



# Motor Neurone Disease Insights Platform

The Motor Neurone Disease (MND) Insights Platform will bring together existing MND datasets across Australia to accelerate identifying potential causes, improving the quality of life for those living with MND and finding a cure.

## Who?

MND is a progressive and debilitating condition that currently impacts around 2,700 people in Australia, with an average time from diagnosis to death of only 27 months. The lifetime risk of developing MND is approximately 1 in 300 by the age of 85, with the risk increasing as people age. Despite these figures, MND remains relatively unknown, and there is no definitive, single source of truth for the prevalence of MND in Australia. We don't know what causes MND, we don't know which therapeutic interventions have the greatest impact, and we don't have a cure.

MND Australia has an actively engaged community of 155,000 members, followers and subscribers across Australia who will welcome Australian Government support.

## What?

Leveraging MND data and insights will dramatically improve what we know about MND. Specifically, greater data infrastructure and analytical capacity will:

- Improve and accelerate diagnosis
- Gain greater understanding of the potential causes of MND
- Target the development of more effective personalised treatments
- Accelerate research for a cure
- Facilitate global collaboration

This Platform will bring together all the MND datasets including MND BioBanks, MND Bio Registry (SALSA), MND Clinical Registry (MiNDAUS), Patient Registry, MND Clinic Databases, State MND Association Databases and numerous small-scale registries and research datasets.

## How and when?

An Australian Government investment of \$12 million over four years:

Year 1 2025/26	Year 2 2026/27	Year 3 2027/28	Year 4 2028/29
Infrastructure setup, stakeholder engagement, initial data integration	Expanded data integration, analytics development	Advanced analytics, collaborative tools, policy support	Final optimisation, maintenance, long term support
\$3.2 million	\$3.3 million	\$2.5 million	\$3 million

## Why?

The MND Insight Platform will support Government objectives to:

- Provide the data and modelling needed to better target NDIS and aged care funding
- Keep MND clinical trials in Australia
- Reduce the economic burden of MND on health and social services.