across existing MND databases. This new national data platform would link, extend, and leverage the strengths of the existing clinical registries, bio registries and other MND databases. This data platform would lead to collaborative learning and tangible outcomes for research, consumer care, and integrated government services, and ultimately better health outcomes for people living with MND. Knowledge and understanding of the disease is key to developing better care and new treatments, and the limited integrated data we have constrains this.

MND Australia is calling for a $12 million investment from the Australian Government over two years, to link and streamline existing MND data registries, expand data collection, and strengthen analytical capabilities across the sector. This is a data-driven solution to improve the diagnoses, treatment, and research of motor neurone disease in Australia.

See our full proposal, attached as Appendix A.

2

Increase access to quality specialist care and research for all Australians living with MND.

MND Australia is proposing a 3-year pathway to close the access to care and research gap for all people with a diagnosis of MND, regardless of age, location, or economic resources.

A diagnosis of MND is devasting enough, but the patchwork access to care, support & clinical trials creates an immediate challenge for people living with MND, their carers and families. The complexity and often rapid progression of the disease is always pushing against system and bureaucratic slow-downs in accessing healthcare and support, which is provided by a combination of State Health departments, My Aged Care, the NDIA, State MND Associations and other not-for profit agencies, and the private health sector.

MND Australia conducted numerous consumer engagement activities in 2025, including an economic & social impact report on MND [1], a national MND community survey (n=495) [5], online focus groups, and a national MND conference. These engagements clearly highlighted that people experience different pathways and options for care and research participation, determined by their age, their state or territory of residence, postcode and their financial status.

Not everyone diagnosed with MND has equal access to services and support

These barriers create significant levels of inequity when accessing MND care in Australia, hence it is imperative that pathways be created to maximise equity of access to specialist care for all Australians living with MND. There is currently no cure for MND, and for most people it progresses rapidly with the average time from diagnosis to end of life being only 27 months. Evidence supports that access to coordinated, specialist MND clinics can extend life by 7-24 months [1, 4]; improve quality of life [1, 5]; and reduce unplanned hospital admissions [6], which average three times longer than the average hospital stay [1] .

Australia currently has 24 specialist MND clinics in seven states and territories. There is no MND clinic in the Northern Territory. Most of these clinics have been established by either a Neurologist or Palliative Care Specialist, with specific interest and expertise in MND.

The multidisciplinary team ideally includes medical specialists (e.g., neurology, respiratory and palliative care), a clinic coordinator, allied health professionals, and nursing [7]. However, the structure, staffing and resourcing of each clinic around the nation varies considerably, with some clinics receiving no dedicated funding to operate the service. In addition, some clinics have no appointed clinic coordinator. This is a vital role [8], acting as the central point of contact for people living with MND and their families; supporting navigation of the health system, providing education and advice, and facilitating communication amongst the person's multidisciplinary team.

The majority of MND clinics in Australia are located in a metropolitan area; and some clinics service a specific catchment area, meaning that in some regions of Australia, people living with MND struggle to access a specialist clinic, and they also struggle to find local professionals with the appropriate knowledge & skills. This is particularly true for people living in rural, regional or remote areas. Responses to our MND Community Survey 2025 found that only 72% of outer regional people living with MND had accessed an MND clinic, compared to 89% in major cities; 34% reported significant issues with travel (compared to 4% in urban areas); and 64% reported difficulty finding allied health professionals with MND experience (compared to 50% in major cities) [5].

Image 1: *Healthcare inequities for people living in outer regional areas. (MND Community Survey Infographic Report [5], p. 1)*

Previous research demonstrated a 4-monthly MND clinic offered in regional NSW provided a significant improvement to available care and also increased the expertise of health professionals in the region [8].

Seventy per cent of 2025 community survey respondents wanted more communication and access to current research opportunities. [5] However, currently, only about a third of the 24 MND clinics are 'research-active' - supporting access to clinical trials. This means that people often must travel great distances, or interstate, to participate in research. We also know that MND clinics collect significant amounts of patient-related data regarding disease presentation and progression, however national collation of this data is extremely limited, as very few MND clinics have access to a research coordinator to facilitate this.

> **What I am facing is so horrendous...MND hasn't had many breakthroughs, treatments are scarce, and those that are available have varying results. None of them are a cure. I'm grateful that organisations like MND Australia, state associations, and Fight MND have helped keep MND in the public arena… There isn't a lot of hope for an individual when given this diagnosis, but hope is what we need, and these organisation help keep it alive."**
>
> -Elizabeth Abrahams, mother of three

In addition to MND clinics, the not-for-profit State and Territory MND Associations provide nation-wide, timely and broad-ranging support services that can help to keep people with MND out of hospital and in their homes for longer [9]. Sixty-four percent of respondents living with MND in our community survey indicated that support from State MND Associations improves their quality of life [5]. Valued supports from State MND Associations include education and information, psycho-social support, equipment loans (e.g. hoists or specialised wheelchairs), and assistance with accessing funding and navigating care [5].

A plan to close the 'care gap.'

MND Australia, the State MND Associations and specialist clinics have a multi-step plan to maximise access to coordinated, specialist care and support for Australians living with MND.

1. **Support implementation of the National MND Guidelines in Australia.** These guidelines are currently being developed by HESRI [10]. When completed, they will provide a best-practice, evidence-based framework to assess and manage care for people living with MND in Australia. However, ensuring these guidelines are embedded into practice requires funding support for MND clinics and State MND Associations.
2. **Ensure all specialist MND clinics have a funded Clinic Coordinator.** Funding clinic coordinators (up to 25, one per clinic) will: a) support adherence to existing [7, 8] and upcoming [10] care guidelines; b) ensure adequate coordination of care is in place for all Australians attending MND clinics, including in the Northern Territory; c) ensuring continuity of care, which averts crises and reduces hospital stays; d) provide adequate resourcing for these roles in the clinics which will reduce pressure on existing staff; and e) support the clinics to pilot expanded models of care, to support more people living with MND in rural, regional and remote areas.
3. **Appoint a Service Improvement Manager within each State MND Association**, to oversee the coordination and implementation of high-quality care and support in the home, based on the best practice care guidelines, and lead collaboration on filling care gaps.
4. **Standardise and coordinate national data collection.** A 'Research and Data Coordinator' for each State, will work closely with the MND Clinic Coordinators and State MND Associations to facilitate a coordinated, national approach to collecting and analysing patient data, to increase our understanding of the disease, as well as the impact of care & support services. This will also support the MND National Unified MND Database rollout and implementation. A greater number of clinics will be supported to participate in research, which means greater access to research trials for people living with MND - a priority for the majority of people. [5]
5. **Utilise results from the '<u>Bridging the Health Equality Gap for Australians with MND'</u> research study.** This mapping exercise, led by Dr Karen Hutchinson, will reveal who is being left behind in accessing best practice care, and what the barriers are (whether financial, geographic, or other). This will allow specialist clinics and State MND Associations to implement a coordinated approach to providing universally consistent, high-quality care for all people living with MND, particularly those who live in rural, regional and remote areas where access to health care and services is lacking. A phased implementation of the coverage plan, focusing on areas that are currently in greatest need, will support best practice of piloting, learning, and adapting models of care.

6. **Secure reliable resourcing for State Associations.** Ensure State Associations are adequately resourced to provide their wide-ranging services. These include but are not limited to home visits; resourcing and managing equipment libraries; and providing NDIS and Aged Care advice and coordination, carer support, respite services, and psycho-social programs. The State Associations often fill the 'care gap' when health services are not available in a particular region. Variable and uncertain funding hampers this important work.

Table 1: *Requested resourcing for MND clinics and State Associations*

Resourcing	Why it's important
MND Clinic Coordinators ***Up to 25 clinic coordinators, one for each MND clinic including the NT***	The clinic coordinator fosters high-quality, evidence-based, and patient-centred care for people living with MND and their carers; facilitates integrated assessments, future planning and ongoing healthcare support for patients across the multi-disciplinary clinical team; and ensues continuity of care which improves outcomes and reduces hospitalisations. Additionally, this position supports outreach services and other healthcare professionals, who might require guidance & support on MND management.
Research coordinator ***7 positions for national coverage***	Receiving communications on available clinical trials, and being supported to access them, is important for people living with MND & their carers [5]. This role will help to expand the number of research-active clinics, ensuring a coordinated, standardized approach to research access and to data collection in both the State Associations and the clinics.
Service improvement manager ***7 positions to support the state associations***	The service improvement managers will be positioned within State Associations to ensure best practice standards are implemented, to monitor progress and to facilitate problem-solving and improvements.
Secure funding for state-based services	Equitable and secure funding across all states and territories is essential to ensure equitable, quality care for all Australians living with MND. Three years of secure funding would allow State Associations to provide essential services to all people living with MND while also working closely with specialist clinics to implement the plan for equitable, quality service provision nationwide.

MND Australia is requesting $10 million per year for three years to include the cost of clinic coordinators, research coordinators, service improvement managers, and secure funding for state-based services.

3

Establish a fast-track aged care pathway for people living with MND

In 2025, it is estimated that 63% of people living with MND were diagnosed at age 65 and over [1]. This means they are shut out of the NDIS and reliant on Aged Care for managing their disease progression.

Waiting for care has devastating consequences for older people. The longer people go without the supports they need, the higher the risk of hospitalisation and earlier entry into residential care – when they can access it, as many are 'clinically declined' [12]. These risks are magnified for older people with MND. Delays to services, assistive technology and home modifications resulted in more than half the respondents to the *2025 MND Community Survey* (n=227) having neither the equipment nor the home modifications required for mobility, personal care, or communication [5].

Prior to the aged care reforms that took place from 1 November 2025, wait times to receive a Home Care Package were unacceptable. Three pain points were responsible for much of the delay:

1. The wait from **registration to receiving an assessment** (untracked, but the Government report into the aged care service stated that it was 'not uncommon' for wait times of 3 – 6 months or even longer [9, p. 43])
2. The wait from **assessment to approval of a package** (1 – 6 weeks); and
3. The wait time from **approval to receiving a package** (12 – 15 months for the highest level of care package, which is what most older people with MND received).

This is in contrast to the NDIS, where the *NDIS Priority Eligibility Decision Pathway* and NDIS MND planners ensures packages are approved in 2 – 5 working days [13]. Many older people with MND died while waiting to receive their package, either in great distress due to the lack of needed supports, or leaving family members with unmanageable debt.

We acknowledge and appreciate the changes made that means the Support at Home Program incorporates a Priority System, including the use of Triage Delegates, reduced wait times for assessment, access to interim funding and categorisations that include an urgent priority.

However, due to the complex, intensive needs for people living with MND, MND Australia recommends a formal 'fast-track' aged care assessment and approval process. At minimum, we would like to see Triage Delegates appointed who have expert information on MND needs and progression, and will urgently progress cases for immediate review and funded at the highest levels.

Ideally, specialised MND planners who have expertise in the level of supports and services that people living with MND need, similar to the *NDIS Priority Eligibility Decision Pathway* and NDIS MND planners, should be made available. Providing similar timeframes to the NDIS fast track pathway for people living with MND will ensure that those aged 65 and over automatically receive urgent prioritisation and the highest level Support at Home package and home modification/assistive technology funding at the time it is needed, according them dignity and respect. Accurate assessments require an understanding of MND, reducing the risk of funding that does not match a persons' needs or that tragically comes too late.

The MND State Associations also report that new Support at Home assessment algorithms are not sensitive to the realities of the severe disability that MND causes, nor its rapid progression. They report that algorithms are assessing older people living with MND at very low package amounts (e.g., Level 2) which the assessors insist they cannot override. Additionally, staff have been informed that a Level 8 package (the highest value) is unavailable to anyone without 'severe cognitive disability.' Anything less than a Level 8 package is leaving older Australians with MND with less financial support to manage their needs than they received under the defunct Home Care Packages. Further, the ability to be reassessed is itself a slow process, as a reassessment cannot be requested until the package has been received. This is creating incredible distress for older people whose health is in severe decline and who may not have the resources necessary to self-fund the care and assistive technology they require.

A fast-track process for people living with MND which includes a team of MND priority access planners and an algorithm that includes MND as a Level 8 condition would support and contribute to the Australian Government's commitment that no one will wait for more than 90 days for a package by the target date of July 2027. As the *Senate Community Affairs References Committee Aged care service delivery Report* concludes, there is an urgent need to fully understand and address the causes of delays. Care cannot wait [12].

A review of the Single Assessment System is recommended in line with the findings of the 2025 *Senate Community Affairs References Committee Aged care service delivery Report* to ensure appropriate care is provided in the time it is needed.

It takes an average of 13 months to receive an MND diagnosis, and average lifespan following diagnosis is a mere 27 months; older age also correlates with a shorter lifespan post-diagnosis [14]. This means that people living with MND will often have significant disability at the point of diagnosis and are likely to experience very rapid decline, requiring immediate supports, including allied health, assistive technology and home modifications.

Guaranteed timely access to supports for people living with MND aged 65 or older will ensure they receive the high-level and fast-changing supports and care they need.

A fast-tracked access pathway, similar to the *NDIS Priority Eligibility Decision Pathway*, will ensure people with MND aged 65 and over are gaining access to services and supports that are key to someone living with this rapidly changing, progressive disease that creates high levels of life-limiting disabilities. Fast-tracked services and supports will facilitate people living with MND aged 65 and over to stay out of hospital and in their homes longer. In 2025 the direct cost of hospitalisation and emergency department visits was $16.2 million for people living with MND [1]. At the moment there is no provision for recognising MND as a priority for funding or urgency. The MND State Associations tell us that since 1 November most MND cases have been marked as ‘moderate’ priority and funding varies from the lowest amounts at Level 1 up to Level 8, without any understandable logic for the differing outcomes.

4

Fund disability supports for older people in the Aged Care system at a comparable level to the NDIS, to ensure people living with MND aged 65 years and over receive the unique supports they need.

MND Australia calls on the Australian Government to invest $287 million per year to ensure people with MND aged 65 and over receive supports and services equitable to those available through the NDIS. Access to these supports must be timely.

Effective 1 November 2025, the highest level of funding under the new Support at Home package is $78,106 per year; there is also the possibility of two one-off payments of $15,000 each for assistive technology and home modifications [15]. In comparison, the average NDIS package for someone with MND is $302,000 per year; this is a difference of over $200,000 per year in package funding. This represents an aged-based inequity that does not reflect the urgency of needs associated with MND, regardless of age.

> **"My Aged Care works at a glacial pace. If I request a pressure-area cushion, I can wait two or three months and pressure areas don't wait for approval...MND moves quickly, but everything around it moves slowly. There's no sense of urgency, no understanding that every delay matters."**
>
> -Gill Lewis, carer of husband Tony

As 63% of people diagnosed with MND are aged 65 and over [1] and therefore ineligible for the NDIS, many are left without the essential, flexible support they urgently need. Our 2025 MND Community Survey [5] found that the inequities of the two systems are unacceptable for 75% of all respondents, including those on the NDIS (71%) who feel the injustice of a two-tiered system.

The aged care system was not built for and is not suitable for someone with a complex condition such as MND. The 2025 *Senate Community Affairs References Committee Aged care service delivery Report* directly addresses this issue in Recommendation 8: "The committee recommends that the Australian Government should consider the adequacy of daily living supports delivered through the at-home aged care system for older Australians living with a disability, in comparison with those delivered through the National Disability Insurance Scheme" [12, p. 115]

Table 2: *Discrepancies between the NDIS and Aged Care packages (adapted from Evo Health and MND Australia, 2025, p. 10) [1].*

	NDIS	Support at Home program
Eligibility	Under 65 years old	Aged 65 and over
Access time	Fast-tracked, typically within 205 days for people with MND.	Time to access varies widely, from 2 – 12 months.
Services	Comprehensive support including personal care, therapies, assistive technology, home modifications, and support coordination.	Basic care services including personal care, limited therapy, and basic equipment.
Access time	Not means-tested, no cap, with an average of $302,000 per year per person with MND in 2025.	Means-tested, with maximum available financial package valued at $78,106 per year. Two one-off payments of up to $15,000 each are also available for assistive technology and home modifications.
Proportion of people	37% of people with MND (1,018 people in 2025).	63% of people with MND (1,734 people in 2025).
Total cost	$305.68 million annually (average).	$187.5 million annually (maximum).

MND Australia requests that equal access to funding regardless of age is prioritised and that this access is timely. We welcome the addition of two new payments of up to $15,000 each that is available within the top tier Assistive Technology and Home Modifications (AT-HM) scheme of the Support at Home program, and also that additional assistive technology is available if assessed as ‘evidence of need’ and/or with a prescription beyond the $15,000. The new End-of-Life Pathway that provides approximately $25,000 for the final 12 weeks of life is also welcomed. However, additional and ongoing funding that is neither time limited nor capped, for care support, assistive technology and home modifications, continues to be urgently needed to meet the specific, high-level needs of people living with MND.

The current funding differences between the NDIS and the new Support at Home program highest level funding means that the 63% of people diagnosed with MND who are aged 65 and over are not getting and may never receive the complex and ever-changing disability supports they need. This causes great distress and hardship for older people living with MND, their families and carers.

MND Australia is urging the government to invest $287 million to ensure equitable supports for all people living with MND regardless of age.

5

Protect future generations by expanding the scope of genetic testing supports to include rebatable genetic counselling and no-cost access to preimplantation genetic testing for *in vitro* fertilisation.

MND Australia recommends and calls on the Australian Government to:

- Improve access to and usefulness of genetic testing for people with MND and their families by making genetic counselling available under Medicare
- Fund no-cost access for those with an MND genetic predisposition who choose to undertake in vitro fertilisation (IVF) and preimplantation genetic testing (PGT-M).

The need for genetic testing and counsellors

Latest research suggests that up to 15% of MND cases involve an inherited genetic fault (familial MND) [16]. For families impacted by familial MND, genetic testing enables opportunities for future family planning to avoid passing on known MND faults.

Genetic screening for MND is now available under Medicare. However, access to genetic counselling, which is a vital part of the screening process, is extremely limited due to low numbers of genetic counsellors.

People living with MND and gene carriers have told us they need better and more timely access to both genetic testing and genetic counselling. Accessing both testing and counselling can be very difficult and varies in states and territories across Australia [17]. Making genetic counselling rebatable under Medicare for people living with MND and other similar diseases with a genetic link will increase access to genetic counsellors and provide future opportunities for new genetic counsellors.

MND clinics provide multidisciplinary treatment and support for people living with MND across Australia, and the health professionals involved in these clinics and services are experienced in MND. Incorporating genetic counsellors into multidisciplinary MND clinics will provide better support for people to identify if they have familial MND and, if so, what their options are.

The need for in vitro fertilisation services

For people who know which genetic fault is causing MND in their family, it may be possible to undergo pre-implantation genetic testing for monogenic disorders (PGT-M). In PGT-M, embryos are created outside the body and tested for the presence/absence of the MND gene fault. Only unaffected embryos are considered suitable to be placed into the womb [18]. This option reduces the chances of passing on an MND-related faulty gene and has the potential to stop MND in future generations.

MND Australia welcomed this testing when it became available within the Medicare Benefits Schedule as a rebatable item in November 2021. However, IVF PGT-M carries significant financial costs (up to $8,0000) even with Medicare rebates. MND Australia recommends the Australian Government fund no-cost access for those who choose to undertake IVF and PGT-M.

References

[[1] MND Australia and Evohealth 2025. *Every moment matters: Addressing the human and economic toll of MND in Australia*, Canberra. Access at https://www.mndaustralia.org.au/advocacy/every-moment-matters

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Appendix A: MND Australia Pre-Budget Submission 2026/27

Leveraging MND Data Capabilities

Creating the National Unified MND Database

JANUARY 30, 2025
MND AUSTRALIA
Canberra

1. Executive Summary: National Unified MND Database Proposal

Every day in Australia, two people are diagnosed and two people die from motor neurone disease (MND). In response, successive Australian governments have made significant and sustained investments in MND research, with more than $100 million committed over the past decade through NHMRC and MRFF grants – establishing Australia as a global leader in understanding this devasting disease. To fully realise the impact of these investments and accelerate translation into better care and a cure, Australia now needs the data infrastructure to connect fragmented and ageing datasets across patient records, research databases, biobanks and genomic data.

In 2025, Evohealth modelling estimated that 2,752 Australians are living with MND, equivalent to approximately 1 in every 10,030 people. The cost of this devastating disease in Australia is estimated at $5.02 billion annually, a figure projected to rise to $7.51 billion by 2050 without any new significant interventions. The disability adjusted life years are estimated at 1,420 years of healthy life lost to disability just in 2025 alone, while years of life lost due to premature mortality were an incredible 15,760 years.[1]

The **National Unified MND Database** will unlock the full value of Australia's past, current and future investments in MND by rescuing legacy datasets and integrating clinical, biological and research data into a single, interoperable platform. By enabling previously siloed databases to work together, it will dramatically increase the power of analysis to improve diagnosis, care management, and research outcomes.

This proposal sets out a national, data-driven solution to one of Australia's most devastating and least understood diseases. By integrating existing registries such as MiNDAUS and AMNDR and applying advanced analytics, including machine learning and AI, the database will enable earlier and more accurate diagnosis, support personalised treatment, accelerate research, and strengthen global collaboration and policy development.

Key objectives of the project include:

- Improving diagnosis and treatment
- Accelerating research
- Supporting precision medicine
- Influencing public health policy

MND Australia, the only national body representing the State and Territory MND Associations, is uniquely positioned to lead and manage this work. We are the custodian of the MiNDAUS registry and facilitate the National MND Lived Experience Network. Additionally, MND Australia hold excellent relationships with the network of researchers, specialist clinics, neurologists, and Fight MND, a not-for-profit which raises funds for MND research. Building on our network centrality and the trust that the MND research and care community places in us, we are proposing a consultative process to create the data platform that will link disparate data together for mutual benefit.

The National Unified MND Database will allow data to be analysed for patterns and insights that are currently undetectable due to underpowered sample sizes.

A phased approach will be taken:

Phase 1: stakeholder engagement, governance and infrastructure setup

Phase 2: data integration and analytics development

Phase 3: analytics, global collaboration, and policy support

Phase 4: Full rollout and continuous improvement

The proposal includes a detailed two-year budget totaling **$12 million**, with allocations for infrastructure, data integration, analytics development, governance, and stakeholder engagement. It also highlights the importance of data governance, ethical use of patient data, and compliance with privacy regulations.

MND Australia is ready to commence this work immediately upon funding. As custodian of the MiNDAUS Registry, we already have data-sharing agreements with most MND clinics, established registry infrastructure, and active consent from more than 1,000 people living with MND who are already contributing data.

We also hold more than 30 years of MND care data through our partnership with State MND Associations and are actively developing an MND data lake proof of concept that integrates clinical, care, registry, research and international datasets. This readiness is matched by strong, visible community support—improving MND data has been identified by people living with MND as a top priority, evidenced by a recent grassroots community-led letter-writing campaign calling on government to invest.

Overall, the proposed National Unified MND Database is seen as a **critical tool for advancing patient care, supporting researchers, and driving policy changes** that can improve outcomes for those living with MND. A modest $12M investment now in data will yield outsized returns in knowledge, improved care, and lives saved – it's the foundation for future breakthroughs.

About Motor Neurone Disease Australia

MND Australia is the national peak body of state organisations that support those living with and impacted by motor neurone disease (MND). Since 1993, MND Australia has been the voice for the MND community. Their national and international networks help increase understanding of the disease and advocate for the needs of those affected.

Acknowledgements

This report was prepared in partnership with Cordelta. Cordelta Pty Ltd is a boutique consulting firm based in Canberra, with over 20 years of government and industry experience.

As a fully employee-owned company, Cordelta specialises in delivering high-performing systems, efficient processes, and engaged people to help organisations achieve better outcomes. Their services encompass transformation, technology, strategy, digital, finance, and procurement, all tailored to meet the unique needs of each client.

2. The Problem

MND Prevalence in Australia

Motor Neurone Disease (MND) is a progressive and debilitating condition that currently impacts around 2,752 people in Australia, affecting roughly 1 in 10,030 individuals. On average, two Australians are diagnosed with MND every day, and two lives are lost to the disease daily. The lifetime risk of developing MND is approximately 1 in 300 by the age of 85, with the risk increasing as people age. Australia has some of the highest prevalence rates of MND in the world.[2]

> The economic impact of motor neurone disease is substantial. In 2025, costs are estimated at $5.02 billion across Australia, including direct economic costs plus burden of disease.

Despite these figures, MND is largely a medical mystery, and there is no definitive, single source of truth for the prevalence or causation of MND in Australia.

Awareness of the disease has grown significantly in recent years, but it continues to impose a heavy burden—both economically and in terms of quality of life. The prevalence rate of MND is estimated at 9.9 per 100,000 Australians, with males accounting for **60%** of cases and **females 40%.** The economic impact is substantial, with the total cost of MND estimated at **$5.02 billion annually across Australia (2025)**.[1] The expenses associated with MND care are significantly higher than those of many other diseases.

Despite the relatively low incidence, the **financial burden on both patients and their support systems is significant**. Currently, there are no effective treatments for MND, and while research efforts are ongoing, major initiatives and data-driven approaches are still in early stages.

Several recent reports have suggested that the incidence of MND may be increasing. As MND is considered a disease of ageing, our ageing population may partly explain this, as well as the fact that we are getting better at diagnosing the disease. It is also thought, however, that other contributors such as unknown **environmental factors** or **physical** trauma may also be playing a role.

Living with MND

MND is a progressive neurodegenerative disorder that affects nerves and muscle tissue. Early signs of physical problems or other symptoms of MND can be mild. Symptoms also vary from person to person. Where the weakness in the body starts depends on which motor neurons are affected first. Some of the early signs are:

- Stumbling due to weakness of the leg or foot muscles
- Trouble holding objects due to weakness in the shoulder or hand muscles
- Slurring of speech or swallowing problems due to weakness of the tongue and throat muscles

People with MND experience muscle weakness, cramps, spasms, and joint stiffness. The signs and symptoms worsen over time, resulting in mobility, breathing, and eating difficulties, and ultimately, death.

Causes

The current level of understanding of the disease is relatively low, with uncertainty around what the causes are — whether environmental, trauma-induced, genetic or a combination. The exact cause of MND in its most common form is not fully understood, but several factors are believed to contribute to its development.

> *"Diagnosed in 2018, we were fortunate to have our dad until October 2020. The genetic mutation for MND C9orf72 exists in our family still, and collectively we are extremely passionate about finding that cure."*
> — Renee, lost several family members to MND

Table 1 – Motor neurone disease causation factors

Category	Sub-category	Description
Genetic Factors	Inherited Mutations	Up to 15% of MND cases are familial, linked to mutations in genes like SOD1, C9orf72, TARDBP, and FUS.
	Spontaneous Mutations	Genetic mutations may also occur in sporadic (non-inherited) cases, potentially leading to MND.
Environmental Factors	Toxins and Chemicals	Exposure to heavy metals, pesticides, or certain chemicals is suggested to increase risk.
	Physical Trauma	Head injuries or repetitive trauma are considered possible risk factors, though evidence is inconclusive.
	Viral Infections	Some viruses have been speculated to play a role in MND development, though unproven.
	Diet and Lifestyle	Low intake of antioxidants or omega-3 fatty acids, or smoking, may increase risk.
Demographics	Age	MND typically appears between the ages of 50 and 70, though it can occur earlier or later.
	Sex	MND is more common in men, though the reasons are unclear.

A **national unified MND database** would support targeted research and shared understanding of trends and emerging patterns of factors that Australians diagnosed with MND may share. Currently, this information is **not systematically collected or shared**. While there have been efforts to make MND a notifiable disease, at this point in time, there is no data available through the National Notifiable Diseases Surveillance System.

Diagnosis

There is no single, simple diagnostic tool or test for MND, and the progression of the disease is difficult to measure or predict. It is also unknown whether the incidence or geographical spread of MND is changing, so resourcing requirements are difficult to ascertain.

Diagnosis comes from a neurologist's expert opinion involving ruling out other conditions and using a combination of **clinical evaluations, imaging, and specialised tests over time**. MND is considered a rare disease and many primary healthcare professionals (HCPs), such as General Practitioners (GPs), may encounter only one or two cases in their entire careers, if any at all. Because many health practitioners may not have seen MND in patients before, referral times to a specialist is often delayed.

> *"My father and best friend David Robinson passed away on 24 April 2016 from this monster disease at just 59 years of age. The pain and impact of his loss on my family is incalculable."*
> — Belinda, lost her dad to MND

Conditions that have similar symptoms must be ruled out. For example, multifocal motor neuropathy (MMN), myasthenia gravis, spinal muscular atrophy, and inflammatory myopathies might present with similar symptoms but require different treatments. It is often a **protracted process**, ruling out other conditions before arriving at an MND diagnosis and can result in **delays of up to two years**. Once an MND diagnosis is made, it is definitive and accurate. See Appendix A for the full list of diagnostic steps.

A **national unified database** would create shared access to deidentified patient records, supporting more **streamlined diagnoses, earlier specialist referrals**, and **guidelines for more efficient diagnostic pathways.**

Figure 1: Steps in diagnosis

Progression of symptoms

MND symptoms usually progress over time, and their spread from one part of the body to another helps confirms the diagnosis.

Upper & lower motor neurons

MND affects both upper (originating in the brain) and lower (originating in the spinal cord) motor neurons. The presence of both types of symptoms is a strong indicator of the disease.

Final diagnosis

Once other possible causes have been ruled out and there is sufficient clinical, electrophysiological, and sometimes genetic evidence, a diagnosis of MND can be confirmed.

Early diagnosis is important for planning treatment, symptom management, and providing supportive care.

Cure and Treatment

There is a significant lack of understanding on how to slow or stop MND progression, or to cure the disease. Several interventions are available, but lack of consolidated data means there is no clear understanding of which interventions consistently help extend and improve quality of life for people with MND.

Best-practice treatment is multidisciplinary, involving neurologists, physiotherapists, occupational therapists, respiratory specialists, and others to address the wide range of symptoms associated with the disease. Currently there are three medications available for use with MND which can slow progression of the disease. *Riluzole* and *Edaravone* are currently available in Australia and the third, *Tofersen*, is expected to be added to the Pharmaceutical Benefits Scheme soon. *Tofersen* is efficacious to those who carry the SOD1 gene mutation.

See Appendix B for a list of treatment and management options currently available to people diagnosed with MND.

Summary

- Medications like *Riluzole* and *Edaravone* can modestly slow disease progression.
- New genetic therapies show promise but currently target small patient groups—underscoring the importance of **genetic screening** of all MND patients.
- Symptom management focuses on relieving pain, improving muscle function, and addressing swallowing and breathing difficulties.
- Multidisciplinary care improves quality of life and helps manage disease progression.
- Though incurable, therapies and treatments aim to improve quality of life for people living with MND and reduce suffering.

3. The Solution

Linking existing data repositories to create a comprehensive data source and robust patient-data capture system is essential in tackling rare diseases like MND. This is critical given the disease's complexity, variability, and comparatively small number of cases. A well-structured data platform can significantly enhance **diagnosis, treatment, and research** for a potential cure. Over time, there is potential for the linked database to not only reduce the financial burden of MND in individuals and households, but also to save money on hospitalisations and urgent care.

A well-organised and truly comprehensive national MND database brings substantial benefits across different stakeholders — including people with MND, carers, clinicians, State Associations, researchers, advocates, policy makers and industry partners.

Unifying the disparate data silos will enable more robust analyses, finding patterns and trends which are currently not possible due to the small number of cases held in even the largest of the databases. Questions around whether there are MND hotspots, for example, or whether Australia's comparatively high number of cases is due to an ageing population or a different factor, can be more easily answered. Additionally, the unified database will assist with identifying promising and best practice in diagnoses and care – an immediate benefit for people living with this inexorable disease. These analyses can be conducted using comparative modelling for the various situations that people who are diagnosed with MND are in; for example, comparing by age, socio-economic status, or access to specialist clinics. It will also support trials for new medications or assistive technology, and allow people living with MND to have direct access to their medical and care records.

An overview of how various stakeholder groups will benefit from the National Unified MND Database is provided in Table 2, with more complete information found in Appendix C.

Table 2: Summary of stakeholder benefits achieved by the National Unified MND Database

Stakeholder	Benefits of a National Unified MND Database
Healthcare providers	• Making MND clinical presentation readily available to GPs and other non-specialist medical practitioners • Detecting patterns of diagnosis, reducing the lengthy diagnosis pathway • Access to full records, allowing analysis of promising treatment regimens • Uncovering patterns for best practice, including the role of allied health professionals
People living with MND, their carers and families	• Direct access to their own records • Ability to share records directly with other professionals involved in their care, which reduces stress and repetition • Supports an individualized, patient-centred precision medicine approach
State MND Associations	• Easily accessible current and legacy data for all clients • Access to client medical and care records • Improved coordination of supports • Ability to analyse patterns nationally

Researchers	• Ability to link all records together to increase the power of MND studies and reviews • Ability to link different kinds of data together (e.g., clinical, demographic or biological) • Ability to target requests (e.g., based on location or gene markers) • Access to other stakeholders who may take part in research • Easier collaboration with other researchers, including internationally
Policy and advocacy	• Identification of service gaps • Analysis of differences in supports or outcomes for improved health equity • Analysis of most efficient, cost-effective support pathways • Improved policy settings for supporting research and care
Industry	• Access to individuals that fit profiles for new or emerging pharmaceuticals, therapies or assistive devises

A linked and truly comprehensive national MND database brings substantial benefits across different stakeholders — including patients, carers, clinicians, state associations, researchers, and industry. More detailed information on how the unified data would facilitate both immediate and longer-term benefits are detailed below.

Improved Diagnosis

1

Centralised patient information

Rare diseases like MND often present with symptoms that overlap with other conditions, making diagnosis challenging. A centralized database that captures clinical symptoms, genetic markers, and patient history can help clinicians compare cases, identify patterns, and diagnose MND more quickly.

Sharing across institutions

Given that MND affects a small population, not all health care providers have the expertise or experience to diagnose it effectively. A shared database allows specialists across regions or countries to pool knowledge, offering diagnostic insights that might not be possible in isolated cases.

Clinical guidelines and best practice

By aggregating patient data, researchers can develop more accurate diagnostic guidelines based on common clinical features, genetic predispositions, and symptom progression across a wide range of cases.

More Personalised Treatment

2

Tailored treatment plans

MND is a highly variable disease, meaning patients may experience different rates of progression or response to treatments. By capturing detailed patient data – such as response to specific therapies, side effects, and genetic variations – databases can enable personalized medicine approaches, where treatment is customized to the patient’s unique condition.

Tracking disease progression

A well-maintained database can track the progression of the disease in individual patients, helping to identify early changes or responses to therapies. This allows for timely interventions and modifications to treatment plans.

Symptom management

Capturing real-time data on symptoms (e.g., respiratory function, muscle strength, cognitive changes) helps doctors adjust supportive therapies, ensuring that patients maintain the best quality of life for as long as possible.

Precision medicine

Precision medicine involves tailoring medical treatment to individual characteristics of each patient. By leveraging genetic and molecular profiling, doctors can identify specific biological markers associated with different forms of MND. This can lead to more effective, targeted therapies that address the underlying mechanisms of each patient’s disease. For instance, in cases where certain gene mutations are identified, gene-specific therapies may be developed to slow or later the disease progression. This evolving field of precision medicine offers hope for more individualized, effective treatment options in MND care.

Accelerating Research

3

Improving and extending quality of life

Improving quality of life and extending the average time for diagnosis to death, currently just over two years, is critical for people living with MND. A national database will provide the foundations and evidence base needed to best target services, support and funding.

Identifying biomarkers

A database that collects genetic, clinical, and biochemical data from MND patients can help researchers identify potential biomarkers – biological signals that indicate disease presence or progression. Biomarkers are critical for early diagnosis, monitoring disease progression, and measuring responses to experimental therapies.

Genomic and epidemiological studies

By pooling patient data from different geographic regions and genetic backgrounds, researchers can conduct large-scale studies to identify genetic mutations or environmental factors that contribute to MND. This can lead to a better understanding of the disease's causes and potential therapeutic targets.

Clinical trial recruitment

One of the challenges in rare disease research is recruiting enough participants for clinical trials. A centralized database can serve as a valuable resource for identifying suitable trial candidates, speeding up recruitment, and enabling more efficient testing of new therapies or drugs. A comprehensive national dataset provides pharmaceutical companies with confidence they can successfully undertake clinical trials and is a significant inducement to bring trials to Australia.

Data for drug development

Pharmaceutical companies rely on large datasets to understand disease mechanisms and to test how potential drugs interact with different patient populations. A detailed database offers a foundation for developing new drugs and tracking their long-term efficacy and safety in real-world settings.

Facilitate Global Collaboration

4

Cross-border collaboration

Rare diseases like MND require global efforts to gather enough data to make meaningful progress. Databases can link researchers and clinicians worldwide, breaking down geographical barriers and enabling collaborative research that is crucial for rare conditions. MND Australia has a relationship with the International Alliance of ALS Associations (including membership from ASEAN countries and representation from the G7 and the European Union) as well as the Pan-Asian Consortium for Treatment and Research in ALS (PACTALS).

Standardising data

By establishing common standards for patient data capture (e.g., the use of consistent terminology, diagnostic criteria, and outcome measures), researchers and healthcare providers can ensure that the data they collect is comparable to useful on an international scale. This enhances the quality of the data pool and supports high-quality research.

Longitudinal studies

Rare diseases like MND benefit from long-term studies to understand the natural course of the disease and the long-term effects of interventions. A patient database that follows individual over many years is invaluable for generating insights that would otherwise be impossible to obtain.

Support Care, Advocacy & Policy

5

Patient-centered care

Better care leads to better outcomes with better data enabling efficient and effective targeting of services, support and funding to people living with MND.

Data collected from patients can help guide the development of more effective patient support systems, ensuring that care is aligned with the actual needs and experiences of those living with MND.

Influencing health policy

Comprehensive data can support advocacy efforts to secure more funding for research, improve healthcare services, and create policy changes that benefit people with MND. Data-driven insights can help demonstrate the disease’s impact on quality of life, life expectancy, and healthcare systems.

Efficient targeting of resources and support

A comprehensive picture of MND in Australia enables the efficient and accurate distribution of resources to ensure the best possible care and support is provided where it is needed. This is especially critical in regional, rural and remote areas. Currently, an estimated 30% of all Australian cases are located in regional, rural or remote areas.

Currently, lines of inquiry into a cure are spread across many domains. There is a need to share both promising pathways and those that show little or no promise, allowing cure research to be more integrated, collaborative, and focused.

Additionally, there is a critical need to focus research and understanding on evidence-based care to improve quality of life, slow disease progression, and increase life expectancy—practical knowledge that can make an immediate difference.

> *"Two years into my MND journey, I now need the full assistance of my husband as my carer for toileting, showering, dressing, getting into bed, positioning all my limbs and head on pillows to sleep — hopefully for three or four hours."*
> Janet, living with MND

Integrating the Existing MND Databases in Australia

There are currently several existing MND databases capturing biological samples and patient data to support research, clinical care, and genetic studies. There is limited information exchange among these databases, and some face obsolescence due to outdated software.

The **National Unified MND Database** will salvage data where necessary and achieve integration across critical elements that support diagnosis, management, and research. This approach is essential for building a unified platform that leverages each system's strengths, while allowing the various databases to speak to one another.

Details on existing databases and system, and how this project plans to incorporate their data and capabilities, are provided in Appendix D.

The feasibility and value of such a project has been demonstrated overseas. The most salient example is the MND Research Data Catalyst project in the UK, which aims to support accelerated research, innovation and best-practice care, with the first phase focused on connecting up existing multi-modal data across the UK. Another example is Enroll-HD, an integrated global clinical research platform for Huntington's Disease which includes both clinical data and biosamples. The Enroll-HD platform has supported breakthroughs in biomarkers and genetic modifiers as well as improving clinical care. [2]

4. Project Proposal

The purpose of the proposed project is to establish the National Unified MND Database — a robust, integrated data platform for Motor Neurone Disease in Australia that enables early diagnosis, accelerates research, fosters global collaboration, supports personalised treatment, and informs advocacy.

This platform will serve as a vital resource for clinicians, researchers, people with lived experience, and policymakers, contributing to a world where people living with MND receive more timely and effective care, and research progresses more rapidly toward new therapies.

Key objectives:

- **Accelerate Research**: Facilitate research on disease progression, biomarkers, and treatment effectiveness by providing a comprehensive, high-quality dataset.
- **Facilitate Global Collaboration**: Enable data sharing among global MND research centres to promote joint research and knowledge exchange.
- **Support Improved Care, Advocacy and Policy Development**: Provide evidence-based insights to support advocacy, public health policy, and healthcare resource allocation.
- **Improve Diagnosis and Treatment**: Enable earlier and more accurate diagnosis, personalise treatments, and support precision medicine initiatives.
- **Protect Current and Future Data**: Rescue dormant or sunsetting data platforms, integrate existing datasets, and streamline data entry to ensure complete patient records.

> We propose to establish a robust platform that captures and integrates patient, clinical, and biological registries, as well as data from practice management software.

Strategic Pillars and Key Steps

The National Unified MND Database will be built on five strategic pillars that will guide the development of the data integration and useability for different stakeholders. Overarching these pillars will be the active participation of key stakeholders, particularly health consumers with lived experience of MND. This will ensure a product that is fit for purpose, robust, meets ethical guidelines, is useful and supports a positive user experience.

1. Data Infrastructure and Integration

- **Database Design**: Build a centralised, cloud-based database integrating patient, clinical, and biological registries with practice management systems. Use relational databases for structured data (demographics, clinical data) and NoSQL databases for unstructured data (genomic sequences, imaging).
- **Data Standardisation & Interoperability**: Develop standardised data collection protocols aligned with HL7 FHIR standards for interoperability with global MND registries.
- **ETL Pipeline:** Establish an Extract, Transform, Load (ETL) pipeline to automate data collection, cleaning, and loading from various sources, regularly updated as new data sources emerge.
- **Data Warehousing & Big Data:** Implement a data warehouse with big-data processing capabilities to handle large volumes of MND-related data, especially genomic and multi-omics data.

2. Data Quality and Governance

- **Data Quality Standards**: Define quality standards for accuracy, completeness, and timeliness. Develop automated checks for missing or inconsistent data and alerts for anomalies.
- **Data Stewardship & Ownership**: Assign stewards for data entry, cleaning, and management across patient, clinical, and biological domains.
- **Governance Framework**: Establish a governance structure defining ownership, access rights, sharing policies, ethics, and compliance.

3. Advanced Analytics and Research Support

- **Machine Learning for Early Diagnosis**: Use historical patient data to predict early signs of MND and enable clinicians to diagnose faster and more accurately.
- **Precision Medicine and Predictive Models**: Employ AI-driven models to identify MND subtypes and predict treatment responses.
- **Longitudinal Data Analysis**: Allow researchers to track disease progression, treatment outcomes, and quality-of-life metrics over time.
- **Data Democratisation**: Provide controlled access to anonymised data for researchers and clinicians to run analyses and contribute to shared knowledge.

4. Global Collaboration and Data Sharing

- **APIs and Protocols**: Develop APIs and common protocols to share data with international MND research organisations, advocacy groups, and health institutions.
- **Data Privacy and Compliance**: Apply strict privacy measures, including anonymisation and encryption, to protect patient identities.
- **Collaborative Research Frameworks:** Partner with international research networks to establish shared research structures and joint studies.
- **Leverage International Datasets:** Access to global datasets will increase the power of AI and machine learning analysis applied to Australian data.

5. Advocacy and Policy Support

- **Patient Portal and Data Access:** Provide secure access for patients to their own data, research updates, and study participation opportunities.
  Include patient feedback to improve system usability and relevance.
- **Data Analytics for Policy Impact:** Use analytics to inform policymakers on disease prevalence, treatment effectiveness, and resource allocation.
- **Public Reporting and Transparency:** Create public-facing dashboards that share aggregated data insights (e.g., prevalence rates, clusters, trial results) to advocate for funding and awareness.

5. Implementation Methodology

Two-Year Plan

The two-year plan outlines project phases and milestones for the National Unified MND Database. It includes:

1. Stakeholder Engagement, governance and Infrastructure Setup
2. Data Integration and Analytics Development
3. Analytics, global collaboration and policy support
4. Full Rollout and Continuous Improvement

Methodology Overview

To create a comprehensive platform capturing patient data, clinical data, biological samples, genomics, care initiatives, diagnosis, and treatment, MND Australia will follow this step-by-step methodology:

Step 1: Define Database Objectives and Stakeholders

- Establish primary goals (e.g., research facilitation, enhanced clinical care, and support initiatives).
- Identify and engage key stakeholders — researchers, clinicians, data scientists, patient advocacy groups, State Associations, and policymakers — to ensure the database meets diverse needs.

Step 2: Establish Data Collection Protocols

- **Patient Data**: Demographics, family history, risk factors, symptom onset.
- **Clinical Data**: Diagnostic info, assessments, treatments, outcomes.
- **Biological Samples**: Protocols for collection, processing, and storage of samples (blood, CSF, brain tissue) at standardised intervals.
- **Genomic Data**: Obtain consent for genetic sequencing (e.g., whole genome) and link to clinical information, ensuring compatibility with international data standards.
- **Care and Support Initiatives**: Capture data on support services, assistive technologies, and quality-of-life interventions.

Step 3: Develop Data Governance and Compliance Framework

- **Ethics and Consent**: Establish ethics-approval protocols and informed consent forms, ensuring transparency on data use.
- **Privacy and Security**: Use encryption, access controls, and compliance with privacy regulations (e.g., Australian Privacy Act, GDPR).
- **Ownership and Access Control**: Define roles and permissions to ensure authorised access to sensitive data.

Step 4: Design the Database Infrastructure

- Use a centralised or hybrid cloud-based system for nationwide access and scalability.
- Employ relational or NoSQL databases for structured/unstructured data.

- Implement mechanisms for linking patient, clinical, and genomic data across MND registries, biobanks, and EHR systems.
- Adopt HL7/FHIR standards for interoperability with international MND databases.

Step 5: Develop Data Collection Tools and Integrate Existing Sources

- Build user-friendly interfaces for clinicians to input data during visits and portals for patients to contribute self-reported information.
- Collaborate with existing registries (e.g., MiNDAUS, SALSA) and state databases to import data and avoid duplication.
- Provide mobile app integration for patients to upload symptom and care data continuously.

Step 6: Implement Quality Control and Data Validation

- **Standardised Data Entry**: Develop clear data-entry guidelines and training for clinicians and researchers.
- **Automated Validation**: Introduce automatic checks for data completeness, accuracy, and consistency.
- **Regular Audits**: Schedule routine audits to maintain integrity and correct any errors.

Step 7: Develop an Analytics and Reporting Platform

- **Data Query & Visualisation Tools**: Integrate SQL-based query systems and visualisation platforms (e.g., Tableau, Power BI) for clinicians and researchers.
- **Machine Learning Models**: Develop predictive models for analysing outcomes, treatment effectiveness, and disease progression.
- **Real-Time Reporting**: Create dashboards for live updates on patient demographics, symptom tracking, and research findings.

Step 8: Establish a Research Collaboration and Data Sharing Framework

- **Data Access Agreements**: Develop sharing policies allowing authorised researcher access while protecting privacy.
- **Research Partnerships**: Facilitate collaboration with national and international MND research networks.
- **Open Data for Genomics**: Provide anonymised datasets to global repositories (e.g., GenBank) for cross-study comparison.

Step 9: Pilot and Scale the Database

- **Pilot Testing**: Run a limited pilot with select clinics and participants to identify and resolve system issues.
- **Feedback Mechanism**: Gather user feedback (clinicians, researchers, patients) to refine usability.
- **Full Rollout and Scaling**: Expand to additional clinics and states with continuous technical support.

Step 10: Maintain and Update the Database

- **Continuous Monitoring**: Track performance, security, and compliance with regulation updates.
- **Ongoing Data Validation**: Regularly update entries and review collection protocols.
- **Adapt to New Technology**: Incorporate advances in genomics, AI, and data storage to keep the system current.

This structured, iterative approach ensures a comprehensive, secure, and scalable MND database that supports both research and patient care.

Key Phases and Activities

Technical Implementation Phases

Phase 1 Stakeholder engagement, governance and infrastructure setup	• **Stakeholder engagement:** Engage with key stakeholders, including people with lived experience, clinicians, researchers, advocacy groups, and policymakers, to understand their needs and requirements. Stakeholder engagement will continue throughout the implementation process. • **Governance:** Governance systems are established, including the active participation of key stakeholder groups. • **Infrastructure development:** Set up the core database infrastructure with scalability capabilities. This includes selecting cloud providers, building data integration pipelines, and setting up security protocols. • **Quality assurance:** Accountability systems and structures are put in place. Subject matter experts for the different types of data and for the creation of the platform itself are incorporated into the project.
Phase 2 Data integration and analytics development	• **Data collection and integration:** Begin data integration by connecting with existing registries and practice management software. Ensure ETL processes are functional and data is flowing accurately into the central repository. • **Data quality validation:** Conduct data validation and standardisation exercises to ensure all integrated data meets quality standards and is interoperable with global databases. • **Develop and test analytical tools:** Implement early-stage analytics tools for clinicians, such as predictive models for diagnosis and treatment planning.
Phase 3 Analytics, global collaboration, and policy support	• **Refine analytics:** Collaborate with researchers to deploy advanced analytical tools for pattern recognition and trend analysis. • **Machine learning and AI integration:** Tools and models that enhance the accuracy of treatment plans and contribute to precision medicine initiatives. • **Establish data sharing agreements:** Develop formal data-sharing agreements with international research organisations, advocacy groups, and health departments. • **Advocacy and reporting tools:** A public dashboard with aggregated data insights and policy-relevant reports, offering a transparent view of MND research and resource allocation progress.
Phase 6 Full rollout and continuous improvement	• **Full rollout:** All stakeholders have agreed access to the integrated platform. • **Continuous improvement:** Management of the platform is put in place. Feedback mechanisms for problems and/or requests for new functionality are established. The project becomes self-sustaining

Key Performance Indicators (KPIs)

- **Data Quality Metrics:** % of accurate, complete, and timely entries in the repository.
- **Diagnostic Accuracy:** Reduction in time-to-diagnosis (currently 13 months on average) and increase in early detection rates.
- **Research Collaboration Growth:** Number and diversity of research projects and publications supported by the platform.
- **Patient Engagement:** Number of patients accessing the portal and participating in research studies.
- **Clinical Trial Participation:** Number of new MND trials commencing in Australia and participants enrolled.
- **Policy Impact:** Uptake of policy recommendations and funding secured based on database insights.

Risks and Mitigations

Risk	Mitigation Strategy
Data Privacy Risks	Strict compliance with privacy laws, data encryption and deidentification, regular audit of access logs. Input and advice from key data experts.
Data Quality Challenges	Automated validation processes and training for clinicians and data entry staff. Active testing of user experience to ensure data entry is straightforward.
Stakeholder Engagement	Continuous communication and demonstration of value through transparent reporting and success stories. Integration of key stakeholders into the governance structure.
Stakeholder reluctance	Early and active engagement with key stakeholders to ensure a system that is responsive and fit for purpose.
Data integration challenges	MND Australia will work closely with highly capable technology experts who have delivered similar integration systems.

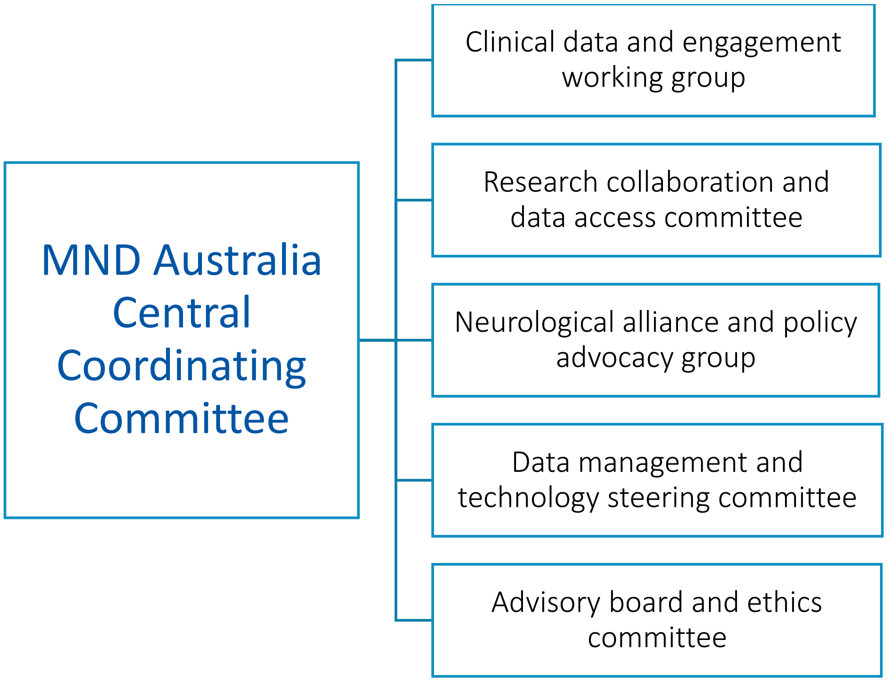
By implementing this data strategy, the MND research community will be equipped to harness data for earlier diagnosis, personalised treatment, and progress toward a cure. The platform will be an invaluable resource for clinicians, researchers, policy makers, and advocates in Australia and globally.

7. Data Governance and Ethical Use of Patient Data

To achieve the objectives of the National Unified MND Database, MND Australia will foster collaboration among MND clinics, research institutions, patient advocacy organisations, and neurological alliances, creating a coordinated ecosystem to advance knowledge, care, and therapy development. Through MiNDAUS, MND Australia already has data-sharing agreements with most MND clinics as well as current patient consent for data sharing in place.

A strong lived experience component will be embedded in all levels of governance to ensure processes and outcomes serve the MND community. The governance structure will be governed by its own terms of reference and regular reviews.

Figure 2: Governance structure



These bodies collectively ensure robust oversight, ethical standards, and alignment across all stakeholders.

The Australian National Unified MND Database will operate under a detailed governance framework focusing on data security, technical standards, patient autonomy, and compliance with national and international standards for clinical registries.

The framework will apply recognised data standards terminology and definitions for each data element, aligned with:

- The Australian Institute of Health and Welfare’s (AIHW) METeOR repository
- The National Institutes for Neurological Disorders and Stroke (NINDS) Common Data Elements
- SNOMED CT-AU clinical terminology

This alignment enhances both national and international interoperability and data sharing.

The robust governance framework will ensure that clinical and biological data collections are usable for research efforts beyond their initial purpose and facilitate integration with existing single-disease research initiatives.

The governance framework will be nimble and adaptive, enabling researchers and clinicians to respond to new scientific discoveries, community feedback, legislative or regulatory changes, and emerging patient and carer needs.

It must also be flexible enough to maintain multiple governance sub-frameworks within it, ensuring the system remains socially and financially self-sustaining.

Ultimately, the database will:

- Lead efforts in rare disease genomics
- Support high-quality clinical data collection
- Enable participation in global research and clinical trials
- Uphold the highest standards of data privacy and ethical use

In establishing the National Unified MND Database, the project will examine a range of governance models.

Models based on biorepositories, clinical registries, or legal entities — each with their own statutory requirements — will be considered. However, none alone can accommodate the integration of all components within this research platform simultaneously.

To address this, the project will develop a Consortium Governance Model that enables the collection and sharing of data across platforms and among researchers.

This model allows multiple institutions to co-exist as an entity and can include within its Terms of Reference the following:

1. Human Research Ethics Committee (HREC) approvals
2. Clinical Trial – HREC approvals
3. Collaborative Research Agreements
4. Research Service Agreements
5. Data and Material Transfer Agreements
6. Commercial Contracts
7. Clinical Standard Practices

The governance framework will be nimble, enabling researchers to respond to new scientific information, community requests, legislative changes, and unmet needs for people living with MND and their carers.

The governance framework will:

- Uphold informed consent from participants
- Maintain data and sample ownership with contributing institutions
- Require commercial waivers from participants
- Support open-access requirements mandated by funders and publishers
- Address intellectual property (IP) generated through data or sample access

It will also ensure the ethical use of data for research purposes, proper attribution in publications, and equitable distribution of income from sample access fees.

This model enables:

1. Contribution to collective research efforts while allowing independent research activities at each site.
2. Unified clinical data collection across all projects while maintaining biological samples for future studies.

3. Proper capture of ongoing consent at every data or sample collection point.
4. Standardised ethics wording and participant consent forms to harmonise data sharing across sites.

The project team will collaborate with Rare Voices Australia to ensure this governance framework meets research needs across rare diseases, promotes ethical and responsible data use, complies with all patient privacy regulations, and is reusable by other research bodies with similar objectives.

More detail on governance and key stakeholders is provided in Appendix E.

8. Resources and Budget

The **National Unified MND Database** requires a commitment of $12 million over two years. This budget covers infrastructure, governance, stakeholder engagement, data integration, analytics development, user interface design, and ongoing maintenance and support.

Year 1: Stakeholder Engagement, Infrastructure Setup, Data Integration and Analytics Development

Key components of the project include:

1. **Stakeholder Engagement**: Resources are allocated each year to maintain strong stakeholder communication and involvement, which is critical for project adoption and success.
2. **User Interface**: Funding ensures the development of user-friendly interfaces for various user groups — clinicians, researchers, patients, and administrators — allowing smooth data entry, extraction, and sharing across platforms.
3. **Compliance and Security**: Includes provisions for alignment with international privacy regulations and standards (e.g., GDPR, HIPAA), ensuring high levels of data protection.
4. **Scalability**: Infrastructure will be designed to handle increasing data volumes and growing numbers of users over time.
5. **Risk Management**: An annual contingency fund will be reserved for unforeseen costs or necessary project scope adjustments.

Year 2: Expanded Data Integration, Analytics Development, and Quality Improvement

In the second year, the focus shifts toward expanding integration with existing registries and databases, developing advanced analytics capabilities, and implementing continuous quality improvement measures.

This includes:

- Incorporation of additional MND clinics and biobanks across Australia
- Enhancement of AI and machine learning tools for predictive modelling
- Expansion of patient and clinician access through the web and mobile platforms
- Ongoing refinement of governance and audit mechanisms

Total Estimated Budget: $12 million (over 2 years)

- Year 1: $8.7 million
- Year 2: $3.3 million

9. Glossary of Terms

Term	Definition
ALS (Amyotrophic Lateral Sclerosis)	The most common form of MND, affecting both upper and lower motor neurons. In many countries (e.g., USA, Canada), “ALS” is used interchangeably with MND.
AMNDR (Australian Motor Neurone Disease Registry)	The first clinical MND registry in Australia, established in 2004, later replaced by the MiNDAUS Registry.
AT (Assistive Technology)	Equipment such as wheelchairs, hoists, or communication aids. Provided at little or no cost by state MND associations through their equipment libraries.
Clinical Trial Phases	Phase 1: Determines intervention safety in humans. Phase 2: Tests efficacy. Phase 3: Compares intervention vs. placebo with large groups. Phase 4: Post-approval monitoring of long-term effects and safety.
EMG (Electromyography)	Diagnostic procedure measuring electrical activity in muscles; also an acronym for the Executive Management Group of MND Australia and its state CEOs.
Familial MND	MND caused by inherited genetic mutations (e.g., SOD1, C9ORF72). Around 15% of cases are familial, though not everyone with a gene develops the disease.
FHIR (Fast Healthcare Interoperability Resources)	An HL7 standard for flexible, interoperable electronic health data exchange.
HL7 (Health Level Seven)	A set of international standards for transferring clinical and administrative health data between systems.
Lived Experience	First-hand understanding gained by individuals living with MND or caring for someone who does, encompassing their insights, emotions, and challenges.
MiNDAUS	The national MND registry launched in 2023 under MND Australia, integrating previous datasets from AMNDR. Focused on coordinated MND care, research, and policy development.

MND (motor neurone disease)	Neurodegenerative condition causing progressive loss of motor neurons, resulting in muscle weakness and paralysis.
MND Clinics	Specialist multidisciplinary clinics across Australia offering coordinated care via neurologists, nurses, therapists, and allied health professionals.
MND-FTD (MND with Frontotemporal Dementia)	A co-occurrence of MND and frontotemporal dementia affecting cognition, reasoning, and behaviour (~15% of cases).
Multidisciplinary Team (MDT)	Coordinated group of health and social-care professionals providing comprehensive support for MND patients.
National Lived Experience Network (LEN)	A network of over 500 people with lived experience of MND, created by MND Australia in 2024 to provide structured community input into research, media, and policy.
NIV (Non-Invasive Ventilation)	Often referred to as “BiPAP”; a respiratory support device improving breathing and extending life expectancy by up to 14 months.
NoSQL	Database design approach for non-tabular data storage and retrieval, allowing flexible data modelling (used alongside relational databases).
PBP (Progressive Bulbar Palsy)	Type of MND affecting speech and swallowing muscles first; generally shorter life expectancy than ALS.
PMA (Progressive Muscular Atrophy)	Rare MND form affecting only lower motor neurons, progressing slower than other types.
SALSA / SALSA-SGC	The Sporadic ALS Systems Genomics Consortium — a global project combining genomic and clinical data (supported by MND Australia via Ice Bucket Challenge funds).
Sporadic MND	Non-familial cases where cause is unknown (approx. 90% of MND cases). Genetic testing generally not recommended for families without history.

10. References

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[2] Sathe, S., Ware, J., Levey, J. et al. (2021). Enroll-HD: An integrated clinical research platform and worldwide observational study for Huntington’s Disease. Frontiers in Neurology, 12, 667420. Access at https://pmc.ncbi.nlm.nih.gov/articles/PMC8416308/

APPENDIX A – Typical Diagnostic Steps

Table 1: Typical steps to achieve an MND diagnosis

Step	Test / Procedure	Purpose and Details
Clinical Examination	Neurological Exam	A neurologist conducts a detailed physical and neurological exam, looking for signs like muscle weakness, atrophy, fasciculations, hyperreflexia, and speech or breathing changes.
EMG & NCS	Electromyography and Nerve Conduction Studies	EMG measures electrical activity in muscles, revealing denervation/reinnervation. NCS assesses nerve signal speed and strength. In MND, sensory conduction is normal, but motor neuron function is impaired.
MRI	Brain and Spinal Cord MRI	Used to rule out conditions mimicking MND such as spinal cord compression, brain tumours, multiple sclerosis, or stroke.
Blood & Urine Tests	Analysis	Used to exclude other causes of muscle weakness (e.g., metabolic or autoimmune diseases). No blood test can specifically diagnose MND.
Genetic Testing	Genetic Screening	In familial MND cases, identifies mutations in SOD1, C9orf72, or FUS. Recommended when there's family history.
Lumbar Puncture	Spinal Fluid Analysis	Helps rule out other neurological conditions like infections or inflammatory diseases.
Muscle Biopsy	Muscle Tissue Analysis	Occasionally done to exclude disorders like muscular dystrophy or inflammatory myopathies. Rarely needed for MND diagnosis.
Respiratory Function Tests	Pulmonary Function Tests	Evaluates breathing function; critical for monitoring disease progression.
Cognitive Testing	Cognitive & Behavioural Assessment	Evaluates for frontotemporal dementia (FTD), associated with some ALS cases.

APPENDIX B – Treatment and Management Options

Table 2: Summary of MND treatment and management options

Category	Treatment / Description
Medications	Riluzole: Extends survival by a few months by reducing glutamate release. Edaravone: Slows functional decline in ALS by reducing oxidative stress (approved in the U.S. and Japan; expected in Australia 2025). Tofersen: Available for those with a confirmed SOD1 mutation via Biogen's compassionate-access program; antisense therapy that blocks production of faulty SOD1 protein.
Symptom Management	Muscle cramps/stiffness: baclofen, tizanidine or gabapentin. Swallowing/speech: speech therapy, assistive devices, feeding tube if severe. Pain management: analgesics, muscle relaxants, physical/occupational therapy.
Physical and Occupational Therapy	Physical therapy maintains mobility and reduces spasticity with stretching and low-impact exercise. Occupational therapy assists with daily activities and adaptive equipment for independence.
Nutritional Support	Dietitian plans high-calorie, easy-to-swallow foods. Feeding tube (gastrostomy) prevents malnutrition and dehydration when swallowing issues arise.
Respiratory Support	Non-invasive ventilation (BiPAP): assists breathing, especially at night. Mechanical ventilation (tracheostomy): major surgical option, rarely used in Australia.
Psychological and Emotional Support	Counselling and support groups for people with MND and families; antidepressants as needed.
Palliative Care	Focuses on comfort, emotional support, and end-of-life decisions; hospice care may be considered in late stages.

APPENDIX C – Impacted Stakeholder Groups

Implementing the data strategy for MND would benefit various stakeholder groups. This appendix provides an overview of how key stakeholder groups may benefit from the National Unified MND Database.

Benefits to People Living with MND and Carers

A comprehensive MND database offers a centralised health record that people living with MND and their carers can manage and update with ease. This personal health record includes:

- Demographic details
- Physical needs (e.g., positioning, nutrition, communication)
- Autobiographical information
- Symptom tracking
- Current medications
- Healthcare provider contacts

Having all this information in one place eliminates the need for patients to repeatedly share their medical history with new clinicians or during hospital stays. It also removes the stress of communicating complex health histories during emergencies or when communication is impaired.

Patients gain transparency over their clinical data, fostering trust and autonomy, while the database enables smooth sharing of health records with new providers, simplifying transitions in care.

Importantly, patients can be notified when they meet the criteria for new clinical trials or research projects, allowing them to easily contribute to advancements in MND research by consenting to their data being used ethically.

Benefits to Clinicians

Clinicians benefit from streamlined access to patient information — both from clinical records and self-reported data. This consolidated access enables healthcare providers to:

- Quickly review recent symptoms and evolving needs
- Deliver more timely, personalised care
- Generate custom reports for efficient patient management
- Track disease progression and health trajectories

For clinical trials, the database will identify suitable participants and accelerate recruitment rates. This centralised approach encourages wider participation, particularly for patients outside large city hospitals. It also motivates more clinicians to participate in trials.

Benefits to State Associations

State MND Associations gain access to valuable clinical information through the national database. This enables them to:

- Stay updated on patients’ changing needs
- Tailor support services accordingly
- Trigger alerts for additional assistance when new or worsening symptoms are reported

A unified database allows consistent, effective support across regions — enabling equitable access to equipment, home care, and NDIS/Aged Care navigation regardless of state boundaries.

This proactive approach enhances the quality of care and responsiveness of services available to people living with MND.

Benefits to Researchers

For researchers, the MND database becomes a critical national resource for identifying study candidates and performing large-scale analyses.

The comprehensive dataset — potentially representing up to 80% of all new MND cases nationwide — empowers researchers to:

- Identify individuals who meet study criteria quickly
- Analyse patterns in disease progression and care outcomes
- Conduct large-scale, high-impact studies with robust ethics clearance
- Collaborate on international research initiatives

The ability to integrate data from multiple sources facilitates collaboration, enabling discovery of best-practice care models and potential treatment pathways.

Benefits to Policy and Advocacy

Policymakers are interested in more efficient and effective policy settings. The National Unified MND Database will provide the necessary data to explore and understand the correlates to different health and wellbeing outcomes for people living with MND. This may include:

- Different care and support packages (e.g., NDIS vs Aged Care)
- Demographic differences (e.g., age, urban vs rural/remote, socio-economic status)
- Access to allied health services, specialist MND clinics, and/or support from a state MND association
- Differences in diagnostic pathways
- Differences in support of primary carer

This nuanced analysis will illuminate differences in outcomes and allow for more precise policy settings to improve health equity and ensure more efficient use of funds.

Benefits to Industry

Pharmaceutical and biotechnology companies rely on accurate data and sufficient patient cohorts to justify clinical trials. A comprehensive MND database provides:

- Verified patient populations for feasibility analyses
- Reliable recruitment networks across clinical sites
- Data-driven confidence in patient follow-up and trial outcomes

This improves Australia's attractiveness as a clinical-trial destination, aligning with key recommendations from the New Frontiers (2021) report. More trials in Australia mean earlier access to potentially life-changing treatments for people with MND.

Summary

A national, centralised MND database offers a multifaceted solution that enhances patient care, improves coordination among healthcare providers and support organisations, and accelerates research efforts.

It makes life easier for people living with MND and their caregivers, while empowering clinicians, state associations, and researchers to work more effectively toward improved outcomes and deeper understanding of MND.

APPENDIX D – Existing MND Databases and Systems

MND BioBanks

Integration Objective: Connect BioBanks with the central database to ensure that biological sample data, including genetic and biomolecular information, is readily accessible to researchers and clinicians, facilitating precision medicine.

Incorporation Approach:

- Data Linkage: Link BioBanks at Flinders University, Macquarie University, University of Queensland, and brain banks to the central database using unique patient identifiers to ensure that genetic and biomolecular data is matched with patient clinical data from other registries.
- Sample Access Protocols: Develop access protocols for researchers to request specific samples, making it easier to conduct genetic research that requires clinical context.

Benefits: Integrating BioBanks data enhances the research capability for genetic and biomolecular studies on MND, enabling researchers to identify biomarkers and genetic traits associated with disease progression and response to treatments.

MND Bio Registry (SALSA)

Integration Objective: Incorporate SALSA’s genetic sample data into the centralised system to support genetic research and enhance predictive modelling for early diagnosis.

Incorporation Approach:

- Data Standardisation: Standardise SALSA's genetic data to align with international formats, enabling linkage with other datasets and facilitating cross-registry genetic research.
- Genetic Data Accessibility: Ensure that SALSA’s 1,500 genetic samples are accessible in a structured format within the central database, with metadata and clinical context provided by other integrated registries.

Benefits: By linking genetic samples with clinical records and patient demographics, researchers can conduct more comprehensive studies on genetic predispositions to MND, supporting the development of preventive measures and personalised therapies.

MND Clinical Registry (MiNDAUS)

Integration Objective: Integrate MiNDAUS as the foundation for clinical and patient data within the comprehensive database, filling gaps in biological sample data by linking it with BioBanks and SALSA.

Incorporation Approach:

- Data Enrichment: Enrich MiNDAUS entries with biological data from BioBanks and SALSA to provide a more holistic view of each patient's health history and genetic background.
- Real-Time Data Synchronisation: Enable real-time data updates for new patient entries and clinical outcomes, ensuring MiNDAUS is always current.

Benefits: MiNDAUS’s integration supports clinicians and researchers by providing real-time access to a centralised, enriched repository of clinical data, allowing for better monitoring of disease progression, response to treatment, and facilitating more targeted therapeutic interventions.

MND Clinic Databases

Integration Objective: Connect the 25 MND clinic databases, including the 12 research-active clinics, to the central database to ensure that treatment and clinical outcomes data are available nationwide.

Incorporation Approach:

- Standardised Data Formats: Develop common data standards for clinic entries to allow data from each clinic to integrate smoothly with the comprehensive database.
- Clinical Outcomes and Treatment Tracking: Capture treatment data and clinical outcomes in the central system, providing an aggregated view of patient responses across Australia’s clinics.

Benefits: With treatment data from clinics integrated into a national database, researchers and clinicians can analyse the effectiveness of various treatments, track patient outcomes in real-time, and identify emerging trends in disease management.

State Association Databases

Integration Objective: Incorporate data from state association databases managed by systems like Salesforce and Echidna to provide a holistic view of patient demographics, treatment navigation, and support needs.

Incorporation Approach:

- Data Unification and Patient Tracking: Map and unify patient data across state databases to create a single, longitudinal patient record that captures support needs, services provided, and demographic information.
- Service and Support Integration: Ensure that state-provided support, such as NDIS and Aged Care navigation, is accessible alongside clinical data, allowing a complete view of patient care beyond clinical treatment.

Benefits: This integration enables better coordination across states, ensuring patients have consistent access to care and resources regardless of geographic location. It also supports data-driven advocacy by highlighting areas where additional support resources may be needed.

Numerous Spreadsheets (Small-Scale Registries and Research Datasets)

Integration Objective: Convert critical data from smaller research datasets and patient/caregiver information into structured entries within the central database to preserve valuable insights from small studies.

Incorporation Approach:

- Data Import and Cleaning Tools: Develop tools to standardise and import spreadsheet data into the database, maintaining quality through data cleaning and deduplication processes.
- Research Metadata Repository: Capture metadata from smaller studies to document research methodologies, sample sizes, and findings, enabling future research replication or meta-analyses.

Benefits: By preserving small-scale study data within a larger repository, the database can support richer, more diverse insights into MND progression, patient experiences, and caregiver support needs, expanding the breadth of data available to researchers.

Integrating these registries into a centralised, comprehensive platform would not only streamline data management across Australia but also unlock powerful capabilities for research, diagnosis, and patient support, ensuring that each patient receives high-quality, well-informed care.

APPENDIX E – Governance Structure

MND Australia – MND Australia Central Coordinating Committee

To achieve the objectives of the MND Data Strategy and Database, MND Australia can play a pivotal role by uniting MND clinics, research institutions, and neurological alliances to create a robust, collaborative ecosystem that advances knowledge, care, and therapeutic development for motor neurone disease.

The MND Australia Central Coordinating Committee (CCC) will serves as the overarching body, providing strategic oversight and ensuring alignment with the MND Data Strategy and Database objectives. Strong lived experience input will be incorporated at all levels of governance.

Responsibilities:

- Develop and monitor overall strategy, including mission, goals, and key performance indicators (KPIs).
- Establish policies for data sharing, privacy, and ethical standards.
- Secure funding and resources to support the initiative.
- Ensure compliance with national and international standards for data management and patient privacy.

MND Clinics – Clinical Data and Engagement Working Group

The Clinical Data and Engagement Working Group will oversee collaboration with MND clinics, facilitating consistent data collection, care practices, and patient engagement. MND Australia already has data sharing agreements and strong relationships in place with most clinics.

Responsibilities:

- Develop standardized protocols for data collection, patient consent, and data entry across all clinics.
- Facilitate training for clinic staff on data management and privacy.
- Act as a liaison between clinics to share best practices and support quality of care improvements.
- Address any challenges clinics face in data collection and integration.

MND Australia collaborates closely with a network of multidisciplinary clinics across Australia to support individuals affected by MND. These clinics provide specialized, comprehensive care tailored to the needs of MND patients through a collaborative approach involving neurologists, nurses, allied health professionals, and other specialists. The primary aim of these clinics is to enhance the quality of life and manage the complex needs associated with MND through expert care and coordinated services. By supporting these clinics, MND Australia ensures that MND patients receive timely access to specialized resources, therapeutic interventions, and supportive care in their respective regions, aligning with their advocacy for equitable and accessible healthcare across Australia.

Summary of clinics by state that MND Australia partners with:

- New South Wales Calvary Health Care MND Service, Kogarah
- Liverpool Hospital MND Clinic, Liverpool
- Macquarie Neurology Clinic, Macquarie University
- Clinica Neurology, Randwick
- Murwillumbah MND Clinic, Murwillumbah
- Hunter New England MND Multidisciplinary Clinic, New Lambton
- Illawarra Multidisciplinary MND Service, Wollongong

- ALS/MND Multidisciplinary Clinic, Concord Hospital, Concord
- Auburn Hospital MND Clinic, Auburn
- Western Australia Fiona Stanley Hospital MND Clinic, Murdoch
- Perron Institute MND Clinic, Nedlands
- Midlands MND Clinic, St John of God Hospital, Midland
- Queensland Princess Alexandra Hospital MND Clinic, Woolloongabba
- Prince Charles Hospital Specialist Outpatient Clinics, Chermside
- Royal Brisbane and Women's Hospital, Herston
- Sunshine Coast University Hospital MND Clinic, Birtinya
- Gold Coast University Hospital, Southport
- ACT Multidisciplinary MND Clinic, University of Canberra Hospital, Bruce
- Victoria Motor Neurone Disease (MND) Clinic, McKellar Centre, North Geelong
- State-wide Progressive Neurological Disease Clinic, Calvary Health Care Bethlehem, Caulfield South
- Northern Health Progressive Neurological Disease Clinic, Bundoora Extended Care Centre, Bundoora
- South Australia South Australian MND Multidisciplinary Clinic, Flinders Medical Centre, Bedford Park
- Tasmania Launceston General Hospital MND Clinic, Launceston

Through partnerships with these clinics, MND Australia ensures a strong, coordinated care network, advocating for the medical and therapeutic needs of the MND community across Australia.

Research Collaboration and Data Access Committee

The Research Collaboration and Data Access Committee will manage the collaboration with research institutions, ensuring secure, ethical, and efficient access to the data repository.

Responsibilities:

- Define eligibility and protocols for research data access.
- Develop data-sharing agreements and maintain a record of approved research projects.
- Review and approve requests for data access from research institutions.
- Track research outcomes and support publications emerging from the shared data.

Australia is at the forefront of motor neurone disease (MND) research, with several institutions and initiatives dedicated to understanding and combating this debilitating condition. Some of the primary research institutions that MND Australia will collaborate with include:

- The Florey Institute of Neuroscience and Mental Health (Melbourne)
- Macquarie University Motor Neuron Disease Research Centre
- University of Sydney's Brain and Mind Centre
- Queensland Brain Institute (University of Queensland)
- Neuroscience Research Australia (Sydney)

Advisory Board and Ethics Committee

The Advisory Board and Ethics Committee will provide guidance on ethical considerations, patient privacy, and compliance with data governance standards.

Responsibilities:

- Review ethical implications of data collection and sharing, ensuring patient-centric practices.
- Approve new data use cases and provide ongoing ethical oversight for the database.
- Conduct periodic reviews of data privacy and compliance with relevant standards.
- Advise on data governance policies to protect patient rights and confidentiality.

Key Project Roles

Project Manager: Reporting to the Executive Committee - this position requires skills in project management and governance in the services industry, an understanding of emerging technologies (preferably in health), established networks, and the ability to communicate and negotiate with a wide range of stakeholders. The Project Manager will be responsible for:

- The overall performance of the project.
- Creation of quarterly reports to the Executive Committee on progress, with what's delivered against measurable performance metrics.
- Development of an effective, coordinated team, supported by required professional training.
- Monitoring database functionality, with defined key performance indicators and to measure, advise on and create a robust governance and business structures to support management of IP, ethics, data ownership and release, legal liability and commercial activity.
- Establish a wide stakeholder network in service provision, research, industry, funding entities, philanthropy and government.
- Play a key role in promoting the uptake and use of the registry in service provision and research in Australia and overseas, industry, and in informing government policy.
- Conduct workshops and compile feedback on user experience.
- Investigate and develop revenue streams and negotiate with funders and government.

The Project Manager will be engaged under contract by MND Australia and will work closely with the management of MND Australia in the execution of their duties. Employment arrangements for other personnel will be determined by the Project Manager and endorsed by the Executive Committee and may involve engagement through an Institution.

Operations Manager: Site liaison, training and support. Collection of feedback from all stakeholders. Prioritise and manage future development of the Registry and its evolution. Management of the national ethics process, amendments and supporting sites with site governance implementation. Creation, updating and dissemination of Standard Operating Procedures and creating data sharing agreements. Conduct the first workshops and compile feedback on user experience.

Data Analysis Integrity and Audit: Responsible for maintaining and auditing the database. Presenting data requests for approval to the Executive Committee and providing approved data to external entities. Creating regular reports for dissemination to stakeholders.

Business Analysts: Business Analysts will collaborate with the Project Manager and Operations Manager to gather and document business requirements, analyse processes, and identify areas for improvement. They will translate business needs into technical requirements, assist in system design, and conduct gap analysis. The role involves facilitating workshops, collecting user feedback, and working with the Software Developer to refine system functionality. They will support training efforts, create user documentation, and assist in preparing reports for the Executive Committee.

User Experience (UX) Designers: Will work with Users and Business Analysts to design intuitive user interfaces with consideration of design, functionality and accessibility.

User Support: Have a thorough understanding of the web interface and be able to respond in a timely manner to requests for support from patients/carers. Provide support to the Operations Manager in the training of users at State MND Associations.

Communication and Marketing: Implementation of the Strategic Communications and Marketing Plan, promotion of the registry using multiple channels to engage with a broad range of stakeholders, including patients, carers, service providers, researchers, and extending to industry and government.

Clinical Lead: Responds to all team members requiring assistance by direct interaction with patients, carers, clinicians, and researchers to provide direct assistance, communication and resolution of issues.

Software Developers: This is an essential position to deliver the key software deliverables proposed in the First Year and subsequent future deliverables as decided by the Executive Committee, informed by end user feedback and to progress the objectives of the project. This will evolve and would include developing the software linkages required for use of home-based monitoring and care management technologies and Telehealth.