NAA Neuro Survey Insights Report

Experiences, Gaps and Priorities for Neurological Care and Research in Australia

AUGUST 2026

NEUROLOGICAL ALLIANCE AUSTRALIA

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NEUROLOGICAL ALLIANCE AUSTRALIA

About Neurological Alliance Australia

Neurological Alliance Australia is a national alliance of around 50 not-for-profit organisations representing the interests and needs of millions of Australians living with neurological and neuromuscular conditions as well as their carers and families. A list of member organisations is on page 42.

The Alliance advocates on shared priorities to improve quality of life, strengthen access to timely and appropriate care and support, and increase investment in neurological research, treatment and better models of care.

Acknowledgement of Support

Neurological Alliance Australia gratefully acknowledges and thanks the individuals and organisations that supported and contributed to the inaugural NAA Neuro Service Gaps and Innovation Survey including:

- people with lived experience, carers and NAA members who contributed to the co-design and development of the survey
- NAA members, health and community organisations, Federal Parliamentarians, clinicians, researchers and other partners who promoted the survey through their networks
- the 3,805 survey participants who generously gave their time to share their experiences and perspectives
- MS Australia for its support and contribution throughout the initiative
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* Financial supporters had no role in the survey design or methodology, data collection, analysis or interpretation of responses, or the development of the findings and recommendations presented in this report.

Neurological Alliance Australia retained sole responsibility for the design, conduct, content and publication of the report and maintained full editorial independence throughout. Financial supporters did not review, influence or approve the report before publication. NAA owns all intellectual property arising from this project.

Contents

Executive summary

Neurological care in Australia is fragmented, delayed, and inconsistently meeting the needs of those it is designed to support.

Opening

Neurological and neuromuscular conditions have a significant and sustained impact on individuals, families, and the healthcare system. The *Neuro Service Gaps and Innovation Survey* report highlights widespread challenges in accessing timely, coordinated, and affordable care across Australia, alongside gaps in research investment, innovation, and the translation of evidence into practice.

Despite advances in treatment and growing recognition of neurological and neuromuscular conditions, many people continue to experience a system that is difficult to access, fragmented in delivery, and inconsistent in meeting their needs. Respondents reported experiencing delays in receiving timely diagnosis and treatment, challenges navigating complex systems, and gaps in access to appropriate care and support, alongside limited awareness of, and participation in, research and innovation opportunities.

For many, outcomes depend not only on clinical need, but on geographic location, condition type, proficiency with the English language, level of health literacy, and an individual's ability to advocate for themselves or coordinate their own care. These findings, together with identified gaps in research investment, translation, and innovation pathways, point to many systemic barriers to how support for people with neurological and neuromuscular conditions is organised and delivered, with important implications for quality of care, health outcomes, and equity of access.

Who took part

The survey captured responses from 3,805 Australians, including people living with neurological and neuromuscular conditions, carers, health professionals, researchers, advocacy organisations, industry representatives, service providers, and policymakers. Respondents were represented across all states and territories and included both metropolitan and regional communities. The respondent gender profile was female at 77.3%, male at 21.2% and Other/prefer not to say at 1.4%.

Connection to neurological conditions

RESPONDENT GROUPS	NUMBER OF PEOPLE
People living with a neurological or neuromuscular condition	2,895
Current or past carers and/or family members	655
Health professionals	147
Advocacy and/or patient organisations	37
Researchers	28
Pharmaceutical Industry representatives	20
Service providers	12
Policymakers	11
TOTAL	**3805**

Numbers reflect total respondents. Completion rates are provided in the main report.

Conditions represented

FIGURE 1A: PEOPLE LIVING WITH A NEUROLOGICAL OR NEUROMUSCULAR CONDITION

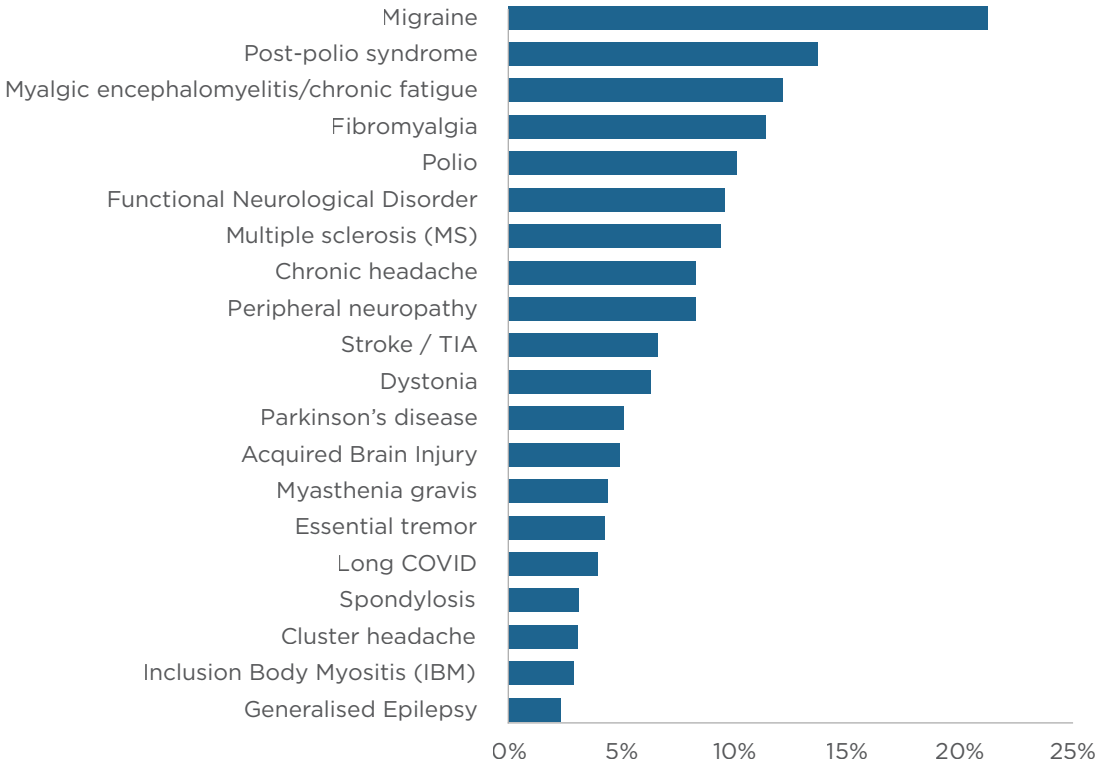
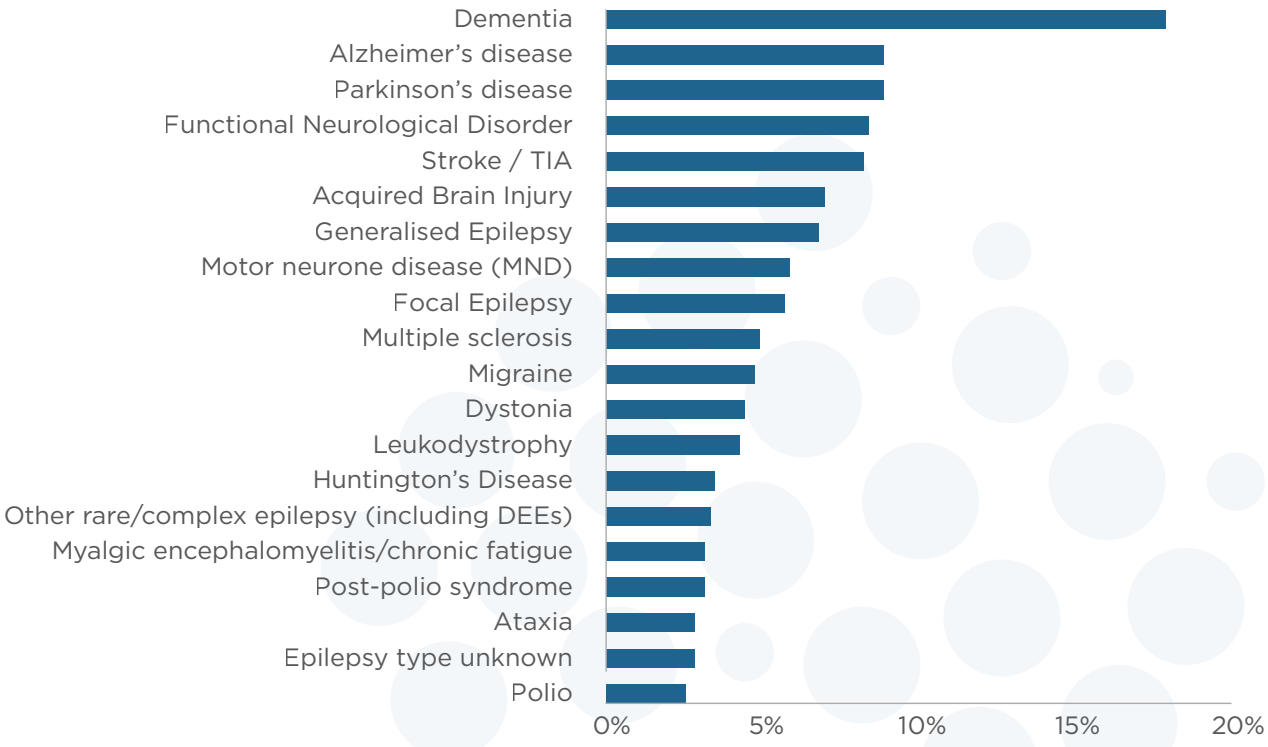


FIGURE 1B: CARERS OR FAMILY OF PEOPLE LIVING WITH THIS NEUROLOGICAL OR NEUROMUSCULAR CONDITION



A wide range of neurological and neuromuscular conditions were represented in the survey, with several participants reporting having more than one condition. The figures show the most frequently reported conditions among people living with a neurological and neuromuscular condition (Figure 1A); and carers or family of people living with a neurological and neuromuscular condition (Figure 1B).

Key findings

The findings reveal consistent gaps across neurological care, support, research and innovation. They reinforce persistent challenges in early diagnosis, accessing timely and affordable treatment and care, navigating fragmented systems, and coordinating services. The findings also highlight workforce constraints, inequities in access, and gaps in research awareness, participation and translation into practice.

Access to care

1 in 2 people report difficulty accessing neurological care

Over half of respondents (51.1%) reported that accessing neurological medical care in their area is somewhat or very difficult, with barriers including specialist availability, long wait times, and challenges navigating referral pathways.

Delayed diagnosis

Nearly 1 in 3 wait more than four years for a diagnosis

A substantial proportion of respondents experienced prolonged diagnostic pathways, with nearly 30% reporting waiting more than four years to receive a diagnosis for their neurological condition.

Cost barriers

Almost half delay or skip care due to cost

Nearly half of respondents (47.5%) reported delaying or skipping care due to cost, reflecting the financial burden associated with accessing healthcare, including specialist consultations, tests, and treatment.

Fragmented care

Only 4 in 10 people report their care is coordinated

Coordination of care remains a significant challenge, with only 38.7% of respondents describing their care as coordinated, while a comparable proportion reported fragmented care.

Carer impact

Nearly 1 in 2 carers provide 36+ hours of care per week

Carers reported substantial caregiving responsibilities, with 46.7% providing 36 hours or more of care per week, highlighting the significant reliance on informal and largely unpaid care.

Support experience

Over 9 in 10 people do not feel fully supported by their healthcare team

Support from healthcare teams was inconsistent, with only 9.4% of respondents reporting they felt fully supported, while many reported only partial or inadequate support.

Research and innovation

Nearly 1 in 2 people are unaware of research opportunities

Awareness of research opportunities is limited, with nearly half of respondents (45.3%) reporting no awareness and a further 37.4% only somewhat aware.

A case for reform – recommendations in brief

Across all stakeholder groups, there is strong alignment on priorities for reform.

Increase investment in neurological research

Increase investment in neurological research and strengthen pathways to translate research into diagnosis, treatment, and care, with a focus on unmet need and supporting real-world impact.

Improve access to diagnosis and specialist care

Improve access to timely diagnosis and specialist care, including neurologists, diagnostic testing, and multidisciplinary services, to reduce delays and improve outcomes for people with neurological conditions and their families.

Strengthen workforce capacity

Build neurological workforce capacity across neurology, allied health, and care services through investment in training, expansion, and improved distribution, particularly in regional and rural areas.

Establish coordinated models of care

Establish coordinated, integrated models of care across health, disability, and aged care systems to reduce fragmentation and improve continuity of care for people with neurological conditions including access to care coordination, navigation, rehabilitation and long-term support across the course of a person's condition.

Reduce inequities in access

Address geographic, age-based, and condition-related inequities to ensure equitable access to neurological care and support, regardless of location or eligibility.

Embed lived experience in system design

Embed lived experience and carer perspectives in research, policy, and service design to ensure systems reflect real-world needs and priorities.

Strengthen data and national coordination

Improve data systems, national coordination, and long-term planning to support decision-making, track outcomes, and align research, policy, and service delivery.

The full recommendations and supporting rationale are presented later in this report. While their order broadly reflects the prominence of issues in the survey findings, should not be interpreted as ranked priorities. Each will require sustained and concurrent attention to achieve meaningful, system-wide improvement.

Across the recommendations, two cross-cutting imperatives are particularly clear: improving coordination and navigation across systems and reducing inequities in access to care and support.

Together, the findings demonstrate the need for a nationally coordinated approach to neurological care and research. Without action, delays, inequities, workforce shortages, and fragmented care will continue to limit outcomes for millions of Australians living with neurological and neuromuscular conditions, as well as their families and carers.

Neurological Alliance Australia, 13 August 2026

Survey methodology and participant profile

About this report

This report provides a national snapshot of the experiences of people living with neurological and neuromuscular conditions, their carers and family members, and stakeholders across the healthcare system.

It presents insights into how neurological care is experienced in Australia, including challenges in accessing services, coordinating care, managing costs, and navigating complex systems.

The findings bring together perspectives from people with lived experience, carers, and stakeholders to identify priority areas for improving neurological care.

Survey purpose and approach

The findings are based on the *Neuro Service Gaps and Innovation Survey (NAA Neuro Survey)*, designed to identify gaps in care, support, research, and innovation and to inform the advocacy and policy work of Neurological Alliance Australia (NAA).

The *NAA Neuro Survey* was informed by the five iterations of the *My Neuro Survey* conducted in the United Kingdom and Republic of Ireland. However, it was designed specifically for the Australian context and incorporates a broader range of stakeholder perspectives.

In the Survey the term 'neurological conditions' was used inclusively to encompass neurological, neuromuscular, and rare or complex multi-system conditions that primarily affect the brain, spinal cord, peripheral nerves, muscles, or nerve–muscle function. The term is used in the same way throughout this report.

The survey was conducted nationally and included responses from people living with neurological conditions, carers and family members, and stakeholders across the healthcare system, including health professionals, service providers, researchers, advocacy organisations, pharmaceutical industry representatives, and policymakers.

Participants provided both quantitative responses and free-text insights on access to care, coordination, delays, costs, support needs, and research and innovation priorities, enabling a comprehensive analysis of system performance alongside lived experience.

Survey dissemination

To ensure broad and inclusive participation, the survey was disseminated through a multi-channel strategy. Email invitations were sent to the networks of NAA members, several health peak organisations, all Federal Members of Parliament and Senators, the Department of Health Disability and Ageing, industry and other partners. The survey was also promoted via the NAA website, newsletters, and social media platforms, and made available in hard copy to support participation from individuals and groups with limited access to digital platforms. The survey was administered online using the SurveyMonkey platform.

The survey was open from 10 March 2026 to 21 May 2026, providing a 10-week window for responses. In total 3,805 responses were received and analysed.

Participant information and data collection

Participants were informed that the survey was anonymous, and no personally identifiable information was collected. Basic demographic and contextual information, such as gender, age, postcode (as a proxy for geographic location), and respondent role (e.g. person with a neurological/neuromuscular condition, current/past carer and/or family member, advocacy or patient organisation, health professional/service provider, researcher, industry representatives or policymaker), was collected to help assess the diversity of the participant pool and to explore whether experiences, service gaps, and priorities for research or system improvement varied across different groups.

Analysis methods

This section outlines the analytical approaches used to interpret both quantitative and qualitative data collected through the survey.

Percentages are calculated based on the number of respondents to each question and may vary due to differing response counts across items.

Data Preparation

Survey responses were reviewed, cleaned, and where possible standardised to support consistent analysis across respondents.

Postcode responses were used to classify participants by state and territory and geographic location, based on standard Australian postcode ranges.

For geographic analysis, postcodes were mapped to the Postal Areas (POA) 2021 by Modified Monash Model (MMM) 2023 concordance. Where postal areas overlapped multiple MMM categories, respondents were assigned the dominant MMM classification based on the largest area of overlap within that POA. As some postal areas span more than one MMM category, geographic classification at postcode level should be interpreted as an approximation.

For reporting purposes, MMM categories were also summarised into metropolitan (MM1) and regional, rural, and remote areas (MM2–MM7). Minor variations in postcode allocation are not expected to materially affect results.

Quantitative Analysis

Quantitative data was analysed using descriptive statistics to summarise response patterns across the survey, including proportions and frequencies. Where relevant, findings were examined across respondent groups to identify differences in experiences, access to care, and priorities for research and system improvement.

Qualitative Analysis

Free-text responses were analysed using a thematic approach. Responses were reviewed and grouped into themes based on recurring keywords and concepts, with particular attention to both frequency and consistency across responses. This approach enabled the identification of common challenges, lived experience insights, and priority areas for improvement.

Survey Limitations

The NAA Neuro Survey provides a national snapshot of the experiences and perspectives of people affected by neurological conditions and stakeholders across the neurological ecosystem. It was not designed to estimate the prevalence of neurological conditions or to produce a statistically representative sample of the Australian population.

Participation was voluntary, and the survey was promoted primarily through NAA members and partner networks. Therefore, the findings may reflect self-selection and differences in the reach and engagement of particular condition communities. Some conditions, demographic groups and stakeholder categories were more strongly represented than others, and findings from groups with small respondent numbers should be interpreted with caution.

It is also acknowledged that several NAA members and other organisations conducted condition-specific surveys during the preceding 12 months. Survey fatigue may therefore have contributed to some neurological conditions being less strongly represented than expected based on their prevalence.

Response numbers varied between questions because of the survey's branching structure and partial completion by 1382 of the total 3805 respondents. Percentages are calculated using the number of respondents to each question. Participants with multiple neurological conditions could also report more than one condition, meaning that total condition percentages exceeded 100%.

Qualitative findings reflect recurring themes identified in free-text responses but should not be interpreted as estimates of how commonly those experiences occur across the broader neurological population.

Overview of survey participants

A total of 3,805 persons participated in the survey, with 2,423 respondents completing it in full, representing a completion rate of 64%. Given the estimated 10-minute completion time and the branching structure of the survey, where respondents completed a core section and one role-specific section, this represents a relatively strong completion rate. Responses from incomplete surveys were also included in the analysis to maximise the use of available data.

Connection to neurological and neuromuscular conditions

Table 1 provides a breakdown of survey participants by their connection to neurological and neuromuscular conditions. The majority of survey respondents were people living with a neurological or neuromuscular condition (76.1% of 3805), followed by current or past carers and/or family members (17.2%). Health professionals (clinicians or allied health) comprised 3.9% of respondents. Smaller proportions included advocacy and/or patient organisations (1.0%), researchers (0.7%), industry representatives (0.5%), service providers (0.3%), and policymakers (0.3%).

This distribution indicates that the survey predominantly reflects lived experience perspectives, while also capturing input from across the broader neurological ecosystem. However, it should be acknowledged that responses were weighted towards some conditions more than others.

TABLE 1. SURVEY PARTICIPANTS BY CONNECTION TO NEUROLOGICAL OR NEUROMUSCULAR CONDITION.

Connection to neurological and neuromuscular conditions	Number of people
People living with a neurological or neuromuscular condition	2,895 (1,766)
Current or past carers and/or family members	655 (475)
Health professionals	147 (111)
Advocacy and/or patient organisations	37 (24)
Researchers	28 (20)
Industry representatives	20 (14)
Service providers	12 (8)
Policymakers	11 (5)
Total	**3805 (2423)**

Numbers in brackets indicate those who fully completed the survey. The total figures include participants who provided partial responses, including some who answered most questions but did not complete the final section(s).

Demographic characteristics

Beyond respondents' connection to neurological and neuromuscular conditions, participants spanned a wide range of age groups, geographic locations, and roles within the neurological ecosystem, enabling the survey to capture diverse perspectives across the care continuum. The inclusion of multiple stakeholder groups, combined with the predominance of lived experience respondents, supports a comprehensive understanding of system gaps, service access, and priorities for research and policy reform.

Most participants were adults, with approximately three-quarters aged over 45 years, reflecting the higher prevalence of many neurological conditions in older populations. The respondent group was predominantly female, with 77.3% identifying as female and 21.2% as male, with a small proportion identifying as non-binary or using another term. These demographic characteristics reflect the overall respondent sample (n = 3805), which was predominantly composed of people living with neurological and neuromuscular conditions.

Respondents were geographically distributed across all Australian states and territories, with the highest representation from New South Wales (26.9%), Victoria (24.6%), and Queensland (20.6%). Smaller but meaningful representation was observed across Western Australia, South Australia, Tasmania, the Australian Capital Territory, and the Northern Territory, indicating national coverage.

TABLE 2. STATE/TERRITORY DISTRIBUTION OF SURVEY PARTICIPANTS (N = 3805)

State	% of all respondents
NSW	26.9%
VIC	24.6%
QLD	20.6%
WA	9.9%
SA	9.7%
TAS	4.6%
ACT	2.7%
NT	0.6%
Other	0.4%

Respondents were geographically distributed across Modified Monash Model (MMM) categories, with 60.4% residing in MM1 metropolitan areas and the remainder in MM2–MM7 regional, rural, and remote locations. Within non-metropolitan areas, representation was observed across all remoteness levels, including regional centres, rural towns, and remote communities.

Geographic classification was based on the Modified Monash Model (MMM) 2023, where MM1 represents metropolitan areas and MM2–MM7 represent regional, rural, and remote areas of increasing remoteness. Classification was applied using postcode-based concordance and should be interpreted as approximate.

This distribution indicates that the survey captured perspectives from individuals living across a range of geographic settings, including those in non-metropolitan areas where access to neurological care, services, and research opportunities is often more limited.

Results

Survey responses identified consistent gaps across care, support, and research for people affected by neurological and neuromuscular conditions. Findings demonstrated systemic challenges in access, coordination, and timeliness of neurological care, with impacts spanning diagnosis, ongoing care, and research engagement across all stakeholder groups.

For the purpose of this report, the term "neurological and neuromuscular conditions" is used to reflect the full range of conditions represented in the survey. Unless otherwise specified, these will be referred to collectively as "neurological conditions" for simplicity.

Key findings

- **1 in 2 people report difficulty accessing neurological care**
- **Nearly 1 in 3 wait more than four years for a diagnosis**
- **Almost half delay or skip care due to cost**
- **Nearly 1 in 2 carers provide 36+ hours of care per week**
- **Only 4 in 10 report their care as coordinated**
- **9 in 10 do not feel fully supported by their healthcare team**
- **Nearly 1 in 2 people are unaware of research opportunities**

Participant characteristics and context of care

Respondents represented a diverse range of living, employment, and support circumstances, providing important context for interpreting experiences of care and access. This section focuses primarily on people living with neurological conditions and their carers or family members, who provide direct insight into lived experience and the context of care.

Carers and family members (n = 650) reported a range of relationships to the people they support, most commonly partners or spouses (37.2%) and parents (37.9%), followed by children (15.4%) and other family members or friends (8.6%). Fewer than 1% identified as paid carers, indicating that the cohort was overwhelmingly composed of informal carers.

They reported supporting individuals across all age groups, most commonly those aged 65–79 years (29.5%) and 45–64 years (18.3%), alongside both younger (0–17 years, 16.3%) and older populations (80 years and over, 12.2%), reflecting the lifelong nature of neurological conditions.

Respondents living with a neurological or neuromuscular condition (n = 2761) reported a wide range of neurological conditions (Figure 1). The most commonly reported included migraine (21.3%), post-polio syndrome (13.8%), myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (12.2%), fibromyalgia (11.4%), polio (10.1%), functional neurological disorder (9.6%) and multiple sclerosis (MS) (9.4%), alongside chronic headache (8.3%). Carers also described supporting individuals with a broad range of conditions, including dementia (17.9%), all epilepsy (12.5%), Alzheimer's disease (8.9%), Parkinson's disease (8.9%), functional neurological disorder (8.4%), stroke (8.3%), and others. Together, these findings reflect the heterogeneous and complex nature of neurological conditions.

FIGURE 1A. PEOPLE LIVING WITH A NEUROLOGICAL OR NEUROMUSCULAR CONDITION

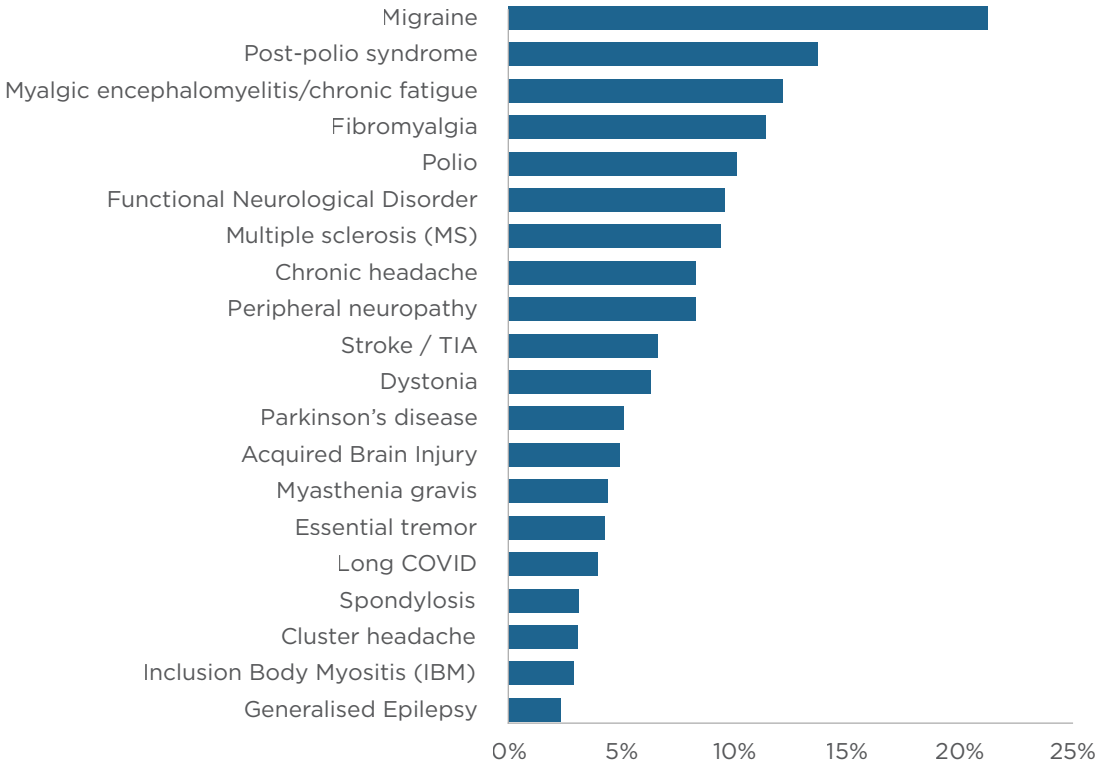


FIGURE 1B. CARERS OR FAMILY OF PEOPLE LIVING WITH THIS NEUROLOGICAL OR NEUROMUSCULAR CONDITION

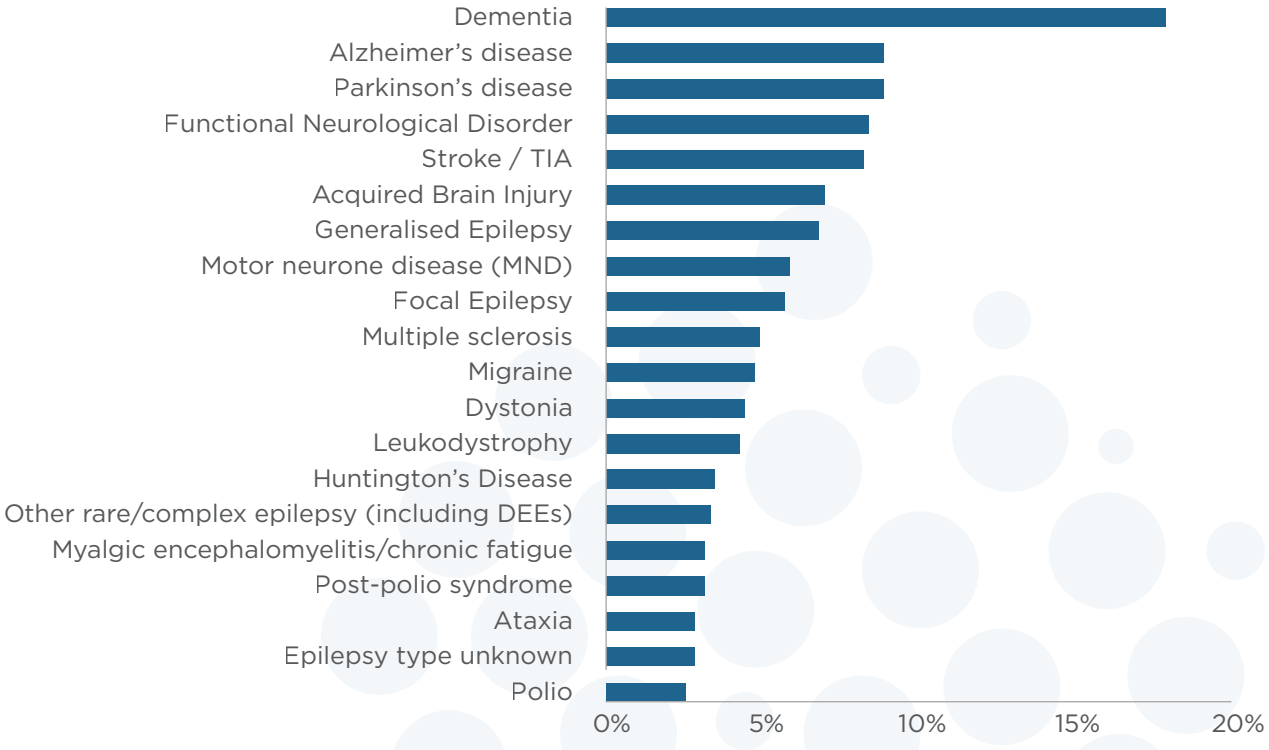


Figure 1. Neurological and neuromuscular conditions most frequently reported by respondents (A) who are living with these conditions (n = 2761) or (B) who are carers or family of people living with these conditions (n = 630). Includes the top 20 ranked conditions listed for selection. Respondents could report more than one condition and therefore percentages do not total 100%. A wide range of conditions were represented, with migraine, post-polio syndrome, ME/CFS, fibromyalgia, and MS among the most commonly reported, alongside a substantial proportion reporting other conditions. Specific neuromuscular conditions were represented through individual condition categories and within the diverse range of conditions reported as free text under 'Other'.

Among respondents living with neurological or neuromuscular conditions, most (67.6% of 2867 respondents) lived at home with family or loved ones, with a further 23.9% living independently. Only small proportions reported living in supported independent living, shared living, or aged care arrangements, indicating that most individuals reside in community settings and rely on informal support. Free-text responses highlighted more complex or unstable living situations, including reliance on multiple supports, supported accommodation, and housing insecurity.

Employment data highlights the substantial functional and economic impact of neurological conditions. Among respondents with neurological conditions, 72.1% (of 2867 respondents) were not currently employed, with smaller proportions in full-time (11.4%), part-time (10.8%) or casual work (5.7%), primarily due to retirement (52.7%) or inability to work because of health or disability (40.8%).

Among carers, 51.5% of 656 respondents were not currently employed. Of those, most were retired (59.2% of 336 respondents), while others had reduced or ceased employment, or were unable to work due to their own health conditions. Notably, 27.7% selected 'other', with responses indicating many are engaged in full-time unpaid caring roles. These findings underscore the significant impact of both neurological conditions and caring responsibilities on workforce participation and the broader economic context in which care is provided.

> "Caring has become a full-time role, with little recognition or support."

Access to formal supports was limited. Less than a quarter of people with neurological conditions (22.2% of 2850 respondents) reported receiving National Disability Insurance Scheme (NDIS) funding, while the majority (74.5%) were not accessing this support. A smaller proportion (7.8%) reported receiving other forms of funding. This partly reflects the transition between disability and aged care systems, as eligibility for the NDIS is limited to people under the age of 65, with many older respondents instead relying on aged care programs such as My Aged Care, Home Care Packages, or the newer Support at Home program.

Satisfaction with funding was mixed. While nearly two-thirds of 706 respondents reported being at least somewhat satisfied (62.8%), fewer than one-third (29.0%) were very satisfied, and over one-quarter (25.9%) reported dissatisfaction. These findings indicate variability in how effectively available support meets individual needs, with many respondents experiencing only partial or inconsistent coverage.

Free-text responses suggested that satisfaction depends not only on the level of support provided, but on whether it is timely, flexible, and aligned with actual needs. Common concerns included rigid funding categories, delays in approvals and reviews, administrative burden, and poor recognition of neurological, fluctuating, or progressive conditions. Many respondents reported inadequate support for therapies, assistive technology, and home modifications, while others described available support as highly beneficial when it enabled independence and day-to-day functioning. These gaps in formal support are also reflected in the extent to which carers are able to meet care needs directly.

Carers' ability to meet care needs varied across support tasks. Almost 59% (58.7% of 578 respondents) reported being able to meet medication management needs to a great or very great extent. This figure was 52.8% for cognitive support, and only 42.2% for mobility and physical assistance needs. A substantial proportion (27.8%) reported being able to meet mobility and physical assistance needs only to a small extent or not at all, indicating that more physically demanding care is harder to sustain without additional support.

Use of formal carer supports was variable, with a substantial proportion of carers (41.2% of 578 respondents) reporting that they had not accessed any formal supports in the past 12 months. Among those who had accessed formal support, the most common were paid carer support (28.4%) and mental health services (24.2%), followed by information and navigation support (15.9%), respite (12.5%), and peer support (10.6%).

Despite this, carers identified a clear need for additional support, particularly increased services for the person they support (46.2% of 578 respondents) and greater assistance with navigating systems and services (38.4%). Financial support (29.1%), reduced administrative burden (25.1%), respite (24.1%), and improved care coordination (23.4%) were also commonly identified as additional needs.

Free-text responses (92 respondents) reinforced these findings, emphasising the need for more coordinated and accessible models of care, including responsive NDIS supports, timely specialist access, and practical supports such as respite and transport. Financial pressures, administrative burden, and gaps in clinician knowledge, particularly for complex or poorly understood conditions, were also highlighted as key barriers to effective care.

Together, these findings highlight the complex health, social, and economic context in which neurological conditions are experienced, characterised by a high reliance on informal care and variable access to formal supports.

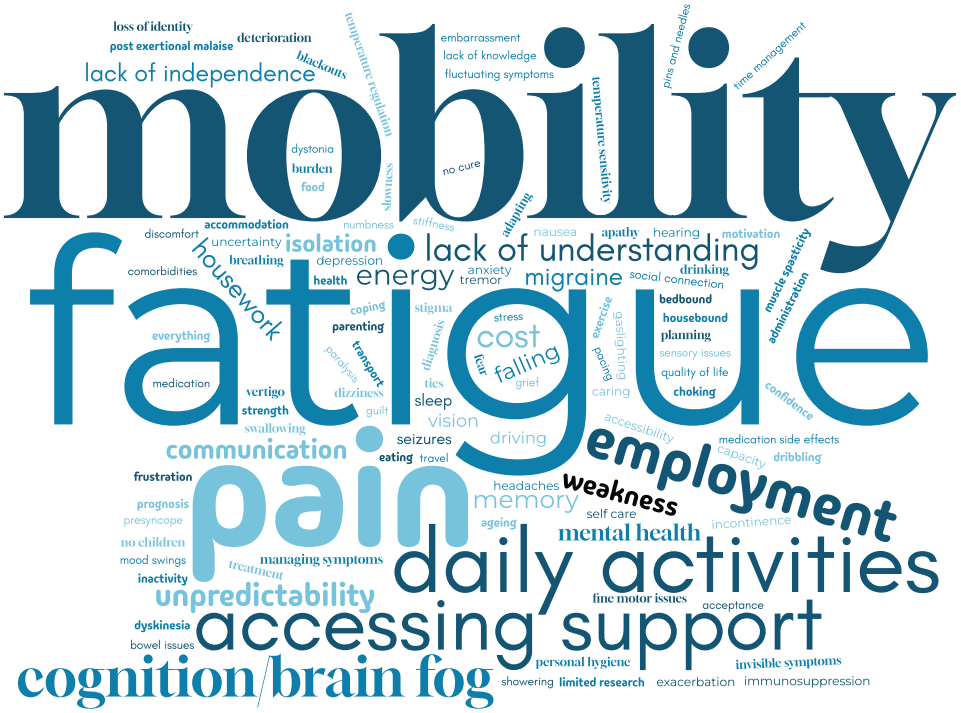
Key insight: Neurological conditions have substantial health, social and economic impacts, affecting independence, workforce participation and family finances, while placing significant and often unsupported pressure on informal carers and families.

Access to care and system performance

Respondents living with neurological conditions (n = 1816) described a range of day-to-day associated challenges, highlighting the complex and multifaceted nature of these conditions. Key themes included mobility, fatigue, pain, and cognitive difficulties such as memory impairment and 'brain fog', alongside challenges with daily functioning and independence (Figure 2). Respondents also frequently reported difficulties accessing support, a lack of understanding of their condition, and the unpredictable nature of symptoms. These experiences highlight the cumulative and wide-ranging impact of neurological conditions.

> "Everyday tasks are exhausting – even simple things take significant time and effort."

FIGURE 2. WORD CLOUD OF THE MOST COMMONLY REPORTED DAY-TO-DAY CHALLENGES EXPERIENCED BY 1816 RESPONDENTS WITH NEUROLOGICAL CONDITIONS.



More prominent terms indicate themes mentioned more frequently in free-text responses. These include physical, cognitive, and psychosocial challenges, alongside difficulties accessing support, reinforcing the multidimensional burden of neurological conditions. *Generated using WordClouds.com.*

Reflecting the complexity of these needs, carers and family members reported providing substantial levels of support. Nearly half (46.7% of 578 respondents) reported providing 36 hours or more care per week, with a further 18.5% indicating that care needs varied significantly. Experiences of support in the caring role were mixed, with a greater proportion reporting limited or no support (45.3% of 578 respondents) than those who felt supported (34.8%).

These findings highlight the scale of informal care underpinning the system, which intersects directly with the access challenges described below.

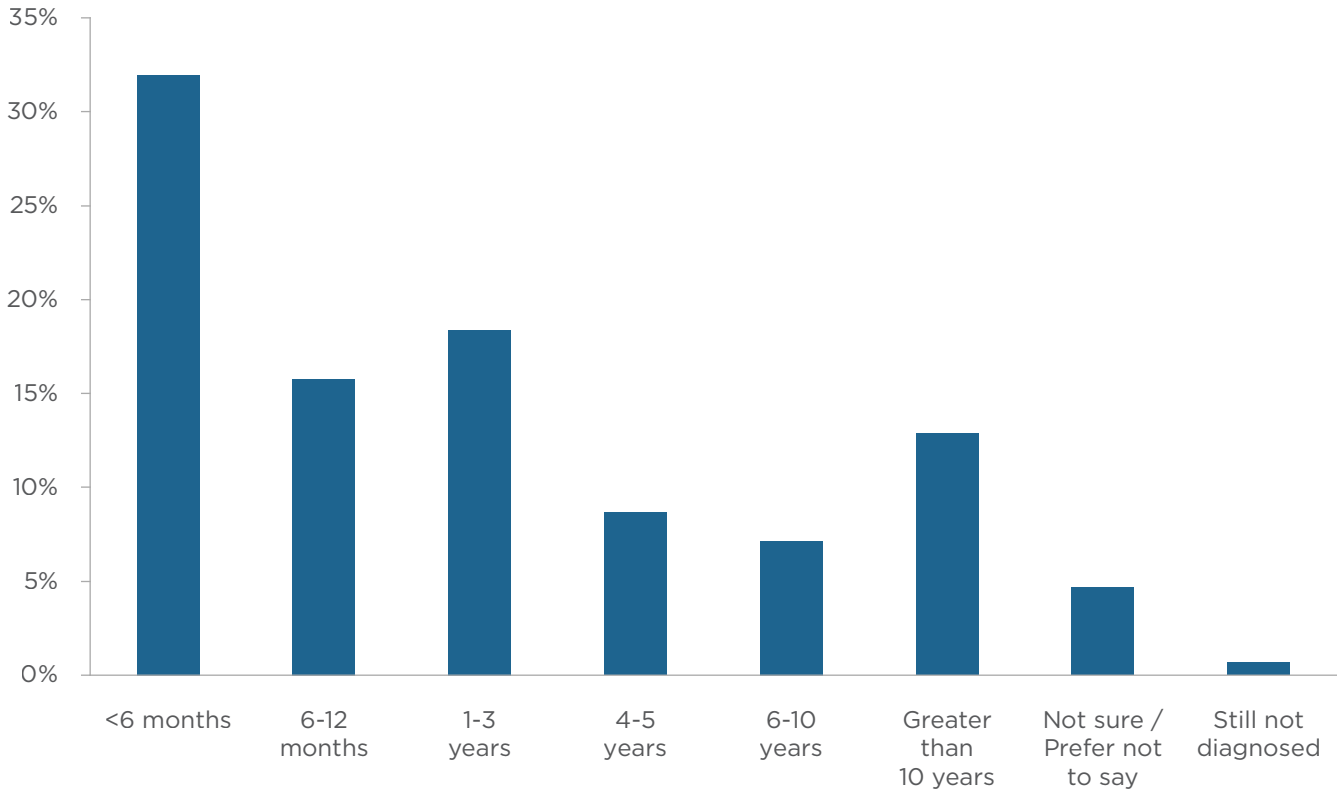
Delays in diagnosis and time to diagnosis

Most respondents with a neurological condition reported having a confirmed diagnosis (95.5% of 2750 respondents), with only a small proportion still undergoing assessment (3.4%) or choosing not to disclose. Among those diagnosed, the vast majority received a clinical diagnosis (94.4% of 2620 respondents), while relatively few were diagnosed through genetic testing (4.3%).

Time to diagnosis varied considerably. While around one-third (32% of 2620 respondents) were diagnosed within six months, a substantial proportion experienced prolonged diagnostic journeys – **29.3% waited more than four years**, including approximately 13% who waited over a decade (Figure 3).

> "I waited years for a diagnosis, even while my symptoms were getting worse."

FIGURE 3. TIME TO DIAGNOSIS FOR NEUROLOGICAL CONDITIONS.



Time to diagnosis varied substantially across 2620 respondents, with the largest proportion diagnosed within six months, but a significant minority experiencing prolonged diagnostic journeys. Notably, a considerable proportion reported waiting more than four years for a diagnosis, including some who waited over a decade.

For those still seeking a diagnosis, timelines ranged from a few months to more than 20 years. The majority of respondents also reported delays in accessing a neurologist or condition-specific specialist, often describing extended waiting periods or an inability to secure an appointment. Many respondents described navigating both public and private systems in an effort to access care, often without resolution, which is reflected in the distribution of respondents attempting to access care through both the public (43.6% of 78) and private (34.6%) systems.

For some conditions diagnosis can be rapid however delays come in identifying and then seeking relevant care and support.

Qualitative responses (n = 78) highlight persistent challenges, including limited access to specialists, particularly in regional and rural areas, long waiting times, and difficulties obtaining recognition or appropriate referral.

Delays in diagnosis were attributed to a combination of workforce shortages, limited specialist expertise, and system-level barriers, including challenges navigating referral pathways and accessing coordinated care. Survey respondents also reported experiences of symptoms not being recognised or taken seriously, particularly for complex, rare, or less well-understood conditions. Financial constraints and geographic inequities further contributed to delays, alongside the inherent complexity of neurological conditions.

Together, these findings highlight the significant variability and, in many cases, prolonged pathways to diagnosis, with important implications for access to timely care and treatment.

Key insight: Delays in diagnosis are widespread and often prolonged, driven by limited specialist access, system navigation barriers, and the complexity of neurological conditions.

Access to medical care and supports

Access to neurological medical care remains a significant challenge for respondents with neurological conditions. In this report, "neurological medical care" refers to specialist medical care relevant to a neurological condition and may include neurology, neurosurgery, rehabilitation medicine, psychiatry and other relevant medical specialties.

Over half of respondents reported that accessing neurological medical care in their area is somewhat or very difficult (51.1% of 2543 respondents), while only 27.8% found it at least somewhat easy (Figure 4).

Qualitative responses (n = 145) highlighted contributory factors including long wait times, limited specialist availability (particularly in regional areas), cost barriers, difficulties navigating referral pathways, and variable clinician expertise, particularly for complex or rarer conditions. Some respondents also reported not being referred to neurological care, being uncertain how to access services, or relying solely on general practitioners for management. Similar challenges were reported for functional supports, with 43.1% indicating difficulty accessing allied health, equipment, or community services.

> "Doctors didn't listen and blocked access to neurology – the wait was over six years. We had to go interstate for care."

Carers reported even greater challenges, with 65.6% of 505 respondents indicating that accessing neurological medical care was somewhat or very difficult, compared with only 17.6% reporting it as at least somewhat easy. Difficulties accessing functional supports were also common (53.3% of 505 respondents), alongside challenges coordinating care, with more than half (52.7% of 505 respondents) reporting that care was somewhat or not coordinated across services.

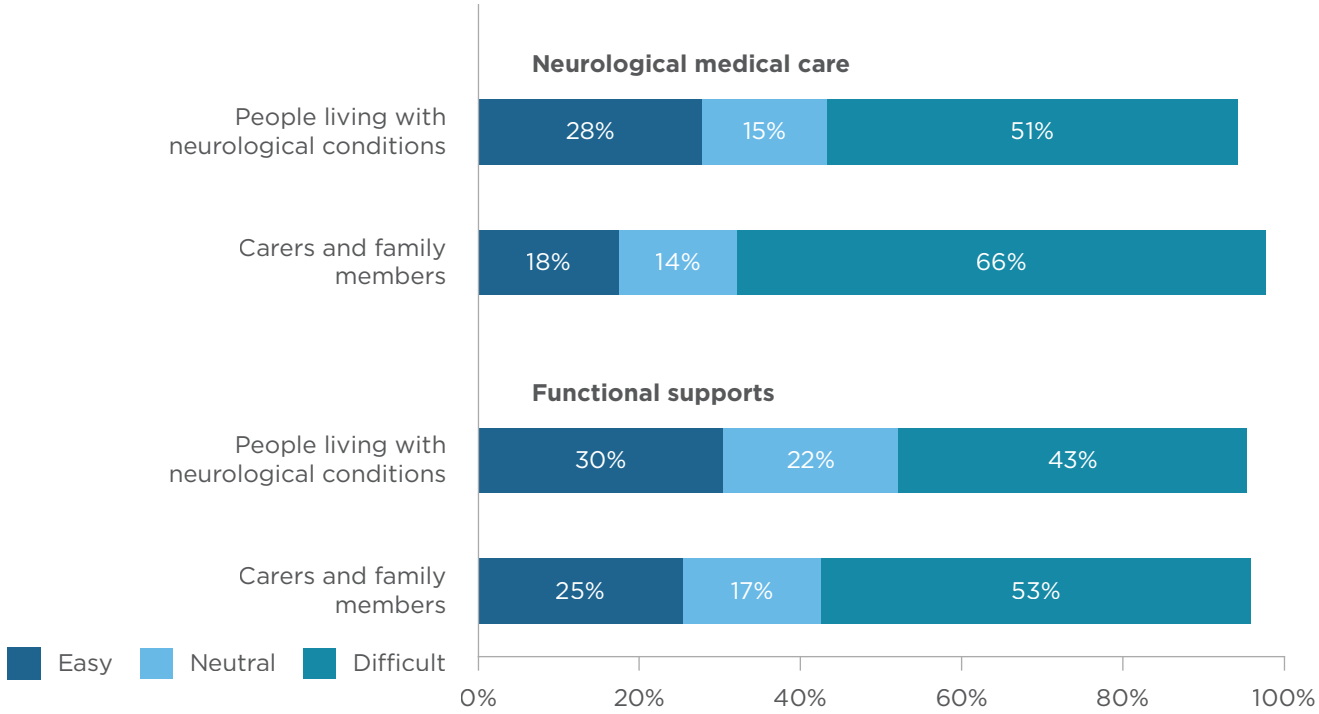
These findings were reinforced at a system level by advocacy and patient organisations (31 respondents), which identified access to services and specialist expertise as the most significant gap (74.2%), alongside delays in diagnosis (45.2%) and challenges navigating complex systems (38.7%).

Health professionals and service providers (136 respondents) similarly identified constraints in service availability, workforce capacity, and access to specialised expertise as key drivers of access challenges. Respondents emphasised shortages of neurologists and condition-specific services, particularly in regional and rural areas, alongside gaps in allied health and support services, highlighting the operational factors contributing to limited access and variability in care.

Together, these findings highlight significant barriers to accessing neurological care and functional supports, particularly for people in regional areas and those navigating complex referral pathways. This is exacerbated by neurological conditions requiring long-term intermittent and variable care, challenges additionally include access to rehabilitation, social connection, housing access, carer support and funding.

Key insight: Access to neurological care remains a significant system challenge, with more than half of respondents experiencing difficulty due to workforce shortages, cost barriers, and complex referral pathways.

FIGURE 4. PERCEIVED EASE OF ACCESS TO NEUROLOGICAL MEDICAL CARE AND FUNCTIONAL SUPPORTS, BY RESPONDENT GROUP.



Respondents rated access as easy (very or somewhat), neutral, or difficult (somewhat or very). Across both service types, a greater proportion of respondents reported difficulty rather than ease, particularly for neurological medical care. Carers and family members (n = 505) consistently reported higher levels of difficulty than people living with neurological conditions (n = 2543). While access to functional supports was relatively more favourable, substantial barriers remain across both areas, highlighting systemic challenges in accessibility and coordination of care.

Access to assistive technology and digital health tools

Assistive technology and digital health tools play an important role in supporting independence, self-management, and access to care for people with neurological conditions. However, access to and effective use of these tools remains variable.

A majority of respondents (58.8% of 1938 respondents) reported using assistive technologies (e.g. mobility aids) or digital health tools (e.g. apps and wearables), while a substantial proportion (38.5%) were not using these supports. Among those using these tools, experiences were generally positive, with 61.5% of 1126 reporting they were somewhat or very easy to use. However, a notable proportion reported neutral or negative experiences, indicating ongoing challenges with usability and suitability.

Among those not using assistive technologies or digital tools, the most common barrier was lack of suitability for individual needs (43.6% of 755 respondents), followed by lack of awareness (17.9%) and cost (10.1%). Additional barriers included perceived lack of benefit, usability concerns, limited availability, and issues related to comfort or privacy. Free-text responses further highlighted delayed diagnosis, limited guidance from healthcare providers, and difficulty identifying appropriate or relevant technologies.

Together, these findings indicate that, while assistive technologies and digital health tools have significant potential to support independence and improve outcomes, access is constrained by barriers related to cost, awareness, suitability, and system navigation. Addressing these challenges is critical to ensuring these supports are accessible, effective, and equitably available across the neurological population.

Key insight: While assistive technologies offer clear benefits, access remains uneven due to gaps in awareness, affordability, and suitability for individual needs.

Services most difficult to access and unmet need

Among people living with neurological conditions, neurology specialist care was most frequently reported as difficult to access (41.1% of 2543 respondents), followed by allied health therapies (25.5%), particularly physiotherapy, exercise physiology and occupational therapy, and NDIS or disability supports (20.6%).

Free-text responses (n = 192) reinforced that these challenges are not limited to individual services but reflect broader difficulties accessing condition-appropriate care within complex and fragmented systems.

Carers reported similar patterns, with the most common challenges including managing costs (36.6% of 505 respondents), accessing specialist care (33.7%), and obtaining a diagnosis (32.3%), alongside difficulties with care coordination and system navigation (30.7%).

Together, these findings indicate that barriers extend beyond individual services to include cost, coordination, and system navigation.

Key insight: Difficulties accessing neurological care extend beyond specialist services to include allied health, disability supports, and community care, reflecting systemic gaps across the care ecosystem.

Challenges navigating public and private systems

Access challenges were further reflected in experiences navigating public and private health systems. In the public system, respondents described extended delays, limited service availability, and eligibility constraints, particularly in regional and rural areas. Some reported disengaging from public services due to delays, lack of continuity, or perceived lack of support.

While the private system sometimes provided more timely access, this was often offset by cost, limiting equitable and sustained use.

Across both systems, respondents highlighted limited condition-specific expertise, fragmented care, and the burden of navigating complex and poorly coordinated pathways.

Fragmentation, coordination, and delays in care

Coordination of care remains a significant challenge for respondents. **Only 38.7% of people living with a neurological condition (n = 1998) described their care as very or somewhat coordinated**, while a similar proportion (41.1%) described it as somewhat not coordinated or not coordinated, indicating substantial fragmentation across services. Qualitative responses further highlighted fragmented pathways and a reliance on individuals to manage and coordinate their own care.

> "I had to coordinate everything myself – there was no single point of responsibility for my care."

Responses regarding support from healthcare teams was mixed. **Only 9.4% of people with neurological conditions (n = 926) reported feeling fully supported,** while over one-third (35.0%) reported feeling somewhat or very unsupported. A further 42.2% reported feeling only somewhat supported, indicating that for many, support is partial or inconsistent across the care pathway.

Carers and family members reported similar, and often more pronounced, challenges. More than half (52.7% of 505 respondents) indicated that care was somewhat or not coordinated across services, reflecting the burden placed on families to navigate complex and disconnected systems. Advocacy and patient organisations (31 respondents) reinforced these findings, with more than half reporting that care for the populations they support is poorly coordinated and largely dependent on individuals and families rather than structured system support.

Health professionals and service providers also described care delivery as highly fragmented, with lack of coordination across services identified as the most significant challenge (66.9% of 136 respondents). Respondents further highlighted delays and referral barriers (47.8%) and limitations in multidisciplinary care (45.6%), reflecting gaps in communication and coordination across services.

These coordination challenges are reflected in widespread and consequential delays in care. Over 41.4% of 1998 people living with neurological conditions reported delays that negatively affected diagnosis or treatment, with a further 7.6% still waiting. Carers and family members reported even higher levels of delay (63.2% of 505 respondents). Advocacy and patient organisations similarly highlighted delays in diagnosis and treatment as a systemic issue, particularly for those in regional and rural areas.

Health professionals and service providers attributed these delays to referral bottlenecks, long waiting times, and challenges coordinating care across services, particularly for people with complex or progressive conditions.

Key insight: Neurological care is fragmented and inconsistently coordinated, with many people experiencing only partial support from healthcare teams and consequential delays that impact access to timely and effective care.

Experiences across the disease journey and system impact

Respondents identified a range of challenges across the neurological disease journey, reinforcing and bringing together findings from earlier sections. The most prominent challenges included managing costs and out-of-pocket expenses (43.7% of 1998 respondents), accessing specialist care (38.0%), and obtaining an accurate diagnosis (34.3%). **Nearly half of respondents (47.5% of 1988 respondents) also reported delaying or skipping care, support, or treatment due to cost**, highlighting the direct and consequential impact of financial barriers on access to care.

> “I had to delay treatment because I couldn’t afford it.”

Among those who delayed or skipped care due to cost, the most commonly impacted services were specialist appointments (53.5% of 929 respondents) and allied health services (47.0%) - particularly physiotherapy, exercise physiology and occupational therapy - followed by mental health support (34.3%) and medicines (33.2%). Other commonly affected areas included GP or primary care (28.4%), assistive devices (29.4%), travel or accommodation (23.1%), and rehabilitation services (17.6%).

These challenges were accompanied by ongoing difficulties navigating complex systems, including care coordination and access to supports such as allied health, rehabilitation, and community-based services. Financial burden, travel, and system navigation barriers further compounded these challenges over time.

Carers and family members reported similar patterns, alongside additional pressures associated with coordinating care across fragmented systems and managing competing demands.

Across stakeholder groups, these challenges were consistently linked to broader system issues including delays, limited access to specialist and multidisciplinary care, and gaps in coordination across services.

Together, these findings highlight the cumulative burden of navigating a complex and fragmented system over time, where challenges are not isolated but intersect across diagnosis, access, coordination, and ongoing care.

Key insight: Challenges across the neurological disease journey are cumulative and interconnected, with cost, access, coordination, and delays reinforcing one another – and, in many cases, resulting in people delaying or skipping care.

Research and innovation

Awareness and engagement in research

Researchers represented a diverse range of neurological research areas and approaches, including neurodegenerative and neurodevelopmental conditions, spanning clinical, translational, and health services research. Many reported working across the continuum from discovery to implementation, including efforts to improve service delivery and real-world outcomes.

Despite the importance of research and innovation in improving long-term outcomes, awareness of clinical trials and research opportunities remains limited among people with neurological conditions and carers. Nearly half of people with neurological conditions (45.3% of 1839) reported no awareness of research opportunities, with a further 37.4% only somewhat aware. A similar pattern was observed among carers, with 43.7% of 488 respondents not aware and 40.4% somewhat aware.

> "I wasn't aware of any research or clinical trial opportunities."

From a provider perspective, health professionals and service providers reported similarly low levels of patient awareness, with most indicating patients were only somewhat aware (43.8% of 121 respondents) or not aware (33.9%), and relatively few reporting high awareness (8.3%) or active involvement (5.0%). Pharmaceutical industry respondents (15 respondents) offered a more optimistic view, suggesting patients are generally somewhat aware (66.7%), although this does not appear to translate into active participation.

Researchers themselves reported high levels of engagement, with over three-quarters (76.9% of 26 respondents) actively involved in research or clinical trials. Only small proportions reported limited awareness or involvement, reflecting a highly engaged research cohort.

Taken together, these findings highlight a disconnect between high levels of research activity and low levels of awareness and participation among people with neurological conditions and carers. This suggests ongoing challenges in communication, visibility, and practical access to research opportunities.

Key insight: Despite high levels of research activity, awareness and participation among people with neurological conditions and carers remains low, highlighting a disconnect between research efforts and real-world engagement.

Barriers to advancing and translating research

Researchers identified significant barriers to advancing neurological research in Australia, with insufficient funding the most prominent challenge (80.8% of 26 respondents), followed by a lack of national coordination and interdisciplinary collaboration (53.8%) and workforce capacity constraints (34.6%). Challenges in translating research into practice were also common (30.8%), alongside limitations in data access, sharing, and infrastructure.

Consistent with this, implementation was identified as the most significant barrier to impact, with 42.3% highlighting challenges in workforce uptake and embedding evidence into clinical care. Additional barriers included limitations in evidence strength and proof of value (19.2%), as well as constraints related to trial costs, infrastructure, and regulatory processes (each 11.5%). Together, these findings indicate that the major challenges lie not only in generating new knowledge, but in coordinating, funding, and embedding research into practice.

Key insight: Progress in neurological research is constrained not only by funding, but by limited coordination, workforce capacity, and challenges translating evidence into practice.

Barriers to participation in research

Barriers to participation in research and innovation programs were consistently reported across all stakeholder groups, spanning both practical and access-related constraints (Figure 5) and information, trust, and design-related challenges (Figure 6).

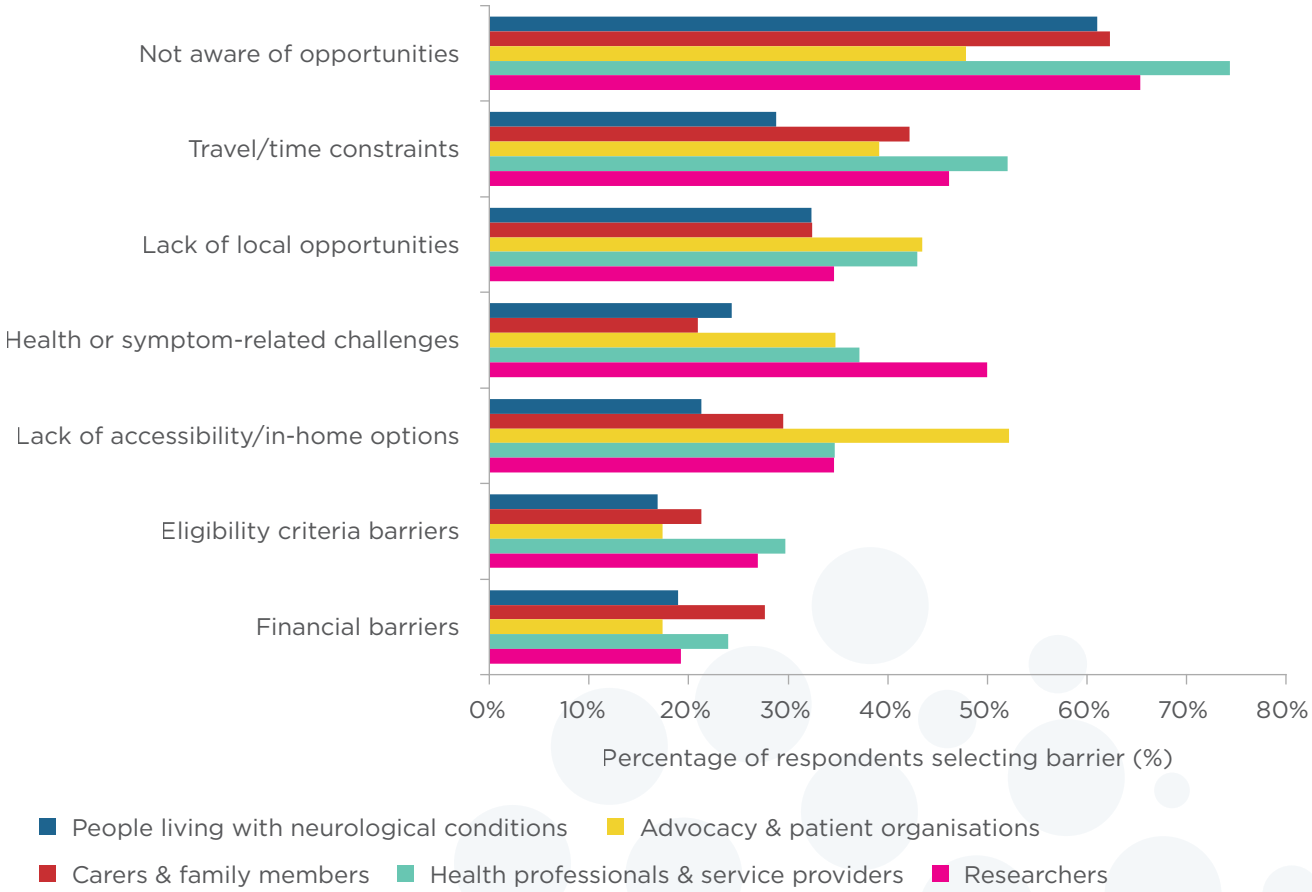
Practical and access-related barriers were the most commonly reported. Among people living with neurological conditions, the primary barrier was lack of awareness of opportunities (61.1% of 1020), alongside structural constraints including lack of local opportunities (32.4%), travel or time constraints (28.8%), and health or disability-related challenges (24.3%). Limited accessibility, financial barriers, and restrictive eligibility criteria were also significant. Carers (488 respondents) reported similar challenges, with additional emphasis on time constraints, competing responsibilities, and the logistical burden of participation. Advocacy and patient organisations (23 respondents) highlighted limited access in regional areas and the need for more inclusive and flexible research models, while health professionals (136 respondents) identified time pressures and difficulties integrating research into clinical practice.

In addition to these practical barriers, information, trust, and design-related barriers also influenced participation. Respondents highlighted challenges related to understanding research information, concerns about risks and data privacy, and limitations in study design and accessibility. Researchers further identified barriers related to complexity of information, cultural and language differences, and lack of flexible participation options. These factors indicate that, beyond practical access, issues related to trust, comprehension, and inclusivity play an important role in determining willingness and ability to engage in research.

Additional responses reinforced these findings, highlighting limited opportunities for rare or complex conditions, exclusion due to eligibility criteria, lack of clinician referral, and a mismatch between available research and patient priorities.

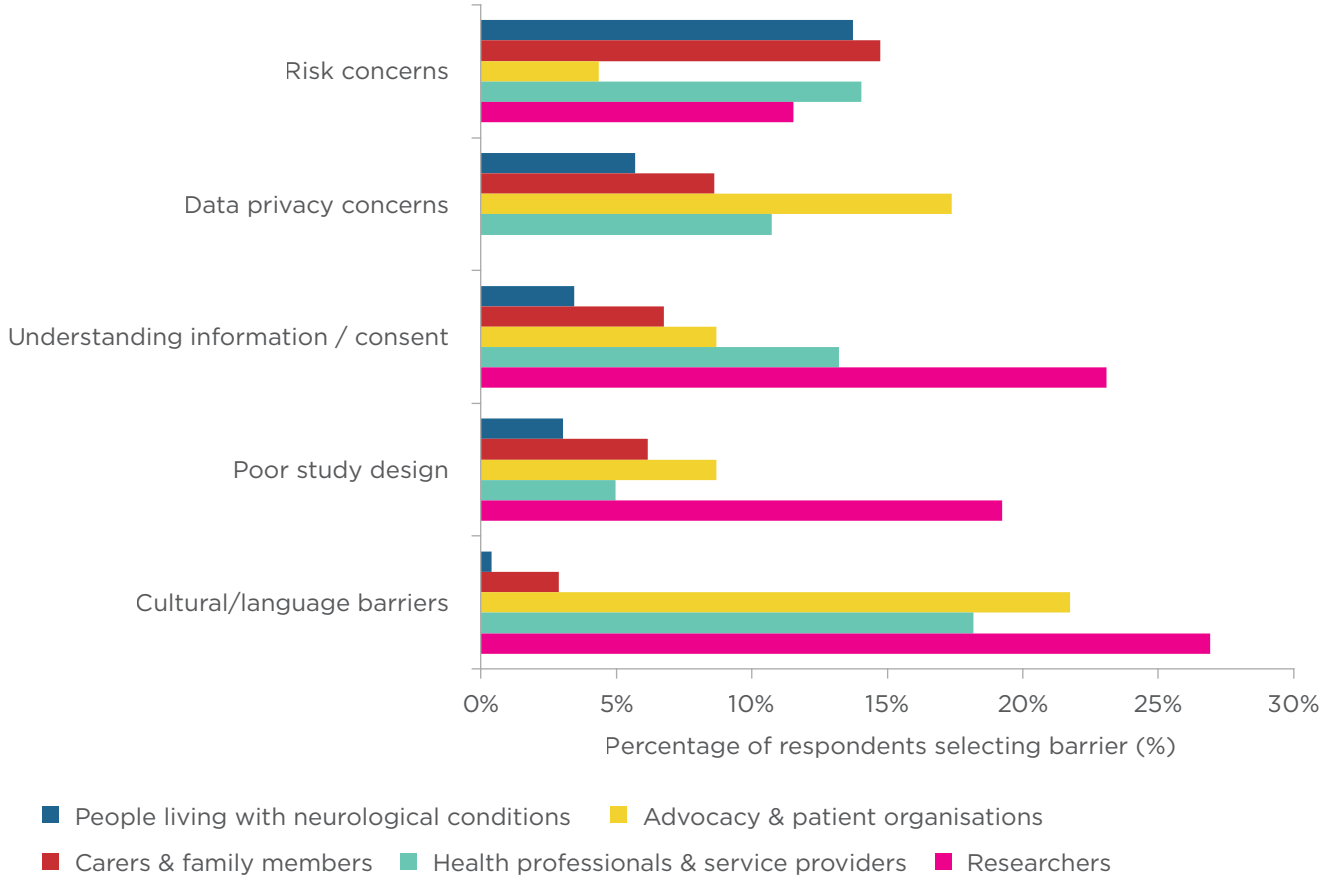
Overall, participation is shaped by a combination of practical, structural, and information-related factors, highlighting the need for more visible, accessible, and inclusive approaches to research engagement.

FIGURE 5. PRACTICAL BARRIERS TO PARTICIPATION IN NEUROLOGICAL RESEARCH AND CLINICAL TRIALS, BY STAKEHOLDER GROUP.



Stakeholders included people living with neurological conditions (1020 respondents), carers and family members (488 respondents), advocacy and patient organisations (23 respondents), health professional and service providers (136 respondents) and researchers (26 respondents). Barriers related to awareness, access, and feasibility were among the most commonly reported. Lack of awareness of opportunities, travel and time constraints, and limited local availability of research emerged as key barriers across groups. Health, symptom-related challenges and accessibility limitations further affected participation, highlighting the significant practical and structural constraints that limit engagement.

FIGURE 6. INFORMATION, TRUST, AND DESIGN-RELATED BARRIERS TO PARTICIPATION IN NEUROLOGICAL RESEARCH AND CLINICAL TRIALS, BY STAKEHOLDER GROUP.



Stakeholders included people living with neurological conditions (1020 respondents), carers and family members (488 respondents), advocacy and patient organisations (23 respondents), health professional and service providers (136 respondents) and researchers (26 respondents). Concerns about risks, privacy, and the design of research studies, alongside difficulties understanding information and consent processes, were commonly reported. Cultural and language barriers further affected engagement for some groups. These findings indicate that, beyond practical access, factors related to trust, comprehension, and inclusivity influence willingness and ability to participate in research.

Key insight: Participation in neurological research is limited by a combination of structural, practical, and informational barriers, including lack of awareness, accessibility challenges, and competing demands on time and health.

Research priorities and unmet needs

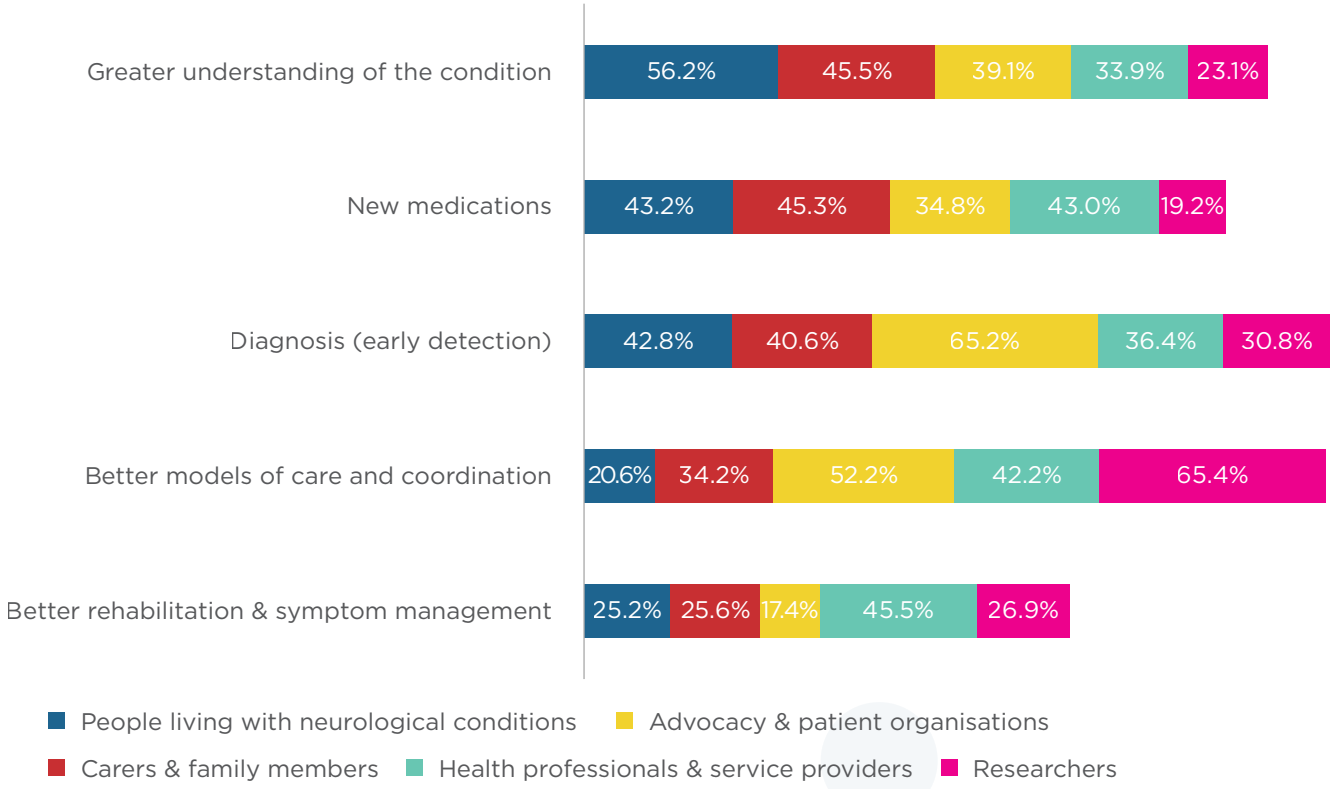
Across all respondent groups, research priorities were broadly aligned (Figure 7), with people living with neurological conditions placing the greatest emphasis on improving understanding of their condition (56.2% of 1796 respondents), developing new therapies (43.2%), and enabling earlier diagnosis (42.8%). Carers and advocacy organisations reinforced these priorities, highlighting the importance of early detection, access to effective treatments, and better coordinated models of care, as well as the need for research that reflects real-world care challenges such as system navigation, service access, and the practical demands of caregiving.

Health professionals and service providers similarly prioritised research that improves functional outcomes and care delivery, with a strong focus on rehabilitation, treatment effectiveness, and models of care. Earlier diagnosis and greater understanding of neurological conditions were also consistently identified, reinforcing the importance of both clinical and system-level improvements.

From a research perspective, there was a stronger emphasis on system-level change, including improved models of care and coordination (65.4% of 26 respondents), prevention and risk reduction strategies (38.5%), and earlier detection and diagnostics (30.8%). This reflects a shift toward upstream approaches, with prevention and early intervention prioritised over downstream treatment.

Additional responses reinforced these priorities while highlighting the need for improved clinician and community education, better access to existing supports and funding, and more patient-centred research aligned with lived experience. Respondents also identified gaps for rare and complex conditions and called for more inclusive, accessible, and holistic approaches beyond treatment-focused models.

FIGURE 7. THE FIVE MOST FREQUENTLY SELECTED RESEARCH AND INNOVATION PRIORITIES TO IMPROVE OUTCOMES ACROSS STAKEHOLDER GROUPS, EXPRESSED AS THE PROPORTION OF RESPONDENTS SELECTING EACH AREA AMONG THEIR TOP THREE PRIORITIES.



Stakeholders included people living with neurological conditions (1796 respondents), carers and family members (488 respondents), advocacy and patient organisations (23 respondents), health professional and service providers (121 respondents) and researchers (26 respondents).

There was strong alignment across stakeholders on the importance of diagnosis, development of new treatments, and improving understanding of neurological conditions. Health professionals (121 respondents) placed relatively greater emphasis on rehabilitation and symptom management, while advocacy organisations and researchers prioritised models of care and system coordination. Overall, the findings highlight shared priorities across clinical and system-level improvement, while also showing variation in emphasis between stakeholder groups.

Pharmaceutical industry respondents (15 respondents) also identified significant unmet need, particularly in neurodegenerative diseases (80.0%), as well as neuroinflammatory, autoimmune, and rare or genetic conditions (46.7%). These priorities aligned with other stakeholder groups, with additional emphasis on prevention, earlier intervention, and more targeted therapies to improve outcomes.

Key insight: Research priorities are strongly aligned across stakeholders, with a shared focus on improving diagnosis, developing effective treatments, and strengthening models of care to improve real-world outcomes.

Key stakeholder perspectives for national and State/Territory leaders

Respondents across all stakeholder groups were asked to identify the single most important message they would convey to national, State and Territory leaders to improve neurological research. Their responses provide a clear and consistent picture of priority areas for reform across funding, access, coordination, and the translation of research into practice.

The dominant message from people living with neurological conditions (1499 respondents) was that neurological research must be better funded, more equitable, and more closely connected to real-world care. Respondents emphasised the need for greater recognition of under-served conditions, earlier diagnosis, stronger clinician education, faster access to treatment, and more meaningful inclusion of lived experience in research design and priority-setting. Many framed investment in research as both a humanitarian and economic imperative, with the potential to reduce long-term disability, improve workforce participation, and alleviate pressure on health and support systems.

Carers and family members (414 respondents) emphasised that improving neurological research must go hand in hand with addressing significant gaps in care, support, and system coordination. Responses highlighted the burden of navigating fragmented systems, with carers often acting as the primary coordinators of care across health, disability, and aged care services. Many described substantial financial strain, including out-of-pocket costs, loss of income, and inadequate funding through the NDIS and aged care systems.

Access to specialist care, long wait times, and workforce shortages, particularly in regional and rural areas, were also prominent concerns. Carers strongly emphasised the need for greater recognition and support for their role, including improved access to respite, financial assistance, and mental health services. While increased investment in research was widely supported, carers stressed that it must translate into real-world improvements in diagnosis, access to care, and quality of life, and reduce reliance on families to compensate for gaps in care delivery.

Advocacy and patient organisations (21 respondents) highlighted the need for coordinated, system-level reform to address fragmentation, duplication, and inequitable access. Priorities included improved coordination across health, disability, and community systems, alongside equitable access to timely specialist care regardless of location or condition type, particularly for people with rare or under-recognised conditions. Inadequate workforce capability and clinician education including for general practice and non-GP specialists leading to delays in diagnosis and fragmented treatment and care plans were also identified as key gaps, alongside the need for increased and more accessible funding to support both research and community-based services.

Australia's neurological care system depends heavily on unpaid family carers, who provide substantial levels of care often without adequate support, respite or financial assistance.

Health professionals and service providers (101 respondents) underscored the need for system-level redesign to address fragmentation, workforce limitations, and inequitable access. Respondents highlighted shortages of specialist and allied health services, particularly in regional and rural areas, as well as inefficiencies across health, disability, and aged care systems. There was strong support for multidisciplinary, integrated models of care, combined with increased investment in workforce capacity, infrastructure, and coordination. Early intervention, prevention, and sustained access to rehabilitation were also identified as critical to improving outcomes and reducing long-term costs.

Researchers (20 respondents) emphasised the need for sustained investment and a stronger national focus on neurological research, highlighting funding constraints and gaps in coordination as key barriers to progress. Respondents identified inequities across populations, including age-related and regional disparities, and called for more inclusive and collaborative approaches that reflect diverse patient experiences. There was also strong emphasis on improving translation of research into real-world outcomes and embedding lived experience in research design.

Pharmaceutical industry respondents (13 respondents) highlighted the need to reform funding, reimbursement, and access systems to ensure patients benefit from innovation. Responses indicated that current health technology assessment (HTA) and Pharmaceutical Benefits Scheme (PBS) processes are not keeping pace with advances in medical research, delaying access to new

treatments. Broader system barriers, including limited specialist capacity and infrastructure, were also identified as constraints to uptake, alongside the need to modernise funding frameworks and strengthen national coordination.

Across all stakeholder groups, there was a clear and consistent call for **greater investment in neurological research alongside more coordinated, accessible, and equitable systems of care**. Respondents emphasised that research must translate into tangible improvements in diagnosis, treatment, and service delivery, supported by stronger workforce capacity, better system integration, and meaningful involvement of people with lived experience and carers.

Key insight: Collectively, these messages point to the need for strong national leadership, sustained investment, and system-wide reform to deliver timely, equitable, and person-centred neurological care.

Key system-level priorities for improving neurological care

While these questions explored different aspects of research and care, responses consistently converged on a common set of system-level priorities, highlighting the strong interdependence between research, service delivery, and real-world outcomes.

Responses from people living with neurological conditions highlighted a consistent set of system-level priorities, describing the real-world impact of delays, fragmentation, and limited access to care. Respondents emphasised persistent challenges in accessing specialist and multidisciplinary services, prolonged waiting times for diagnosis and treatment, and the consequences of delayed or missed diagnosis, often resulting in disease progression and reduced function. There was also widespread concern about gaps in workforce capability, including limited clinician knowledge of neurological conditions and experiences of patients not being believed or appropriately supported.

Respondents further described the burden of navigating fragmented systems without coordination, alongside significant financial barriers to accessing care, including specialist services, allied health, medications, and assistive technology. Together, these findings demonstrate that system-level limitations are directly experienced as barriers to timely, coordinated, and equitable care.

Carers and family members identified a similar set of priorities, with a strong emphasis on improving access to multidisciplinary and specialist care, reducing waiting times, and enabling earlier and more accurate diagnosis. Responses highlighted delays across the care pathway, including prolonged waiting times for neurologists, diagnostic testing, and access to supports, contributing to worsening outcomes and increased stress for families.

Care coordination and system navigation were also key challenges, with carers frequently acting as the primary coordinators of care across fragmented health, disability, and aged care systems. Financial burden was a major concern, including high out-of-pocket costs, loss of income, and difficulties accessing timely and adequate support through funding systems. Carers also emphasised the need for improved access to respite, information, psychological and psychosocial support, alongside increased investment in research that translates into better treatment options and quality of life.

Advocacy and patient organisations emphasised the need for stronger national leadership and system-level reform to address persistent gaps in neurological care, including the under-recognition of neurological conditions within national health policy. Key priorities included improving access to coordinated, multidisciplinary care, strengthening integration across health, disability, and aged care systems, and ensuring equitable access to services, particularly for people in regional and remote areas and those with complex or rare conditions. Organisations also highlighted the importance of workforce capacity, data systems and registries, and sustained investment to support more consistent, timely, and coordinated care.

Health professionals and service providers reinforced these findings, identifying workforce capacity, multidisciplinary care, and system coordination as critical areas for improvement. Priorities included increasing access to specialists and multidisciplinary teams, strengthening care pathways, expanding care coordination roles such as nurse navigators, and improving funding models. Respondents also highlighted the need to reduce delays in diagnosis and treatment, improve integration across health, disability, and community systems, and address inequities in access, particularly in regional and remote areas.

Several scalable models were identified, including multidisciplinary clinics, nurse-led coordination models, telehealth and outreach services, and disease-specific programs. However, limited awareness of consistent or nationally adopted approaches reflects ongoing system fragmentation.

From an industry perspective, pharmaceutical respondents emphasised access to treatments and reimbursement processes as key barriers to improving outcomes. Responses indicated that current health technology assessment (HTA) and Pharmaceutical Benefits Scheme (PBS) processes are not keeping pace with advances in medical research, delaying access to new treatments. It is noted that the HTA Review made 50 recommendations for reform that will (1) address inequities in access, (2) improve timely access to medicines, (3) improve engagement, and (4) invest in HTA capability to make it adaptable and future-proof. NAA urges the Government to implement all recommendations which will better support people with neurological conditions.

Broader system barriers, including limited specialist capacity and infrastructure, were also identified by pharmaceutical respondents as constraints to uptake. Respondents emphasised the need to modernise funding frameworks, improve coordination, and strengthen national data infrastructure to support implementation and evaluation.

Researchers identified funding and research infrastructure as critical enablers of progress, including the need for increased and targeted investment, nationally coordinated data platforms and registries, and improved alignment across research and health systems. Respondents also highlighted the need to streamline governance processes, such as ethics and multi-site approvals, to support more efficient and collaborative research and enable translation into practice.

Policymakers identified access to specialist care and integration across health, disability, and ageing systems as the most significant policy gaps, alongside challenges in early diagnosis and translating research into practice. Key barriers included workforce capacity and distribution, funding and sustainable investment, the absence of a coordinated national strategy, and inequities in access across regions and populations.

When ranking priorities for the next five years, policymakers placed greatest importance on improving access to specialist care, strengthening earlier and more accurate diagnosis, accelerating access to innovative therapies, and building workforce capacity. They also emphasised that immediate gains can be achieved through improving care coordination, aligning data systems, strengthening continuity of care, and delivering targeted investments, particularly for people with complex needs or those underserved by current funding models.

Overall, these findings demonstrate a clear and consistent set of system-level priorities across all stakeholder groups, reflecting strong alignment between lived experience, clinical, policy, and industry perspectives.

Collectively, these priorities reinforce the need to improve access to care and treatment, strengthen workforce capacity, reduce delays in diagnosis, and enhance coordination across systems. Aligning policy, funding, and research will be critical to delivering timely, equitable, and effective neurological care.

Key priorities for reform in neurological care and research

Across all stakeholder respondent groups, the findings point to the need for a coherent and interconnected reform agenda.

Priorities include greater investment in neurological research and its translation into practice; earlier and more equitable access to diagnosis, GP and non-GP specialist and multidisciplinary care; a stronger and better-distributed neurological workforce; and improved coordination across health, disability and aged care systems.

Reform must also address inequities associated with geography, age and condition type, while embedding lived experience and carer perspectives in research, policy and service design.

Together, these priorities demonstrate that improvements in research, care and support cannot be pursued in isolation, but require coordinated national leadership, aligned funding and sustained system-wide action.

Key priorities are to:

- increase investment in neurological research and its translation into practice
- improve access to timely diagnosis, specialist and multidisciplinary care
- reduce delays across diagnosis, referral and treatment pathways
- strengthen workforce capacity, capability and specialist availability
- address fragmentation and improve coordination across health, disability and aged care systems
- reduce inequities across geographic regions, age groups and condition types
- align policy, funding and service delivery to support integrated, person-centred care
- embed lived experience and carer perspectives in research, policy and system design.

Conclusion

The findings of this survey demonstrate a consistent and urgent need for system-level reform to improve neurological care and research in Australia. Despite differences in perspective, there was strong alignment on the key challenges facing people living with neurological and neuromuscular conditions, including delays in diagnosis and treatment, limited access to specialist and multidisciplinary care, fragmented systems, workforce constraints, inequitable access and significant financial burden.

These challenges are interconnected. Delays in diagnosis, gaps in workforce capacity, and poor coordination across health, disability and aged care systems compound one another, contributing to inequitable access, fragmented care, poorer outcomes and increased pressure on individuals, carers and families. While greater investment in neurological research remains critical, stakeholders consistently emphasised that research must translate into real-world improvements in diagnosis, treatment, care, access, and quality of life.

Reform must extend beyond diagnosis and specialist treatment to include care coordination and navigation, rehabilitation, long-term support, and recognition of the broader social and economic impacts of neurological conditions. It must also embed lived experience and carer perspectives to ensure that research, policies and services respond to the needs of those most affected.

Together, the findings highlight the need for coordinated national leadership, sustained investment and system-wide reform to ensure that neurological care in Australia is timely, equitable, and responsive to the needs of those it serves. The consistency of these findings across stakeholder groups underscores the importance of acting now to address longstanding gaps and to build a more effective, integrated and sustainable neurological care system for the future.

Alignment with national policy and reform

The survey findings and recommendations align closely with several current Australian Government strategies and reform agendas. This alignment provides an opportunity to respond to the identified gaps through existing national policy, funding and implementation mechanisms, while ensuring that the particular needs of people living with neurological conditions are recognised.

Briefly, the following table highlights this alignment, however these strategies and reform agendas do not remove the need for neurological-specific action.

National strategy or reform agenda	Alignment with the survey findings and recommendations
National Strategic Framework for Chronic Conditions 2026–2035	Its focus on integrated and multidisciplinary care, continuity across the life course, equity and system-level reform directly aligns with the recommendations to improve timely access to care, establish coordinated models across systems and reduce inequities.
National Health and Medical Research Strategy 2026–2036	Its emphasis on strengthening national research coordination and translating research into real-world impact supports the recommendations to increase investment in neurological research, improve translation into practice and strengthen data and national planning.
National Medical Workforce Strategy 2021–2031 and Stronger Rural Health Strategy	These strategies provide established mechanisms for longer-term workforce planning, improved workforce distribution and greater access in rural and remote communities. They align with the recommendations to strengthen neurological and allied health workforce capacity and reduce geographic inequities, although a more specific focus on neurological workforce needs remains necessary.
Australia's Disability Strategy 2021–2031 and the recommendations of the 2023 NDIS Review	These agendas reinforce the need for more inclusive and connected systems of support, improved navigation across mainstream and disability services, and meaningful involvement of people with disability in decisions affecting their lives. This aligns particularly with the recommendations on integrated care, navigation, equity and lived experience.
Health Technology Assessment reform agenda	Current reforms relating to access and equity, assessment pathways, transparency and consumer engagement are relevant to concerns about delays in accessing innovative treatments. They also support the recommendations to improve research translation, reduce inequities and embed lived experience in decision-making.

The survey provides neurological-specific evidence that can inform the implementation of these broader national strategies and reforms. It also highlights the importance of coordinating action across them, as people living with neurological conditions frequently interact with health, disability, aged care, research and treatment-access systems simultaneously.

Meaningful improvement will therefore depend not only on progress within individual strategies, but on their collective implementation in a coordinated and person-centred way.

Recommendations

Based on the survey findings, the following recommendations are proposed to address the key gaps in neurological care and research identified across stakeholder groups. While the order broadly reflects the prominence of issues with the survey results, the recommendations should not be interpreted as ranked priorities; each is important and will require attention to achieve meaningful, system-wide improvement.

1. Increase investment in neurological research and its translation into practice

Sustained and targeted investment is required to improve understanding of neurological conditions and accelerate the translation of research into diagnosis, treatment, and care. Investment should prioritise areas of unmet need and strengthen pathways that ensure research delivers real-world impact. NAA's *Count Us In* campaign called for the establishment of a Neurological Research Mission within the Medical Research Future Fund.

2. Improve access to timely diagnosis and specialist care

Long delays in diagnosis and limited access to specialist services were consistently identified across stakeholder groups. Improving timely access to neurologists, diagnostic testing, and multidisciplinary care is critical to improving outcomes and reducing disease progression for people with neurological conditions and their families.

3. Strengthen workforce capacity across neurology and allied health

Shortages of neurologists, allied health professionals, and trained care staff are limiting access to care, particularly in regional and rural areas. Investment in workforce training, recruitment, and distribution is essential to meet current and future demand.

4. Establish coordinated, integrated models of care across systems

Fragmentation across health, disability, and aged care systems places a significant burden on people living with neurological conditions and their carers and family members. Coordinated, multidisciplinary models of care are needed across the life course of a person's condition supported by clear referral pathways, shared planning, effective information transfer, care coordination and navigation, and access to rehabilitation and long-term support. These models should connect primary, specialist, hospital and community-based care to improve continuity, reduce duplication, and support better outcomes. NAA's *Count Us In* campaign calls for improved Aged Care, Health and Disability sector integration.

5. Reduce inequities in access to care and support

Significant disparities in access to neurological care and support exist across geographic regions, age groups, and condition types, particularly for people in regional areas and those over 65. Policies and funding models must ensure equitable access regardless of location, age, or eligibility category.

6. Embed lived experience and carer perspectives in system design and research

Stakeholders consistently emphasised the importance of embedding lived experience and carer perspectives in research, policy, and service design. Greater inclusion will ensure systems are responsive to real-world needs and improve acceptability and outcomes.

7. Strengthen data, coordination, and national planning for neurological care

Improved data systems, national coordination, and long-term planning are needed to support decision-making, track outcomes, and align research, policy, and service delivery across the neurological care system.

Neurological Alliance Australia

13 August 2026

Appendix

TABLE A1. NEUROLOGICAL AND NEUROMUSCULAR CONDITIONS REPORTED BY PEOPLE LIVING WITH THESE CONDITIONS (N = 2761) IN DECREASING RANK ORDER

Neurological or Neuromuscular Condition	Percent of respondents with this condition
Migraine	21.26%
Post-polio syndrome	13.73%
Myalgic encephalomyelitis/chronic fatigue syndrome	12.17%
Fibromyalgia	11.41%
Polio	10.11%
Functional Neurological Disorder	9.60%
Multiple sclerosis (MS)	9.42%
Chronic headache	8.33%
Peripheral neuropathy	8.29%
Stroke / TIA	6.63%
Dystonia	6.34%
Parkinson's disease	5.11%
Acquired Brain Injury	4.96%
Myasthenia gravis	4.42%
Essential tremor	4.27%
Long COVID	3.95%
Spondylosis	3.15%
Cluster headache	3.08%
Inclusion Body Myositis (IBM)	2.90%
Generalised Epilepsy	2.32%
Ataxia	2.14%
Focal Epilepsy	2.06%
Brain tumour	1.96%
Dysautonomia / POTS / autonomic neuropathy	1.88%
Brain aneurysm	1.77%
Idiopathic intracranial hypertension	1.77%
Epilepsy type unknown	1.74%
Myositis	1.70%
Periodic limb movement disorder	1.56%
Other neurological or neuromuscular condition	1.34%
None of the above	1.23%

Neurological or Neuromuscular Condition	Percent of respondents with this condition
Motor neurone disease (MND)	1.01%
Leukodystrophy	0.91%
Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)	0.87%
Multifocal motor neuropathy	0.83%
Neurodevelopmental condition	0.83%
Other	0.83%
Spinal muscular atrophy (SMA)	0.80%
Vasculitis	0.80%
Pernicious anaemia	0.76%
Chiari malformation / syringomyelia / tethered cord	0.69%
Dementia	0.69%
Congenital muscular dystrophy or Myopathy	0.65%
Cranial neuralgia / facial pain	0.65%
Meningitis	0.65%
Narcolepsy	0.65%
Spinal cord / nerve root disorder or injury	0.65%
Charcot-Marie-Tooth Disease (CMT)	0.62%
Facioscapulohumeral Muscular Dystrophy (FSHD)	0.62%
Hydrocephalus	0.62%
Limb-Girdle Muscular Dystrophy	0.62%
CSF leak / intracranial hypotension	0.58%
Guillain-Barré syndrome	0.54%
Alzheimer's disease	0.51%
Encephalitis	0.51%
Hemifacial spasm	0.51%
Prefer not to say	0.51%
Autoimmune encephalitis	0.47%
Mitochondrial disease	0.47%
Vestibular disorder / PPPD / Meniere's disease	0.47%
Myotonic Muscular Dystrophy	0.40%
Other rare/complex epilepsy (including DEEs)	0.40%
Hereditary spastic paraplegia / SPG7	0.36%
Myoclonus/dyskinesia/fasciculation syndrome	0.33%
Corpus callosum disorder / agenesis	0.29%

Neurological or Neuromuscular Condition	Percent of respondents with this condition
Multiple system atrophy (MSA)	0.29%
Transverse myelitis	0.29%
Acoustic neuroma	0.25%
Complex regional pain syndrome	0.25%
Neurofibromatosis	0.25%
Spinal tumour	0.25%
Cerebrovascular malformation / vascular disorder	0.22%
Restless legs syndrome / Willis-Ekbom disease	0.22%
Cavernoma	0.18%
Huntington's Disease	0.18%
Spina bifida	0.18%
Becker Muscular Dystrophy	0.14%
Brain cyst / cystic mass	0.14%
Central sensitisation / allodynia	0.14%
Cranial nerve / nystagmus disorder	0.14%
Fragile X-associated Tremor Ataxia syndrome (FXTAS)	0.14%
Meralgia paresthetica	0.14%
Muscular dystrophy type unknown	0.14%
Myotonia/neuromyotonia	0.14%
Neuromyelitis optica	0.14%
Neuropathic pain syndrome	0.14%
REM sleep behaviour disorder / parasomnia	0.14%
Stiff person syndrome	0.14%
Tourette syndrome	0.14%
Arthrogryposis multiplex congenita	0.11%
Cerebral palsy	0.11%
Focal peripheral nerve entrapment / neuroma	0.11%
MOGAD	0.11%
PFBC / superficial siderosis / CADASIL	0.11%
Progressive supranuclear palsy (PSP)	0.11%
Spasmodic dysphonia	0.11%
Brachial neuritis / neuralgic amyotrophy	0.07%
Duchenne Muscular Dystrophy (DMD)	0.07%
HNPP	0.07%

Neurological or Neuromuscular Condition	Percent of respondents with this condition
Idiopathic hypersomnia	0.07%
Neuro-Sjögren's	0.07%
Pompe disease	0.07%
Rett syndrome	0.07%
Sensory/autonomic ganglionopathy	0.07%
Acute demyelinating encephalopathy	0.04%
Acute intermittent porphyria	0.04%
Auditory neuropathy spectrum disorder	0.04%
CNS/cerebral lupus	0.04%
Demyelinating disease	0.04%
Distal muscular dystrophy	0.04%
Dystrophinopathy	0.04%
Emery-Dreifuss muscular dystrophy	0.04%
Friedreich's ataxia	0.04%
HOMER gene-related condition(s)	0.04%
Machado–Joseph disease / Spinocerebellar ataxia type 3	0.04%
Methylmalonic acidemia	0.04%
Moebius syndrome	0.04%
Neurosarcoidosis	0.04%
Oculopharyngeal muscular dystrophy	0.04%
Polymicrogyria	0.04%
Raeder's syndrome	0.04%
RRN3/TIF-IA gene mutation	0.04%
Schwannomatosis	0.04%
Sciatica / radiculopathy	0.04%
SUNCT	0.04%
Toxic encephalopathy	0.04%
Tuberous sclerosis complex	0.04%
VCP muscular dystrophy	0.04%
Visual snow syndrome	0.04%

TABLE A2. NEUROLOGICAL AND NEUROMUSCULAR CONDITIONS REPORTED BY CARERS AND FAMILY OF PEOPLE LIVING WITH THESE CONDITIONS (N = 630) IN RANK ORDER.

Neurological or Neuromuscular Condition	Percent of respondents who are carers or family of a person living with this condition
Dementia	17.94%
Alzheimer's disease	8.89%
Parkinson's disease	8.89%
Functional Neurological Disorder	8.41%
Stroke / TIA	8.25%
Acquired Brain Injury	6.98%
Generalised Epilepsy	6.83%
Motor neurone disease (MND)	5.87%
Focal Epilepsy	5.71%
Multiple sclerosis	4.92%
Migraine	4.76%
Dystonia	4.44%
Leukodystrophy	4.29%
Huntington's Disease	3.49%
Other rare/complex epilepsy (including DEEs)	3.33%
Myalgic encephalomyelitis/chronic fatigue syndrome	3.17%
Post-polio syndrome	3.17%
Ataxia	2.86%
Epilepsy type unknown	2.86%
Polio	2.54%
Brain tumour	2.38%
Other neurological or neuromuscular condition	2.38%
Fibromyalgia	2.06%
Chronic headache	1.90%
Duchenne Muscular Dystrophy (DMD)	1.90%
Peripheral neuropathy	1.90%
Autoimmune encephalitis	1.75%
Hydrocephalus	1.75%
Brain aneurysm	1.43%
Cerebral palsy	1.43%

Neurological or Neuromuscular Condition	Percent of respondents who are carers or family of a person living with this condition
Dravet syndrome	1.43%
PANS / paediatric acute-onset neuropsychiatric syndrome	1.27%
Essential tremor	1.11%
Lennox–Gastaut Syndrome	1.11%
Tuberous sclerosis complex	1.11%
Agenesis of the corpus callosum	0.95%
Long COVID	0.95%
Mitochondrial disease	0.95%
Multiple system atrophy (MSA)	0.95%
Inclusion Body Myositis (IBM)	0.79%
Neurofibromatosis	0.79%
None of the above	0.79%
Vasculitis	0.79%
Charcot-Marie-Tooth Disease (CMT)	0.63%
Congenital muscular dystrophy or Myopathy	0.63%
Encephalitis	0.63%
AVM / arteriovenous malformation	0.48%
Friedreich's ataxia	0.48%
Hereditary spastic paraplegia	0.48%
Myositis	0.48%
POTS / dysautonomia	0.48%
Progressive supranuclear palsy (PSP)	0.48%
Spinal muscular atrophy (SMA)	0.48%
Spondylosis	0.48%
Tourette syndrome	0.48%
Cavernoma	0.32%
Cerebral palsy - spastic diplegia	0.32%
Cluster headache	0.32%
Dandy-Walker syndrome	0.32%
Facioscapulohumeral Muscular Dystrophy (FSHD)	0.32%
Limb-Girdle Muscular Dystrophy	0.32%
Lissencephaly	0.32%

Neurological or Neuromuscular Condition	Percent of respondents who are carers or family of a person living with this condition
Machado–Joseph disease / Spinocerebellar ataxia type 3	0.32%
Myotonic Muscular Dystrophy	0.32%
Periodic limb movement disorder	0.32%
Prefer not to say	0.32%
Radiation necrosis	0.32%
Trigeminal neuralgia	0.32%
Acoustic neuroma	0.16%
Aicardi-Goutières syndrome	0.16%
Alpha-mannosidosis	0.16%
Becker Muscular Dystrophy	0.16%
CASPR2-associated autoimmune neurological condition	0.16%
Chiari malformation and syringomyelia	0.16%
Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)	0.16%
Chronic vertigo / vestibular disorder	0.16%
COL4A1/TUBB2A/TUBB2B-related neurodevelopmental/cerebrovascular disorder; focal cortical dysplasia; leukoencephalopathy	0.16%
Congenital toxoplasmosis with neurological involvement	0.16%
Corticobasal degeneration (CBD)	0.16%
CSF leak / intracranial hypotension	0.16%
Gould syndrome / COL4A1 or COL4A2-related disorder	0.16%
Guillain-Barré syndrome	0.16%
Idiopathic intracranial hypertension	0.16%
Juvenile Batten disease / CLN3	0.16%
Juvenile Batten disease / neuronal ceroid lipofuscinosis	0.16%
KBG syndrome	0.16%
Klippel-Feil syndrome	0.16%
Labrune syndrome	0.16%
Late-onset Tay-Sachs disease	0.16%
Microcephaly	0.16%
Moyamoya disease	0.16%

Neurological or Neuromuscular Condition	Percent of respondents who are carers or family of a person living with this condition
Multiple syrinx / syringomyelia	0.16%
Muscular dystrophy - type unknown/being confirmed	0.16%
Myasthenia gravis	0.16%
Narcolepsy	0.16%
Neuromyelitis optica	0.16%
Niemann-Pick disease	0.16%
Periventricular nodular heterotopia (PVNH/ PBNH)	0.16%
PERM / anti-glycine receptor stiff-person spectrum disorder	0.16%
Pernicious anaemia	0.16%
POEMS Syndrome	0.16%
PPPD / persistent postural-perceptual dizziness	0.16%
Pure akinesia with freezing of gait	0.16%
REM sleep behaviour disorder	0.16%
Rett syndrome	0.16%
Spina bifida	0.16%
Spinal cord injury	0.16%
Spinal injury / post-laminectomy condition	0.16%
Spinal tumour	0.16%
Stiff-person spectrum / PERM	0.16%
Subcortical band heterotopia	0.16%
Superficial siderosis	0.16%
SYNGAP1-related neurodevelopmental disorder	0.16%
TCF20-related neurodevelopmental disorder with hypotonia	0.16%
Transverse myelitis	0.16%

Current Organisational Members

Current Associate Members

Individual researchers from:

- Macquarie University, NSW
- Murdoch Children's Research Institute, VIC
- Neuroscience Research Australia and Royal Prince Alfred Hospital, NSW
- Perron Institute for Neurological and Translational Science, WA

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