



NEURO MATTERS

THE STATE OF NEUROLOGICAL CONDITIONS
& SUPPORT IN QUEENSLAND

UNDERSTANDING **IMPACTS**, ADDRESSING **NEEDS**
& SEIZING **OPPORTUNITIES** TO **TRANSFORM LIVES**



NEED, IMPACT, OPPORTUNITY

TRANSFORMING THE LIVES OF QUEENSLANDERS
WITH NEUROLOGICAL CONDITIONS

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1. Foreword

Despite their profound impact, neurological conditions as a disease group are often overlooked, under-reported and lack adequate funding. The authors of this vital report are, therefore, to be commended for shedding light on the significant challenges faced by Queenslanders living with neurological conditions.

This report represents the collaborative efforts of Epilepsy Queensland, MS Queensland, and Parkinson's Queensland. They have diligently collaborated to gather data, insights, and opportunities to enhance understanding of the prevalence and impact of neurological conditions throughout the state.

The findings are compelling. They reveal a pressing need for targeted action to address the stigma, discrimination, and healthcare challenges faced by those living with these conditions.

A key message from this report is that neurological conditions should not be treated in isolation. They are interconnected with other health issues and require a holistic and integrated approach to care and support. This calls for the development of both a State Neuro Action Plan and a National Neuro Action Plan.

Queensland now has a unique opportunity to take the lead in transforming the lives of those affected by neurological conditions. By implementing the recommendations outlined in this report, we can reduce the burden of disease, improve the quality of life for individuals and their families, and alleviate the strain on healthcare systems.

It is my hope that this report serves as a catalyst for further actions in other states and territories, culminating in a national action plan for neurological conditions.

The need is compelling. The impact is undeniable. It is now time to make a meaningful difference for the one-in-four Queenslanders with neurological conditions.



Rohan Greenland
Chair
Neurological Alliance Australia

CEO
MS Australia

2. CEO Perspectives

Queensland has a unique opportunity to craft a lived experience led framework facilitated by collaborative partnerships to truly transform the lives of people and their families living with Neurological Conditions.

Epilepsy Queensland, MS Queensland and Parkinson's Queensland have been informally collaborating on improving the outcomes for people with Neurological Conditions for several years and bring forward this important foundational report outlining the state of play in relation to the prevalence and impact resulting from Neurological Conditions in Queensland.

For the first time, we've collated data, insights, and opportunities to outline a holistic picture of the many forms of Neurological Conditions. It is a sobering read.

We know from our own 70+ years working in the field that there are numerous clinical challenges that accompany Neurological Conditions. These challenges are compounded by widespread misunderstanding, stigmatisation and systemic discrimination, which in some cases impact the individual and their families far beyond the condition itself.

The *World Health Organisation's (WHO) Intersectoral Global Action Plan on Epilepsy and other Neurological Conditions* is a highly relevant framework to guide Queensland's Public Health System in formulating prioritised targeted responses to Epilepsy and other Neurological Conditions. These critical actions should occur before the burden of disease has significantly impacted not just on the 1 in 4 Queenslanders with a diagnosis but also reducing the enormous pressure that will inevitably be endured by the people and systems that support them.

The **need** is clear based on this report. The **impact** is far reaching and profound. The **opportunity** is ours to collectively make a positive and critical transformation.



Chris Dougherty

Chief Executive
Epilepsy Queensland



David Curd

Chief Executive
MS Queensland

Contributors

Chris Dougherty (CEO, Epilepsy Queensland)

David Curd (CEO, MS Queensland)

Dr Janette Hancock (Associate Consultant, I-exchange Australia)

Samantha Billington (Executive Projects Lead, MS Queensland)

Regina Gleeson (Quality, Legal & Risk Manager, MS Queensland)



3. Glossary

Acronym	Full Name
ABI	Acquired Brain Injury
AIHW	Australian Institute of Health & Welfare
CALD	Cultural & Linguistic Diversity
D&FV	Domestic & Family Violence
DALYs	Disability-Adjusted Life Years
GDP	Gross Domestic Product
GP	General Practitioner
HCP	Home Care Packages
IGAP	Intersectoral Global Action Plan
MD	Muscular Dystrophy
ME/CFS	Myalgic Encephalomyelitis / Chronic Fatigue Syndrome
MND	Motor Neurone Disease
MS	Multiple Sclerosis
NAA	Neurological Alliance Australia
NCMCC	National Centre for Monitoring Chronic Conditions
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NHS	National Health Service
NSF	National Service Framework
NSW	New South Wales
NWH	Neuro Wellness Hub
NT	Northern Territory
PBS	Pharmaceutical Benefits Scheme
QLD	Queensland
SA	South Australia
WA	Western Australia
UK	United Kingdom
US	United States
WHO	World Health Organisation
YLD	Years Lived with Disability
YLL	Years of Life Lost

4. Executive Summary

Finding out you have a Neurological Condition can be confronting and confusing, especially if you don't have easy access to advice and support. Neurological Conditions are tough to diagnose and treat. They create substantial challenges for patients, caregivers, families and healthcare systems.

The prevalence of Neurological Conditions in Queensland and across Australia is on the rise. It's impact is significant and far-reaching, and yet Neurological Conditions do not garner the attention that many other chronic diseases receive.

Part of the reason for this collective ignorance or misunderstanding that has arisen is the lack of reliable, comprehensive data on the prevalence, incidence, and impact of Neurological Conditions, which is largely limited and fragmented. Significant data gaps hinder comprehensive understanding and effective planning. Awareness-raising campaigns are either non-existent or small-scale, focused on individual conditions rather than Neurological Conditions as a 'whole'.

This report identifies alarming statistics and presents promising ways to move forward. To help people with Neurological Conditions receive optimal care for their complex, often long-term conditions. It found that **many of the Conditions that fall under the banner of Neurological Conditions share common symptoms, care needs, and treatments and that addressing them requires well-designed, integrated, responsive, and multidisciplinary responses.**

The report shows that Neurological Conditions require a macro view to understand how they are connected and coexist with other health conditions. It is crucial to understand how these conditions impact specific cohorts differently to provide personalised care and support.

The most significant and costly risk for Queensland is to do nothing.

There is an opportunity now to take strategic yet impactful steps to build a comprehensive state wide response to tackling Neurological Conditions. The following condenses these steps into seven key actions:

- **Coordinate Efforts** by establishing a dedicated sector led Queensland Neuro Alliance to bring together lived experience, peak organisations and key government stakeholders. This 'Neuro Alliance' will provide timely advice and co-designed solutions for enhancing the quality of care and support for those people, families and communities impacted by Neurological Conditions.
- **Develop A Cross-Government Neuro Care Framework** that delivers a comprehensive approach to developing Neurological awareness and care throughout the state, focusing on providing timely, integrated, and effective responses tailored to the specific needs of different cohorts and communities.
- **Educate, Promote, & Raise Awareness** about the profound impact of Neurological Conditions on individuals, families, and communities through a targeted, collaborative and multi-channel campaign. The campaign should inspire action and engagement by highlighting real stories, providing critical

information and encouraging proactive steps towards better Neurological health.

- **Develop Innovative Engagement Tools** for people with Neurological Conditions to significantly enhance their quality of life by providing accessible, user-friendly interfaces for interaction and support, such as a centralised **Neuro Gateway** drawing on existing curated content from the sector.
- **Create New Models Of Integrated Care & Support** to help people living with Neurological Conditions access holistic services that address the physical, cognitive and emotional aspects of their condition, such as a network of 'Neuro Wellness Hubs' strategically located across Queensland.
- **Invest In Improved Research & Data** that maps Queensland's similarities and differences across diverse demographic and social determinants. This will help facilitate the development of tailored interventions and policies that effectively address the specific needs of various population groups, ensuring more equitable and effective outcomes for all.
- **Improved Navigation Support Between The NDIS, Aged Care, Health Care & Disability Care Systems** to ensure people affected by Neurological Conditions have their needs met, regardless of which system they access.

Immediate action is required from the government and stakeholders to address these pressing issues and create a sustainable support system. This report is just the start of a conversation that will hopefully underpin and inform tangible actions that will **create a life-changing positive impact for the 1 in 4 Queenslanders living with a Neurological Condition.**

5. Summary of Sections

Each component of the report reveals crucial insights into the state of Neurological Conditions in Queensland, providing detailed Neurological data, analysis, and potential opportunities for action. Collectively, these components outline the current landscape, challenges, and crucial steps necessary to advance support and care for individuals with Neurological Conditions. The components cover the prevalence of conditions, their impact, financial support systems, support gaps, demographic considerations, responses in other states and internationally, and the benefits of awareness, early diagnosis, and targeted responses.

Component 1

Prevalence Of Neurological Conditions by Condition & Cohort

This component examines the increasing prevalence of Neurological Conditions in Australia and Queensland and highlights distinct patterns based on age, sex, and cultural background. It explores conditions such as MS, Migraines, Dementia, and ME/CFS, revealing that they are more common in women, while MND and Brain Injuries are more frequent in men. The analysis emphasises that First Nation people face a higher risk and severity of certain neurological conditions due to factors such as unhealthy diet, lack of exercise, smoking, and limited access to healthcare. It also highlights that ethnicity statistics for neurological conditions are severely underrepresented. The component emphasises the need for tailored health services and programs to effectively address these conditions.

Insights:

- C1-I-1** Prevalence estimates across all Neurological Conditions are increasing in Australia and in Queensland.
- C1-I-2** Prevalence data, where available, show clear age, sex and cultural patterns.
- C1-I-3** Some Neurological Conditions are unequally distributed between sexes and across age groups. MS, Migraines, Dementia and ME/CFS are more common in women, whereas MND and brain injuries are more frequent in men.
- C1-I-4** Dementia, Stroke, and Parkinson's Disease are more prevalent as age increases; however, MS and ABI primarily affect younger and middle-aged adults, while Muscular Dystrophy is present in childhood, and Epilepsy is present across the lifespan, with the highest diagnosis in young people (under 5) and the elderly (over 55).
- C1-I-5** First Nations Peoples are at a higher risk and severity of some Neurological Conditions due to modifiable and structural risk factors such as unhealthy diet, lack of exercise, high rates of smoking and poorer access to healthcare

services.

C1-I-6 One in five Queenslanders were born overseas, yet ethnicity statistics for Neurological Conditions are severely underrepresented in current data collection. Stigma, cultural beliefs, and lack of specific reporting are likely contributing factors to this.

C1-I-7 Impact Data suggests more people are diagnosed with early onset across many Neurological Conditions.

C1-I-8 The significant differences in how Neurological Conditions affect men, women, various age groups and populations highlight the importance of considering these patterns when planning health services and programs.

Component 2

Impact Of Neurological Conditions

This component examines the chronic nature and extensive impact of Neurological Conditions and highlights that these conditions often last several years or a lifetime. It explores how neurological conditions lead to various functional impairments, chronic pain, diminished quality of life, and significant emotional stress for families and caregivers. The analysis reveals the considerable healthcare burden and indirect financial costs associated with these Conditions, highlighting the need for holistic care approaches and comprehensive support systems.

Insights:

C2-I-1 The chronic nature of many Neurological Conditions lasts several years or even a lifetime.

C2-I-2 As the prevalence of Neurological Conditions grows, its contribution to the overall disease burden and social and economic impact in Queensland will escalate.

C2-I-3 Individuals with Neurological Conditions share many of the same impacts and needs. Neurological Conditions can:

- cause a range of functional impairments that affect mobility, dexterity, behaviour, communication or speech, cognition, consciousness, & emotion;
- result in chronic pain and discomfort;
- diminish the quality of life, limit education and work opportunities, reduce the ability to participate in activities and undermine financial security;

- cause significant emotional stress for families and caregivers due to their chronic and progressive nature;
- lead to feelings of stigmatisation;
- cause significant burden on the healthcare system, with conditions often requiring long-term care, including hospitalisations, medications, and rehabilitation;
- result in indirect financial burden through loss of productivity, caregiver burden, and long-term disability;
- negatively impact the individual's mental health due to their association with depression, anxiety, and cognitive impairment; and,

C2-I-4 Neurological Conditions can affect:

- men and women differently, with some Neurological Conditions being more common in men and others more common in women.
- children at birth or a young age, or adults in mid to late life, significantly changing their life trajectories as well as impacting their families; and
- informal caregivers, especially those looking after individuals with cognitive impairments or behavioural and mental health issues.

Component 3

Financial Support Systems & Participation by Cohort

This component examines the financial support systems available to individuals with Neurological Conditions, emphasising the critical importance of early access to funding packages and support. It explores the impact of thin NDIS markets, particularly in rural and remote areas, revealing that many Queenslanders are missing out on essential NDIS and aged care funding and supports. The analysis emphasises the significant economic burden of managing Neurological Conditions, estimated at an annual cost of \$24 Billion, underlining the need for targeted planning and resource allocation.

Insights:

C3-I-1 The costs associated with living with a Neurological Condition can be significant. These costs can impact daily living, from poor symptom management and financial stress to difficulties in maintaining employment and increased social isolation.

C3-I-2 The management of Neurological Conditions in Queensland incurs a significant economic burden, with an estimated annual cost of **\$24 Billion**



to the Government.

- C3-I-3** The substantial economic burden highlights the urgent need for targeted planning and resource allocation to manage the projected growth of Queenslanders living with a Neurological Condition.
- C3-I-4** Early access to funding packages and support can help manage the symptoms effectively and allow individuals to maintain a higher level of independence for a longer period.
- C3-I-5** There is a notable lack of comprehensive state-specific data on Neurological Conditions in Queensland, hindering a complete understanding of their effects on Queensland's healthcare system and the broader economy. This includes an absence of detailed NDIS and Aged Care funding breakdowns by Neurological Condition, categorised by age band and demographic distribution. The recent announcement of a \$550,000 Department of Health and Aged Care grant to the Australian Institute of Health and Welfare (AIHW) to develop a Neurological Condition dashboard will help address these data gaps.
- C3-I-6** What little data is available suggests some Queenslanders with Neurological Conditions are missing out on critical NDIS and Aged Care funding and supports.
- C3-I-7** Thin NDIS markets in rural and remote locations exacerbate the burden of Neurological Conditions for people living in those areas.
- C3-I-8** Incurable conditions like MS, early onset Parkinson's Disease and Dementia, which have fluctuating functional impacts and are likely to meet NDIS full access criteria over time, need streamlined access pathways to the NDIS before substantial functional decline occurs.
- C3-I-9** Every person with a disability must have equity of access to services and support to facilitate quality of life, independence, safety, and community participation, especially for those with rapidly progressing, degenerative, and complex disabilities like MND.
- C3-I-10** It is critical that the NDIS and Commonwealth Government-funded aged care systems provide comparable funding and accessible services, irrespective of age.
- C3-I-11** Increasing awareness, education, and understanding of Neurological and Neuromuscular Conditions among NDIA staff is essential for better administration of the NDIS. The recent approval to establish a Neurological Working Group within the NDIA will help address this issue.

Component 4

Map Support Gaps & Unmet Needs

This component examines the support gaps and unmet needs of people living with Neurological Conditions in Queensland and highlights the shortage of neurological specialists. It explores the impact of long wait times, delayed treatments, and barriers to accessing specialists, revealing significant disparities in service distribution, particularly in rural and remote areas. The analysis emphasises the urgent need for improvements in diagnostic communication, access to specialised care, and user-friendly information, underlining the necessity for innovative, holistic care solutions.

Insights:

- C4-I-1** There are not enough Neurological Specialists in Australia to meet the current, let alone future, growing needs of people with Neurological Conditions. This shortage leads to long wait times, delayed treatment, unnecessary presentations to hospital emergency wards, extended hospital stays and significant emotional distress.
- C4-I-2** With the number of people requiring Neurological care growing daily, it is critical to address service disparities, augment data collection, and guarantee comprehensive access to Neurological care.
- C4-I-3** Timely and equitable access to neurological services is crucial for treating and managing Neurological Conditions effectively.
- C4-I-4** Barriers to accessing Neurological Specialists can lead to delayed reviews, and treatments impacting multiple aspects of their life.
- C4-I-5** A significant disparity in service distribution, particularly in rural and remote areas, leads to uneven healthcare coverage. It is essential to find ways to ensure everyone in Queensland can access a Neurological Specialist when needed, regardless of their location.
- C4-I-6** Critical action is needed to improve diagnostic communication, access to specialised care in rural and remote regions, and user-friendly information.
- C4-I-7** Urgent unmet needs of Queenslanders with Neurological Conditions require immediate attention to enhance the quality of these peoples lives through the provision of comprehensive care.
- C4-I-8** Addressing the substantial challenges in Neurological care requires innovative holistic care and support solutions. This includes integrating health services with Neurological Care, as exemplified by the Neuro Wellness Hub initiative.

Component 5 Demographic Considerations

This component examines specific demographic considerations for Neurological Conditions and highlights that women and men may experience these conditions differently. It explores the barriers faced by First Nation peoples and those with different cultural backgrounds, greater exposure to modifiable risk factors, and the influence of socioeconomic status on health outcomes. The analysis reveals disparities in healthcare access and the significant impact of comorbidities, underlining the need for comprehensive data and targeted health strategies.

Insights:

- C5-I-1** Women and men experience the impact of some Neurological Conditions differently.
- C5-I-2** First Nations Peoples face numerous barriers to diagnosis and support for Neurological Conditions. They often have poorer access to healthcare services, which exacerbates their conditions. Key barriers include availability, cost, and the lack of culturally appropriate services.
- C5-I-3** First Nation peoples experience greater lifetime exposure to potentially modifiable risk factors for some Neurological Conditions.
- C5-I-4** The burden of individual Neurological Conditions attributable to various risk factors differed amongst people of different ages, sexes, socioeconomic status, and cultural backgrounds.
- C5-I-5** Socioeconomic status influences health outcomes for people with Neurological Conditions.
- C5-I-6** Disparity in healthcare access and support often leads to increased Disability and exacerbates the challenges associated with managing a Neurological Condition.
- C5-I-7** Neurological Conditions mental health and other disorders rarely exist in isolation.
- C5-I-8** Comorbidities significantly impact the severity, care needs, management and outcomes of Neurological Conditions.
- C5-I-9** Caregivers are at risk of poor health, too. People with Chronic Neurological Diseases are in the constant care of their families throughout much of their condition, placing significant physical and emotional burdens on caregivers.

Component 6 Neuro Response in Other States / Territories



This component examines the Neurological strategies in other Australian States and Territories and highlights the absence of a comprehensive health plan to address the growing burden of Neurological Conditions. It explores the NAA's recommended initiatives and recent AIHW funding, revealing the critical importance of Neurological Conditions to public health. The analysis emphasises that doing nothing is a risky, costly, and unacceptable option, highlighting the need for a coordinated, proactive response.

Insights:

- C6-I-1** Neurological conditions have been similarly neglected in Australia's public health and disability frameworks. They are often treated as isolated diseases rather than a collective concern, leading to a lack of comprehensive strategies to address their impact
- C6-I-2** An analysis of Australian state and territory health plans reveals that neurological conditions are rarely highlighted. Most plans focus on other chronic diseases like diabetes, heart disease, and mental health, with neurological conditions mentioned sporadically, if at all.
- C6-I-3** The gaps in the recent burden of disease findings by the Australian Institute of Health and Welfare (AIHW) and the WHO's Intersectoral Global Action Plan (IGAP) offers an opportunity where Queensland can take a leadership role in prioritising neurological conditions.

Component 7

Neuro Response Internationally

This component examines neurological care frameworks Worldwide and highlights consistent themes in National plans. It explores the importance of co-designing plans with lived experience and a patient-centred approach, revealing the critical need for service integration across different levels of care. The analysis emphasises the necessity of improving access to Specialist Neurological Services and investing in training for healthcare providers, underlining the need for robust data collection and public awareness campaigns.

Insights:

- C7-I-1** There are consistent common themes throughout England's, Ireland's, Scotland's, and Canada's National Neurological Care Frameworks.
- C7-I-2** Plans are co-designed with lived experience.
- C7-I-3** Plans emphasise a patient-centred approach, where care is tailored to individual needs through shared care planning and decision-making.
- C7-I-4** Integration of services across different levels of care is key, including coordination between primary care, secondary care, specialist services,

and community health services. This enables seamless care transitions and comprehensive treatment plans.

- C7-I-5** Improving access to Specialist Neurological Services is a common component. This includes increasing the availability of Neurologists, enhancing Telehealth Services, and ensuring timely referrals to Specialists for early diagnosis and treatment.
- C7-I-6** The use of interdisciplinary teams, including Neurologists, Nurses, Therapists, and Social Workers, is a priority for responding to the multifaceted needs of Neurological patients.
- C7-I-7** Investing in training and education for healthcare providers to build a skilled workforce is essential.
- C7-I-8** Raising public awareness about Neurological Conditions and reducing stigma is critical.
- C7-I-9** Ensuring equitable access to Neurological care for all population groups, including at risk and vulnerable populations and rural communities is a must.
- C7-I-10** Implementing robust data collection and monitoring systems to track outcomes, measure effectiveness, and inform policy decisions is essential.
- C7-I-11** Despite having a National Plan in place since 2005, there is still significant room for improvement in the UK's response to Neurological Conditions. This is not a good sign for jurisdictions that have not yet considered a plan.

Component 8

Benefits Of Awareness, Early Diagnosis, & Targeted Response

This component examines the benefits of awareness, early diagnosis, and targeted responses and highlights that prevention and early detection are crucial for reducing the burden on individuals, communities, and the public healthcare system. It explores the importance of a holistic approach to primary care and the role of specialist planning and care coordination, revealing the significant cost savings from awareness campaigns. The analysis emphasises the need for robust, standardized data and research, underlining the importance of comprehensive surveys to map current service gaps.

Insights:

- C8-I-1** Given the broad impacts of Neurological Conditions the prevention and early detection are crucial for reducing the burden on individuals, communities, and healthcare systems.

- C8-I-2** If individuals do not receive timely and effective interventions after diagnosis, the impact on the health care system is significant.
- C8-I-3** A more holistic approach to primary care for patients that unites general practitioners, specialists, and allied health professionals, along with access to assistive technology, is crucial for maintaining quality of life, social engagement, and independence.
- C8-I-4** Specialist planning and care coordination, including a proactive decision-making framework are essential to achieving improved health care outcomes.
- C8-I-5** Barriers to accessing care, such as a lack of access to specialists insufficient training for GP's exist in rural and remote areas, making it challenging to receive specialist care and support.
- C8-I-6** Awareness campaigns for Neurological Conditions save money. By educating the public about symptoms and encouraging timely medical consultations, campaigns can reduce the burden on healthcare systems, lower emergency care costs, and improve management of Chronic Conditions.
- C8-I-7** The lack of a large-scale national or state Neurological survey makes it difficult to map the current gaps in the neuro service landscape fully.

5. Opportunities For Action

Component 1

Prevalence of Neurological Conditions by Condition & Cohort

C1-O-1

Data Collection Improvement:

Prioritise financial investment, resource allocation, and coordinated data collection strategies to address gaps in gender and ethnic - specific research on the profound difference between men and women and CALD and First Nations populations living with Neurological Conditions.

C1-O-2

Targeted Messaging:

Implement early awareness and intervention campaigns tailored to the specific needs of different demographic groups, ensuring messages resonate with all gender identities, First Nations Peoples, and CALD groups.

C1-O-3

Tailored Approaches:

Develop gender-specific medical treatments and preventive strategies, recognising that men and women often have distinct biological and physiological differences. These differences may require tailored diagnostic procedures and therapeutic approaches to effectively address gender-specific health needs and improve overall outcomes for both men and women.

C1-O-4

Disparity Awareness:

Plan support services with a greater understanding of the disproportionate impact on caregiver burden, loss of productivity, and higher healthcare costs across different cohorts.

Component 2

Impact of Neurological Conditions

C2-O-1

Coordinate Efforts:



By establishing a dedicated sector led Queensland Neuro Alliance to bring together lived experience, peak organisations, and key government stakeholders. The Neuro Alliance would provide timely advice and co-designed solutions for enhancing the quality of care and support for those people, families and communities impacted by Neurological Conditions.

C2-O-2 **Develop A Neuro Care Framework:**

Create a comprehensive approach to Neurological care throughout the state, focusing on providing timely, integrated, and effective responses tailored to the specific needs of different patient groups. A Neuro Action Plan would form an important element of the Framework.

C2-O-3 **Educate, Promote, and Raise Awareness:**

About the profound impact of Neurological Conditions on individuals, families, and communities through a targeted, collaborative and multi-channel campaign. The campaign would inspire action and engagement by highlighting real stories, providing critical information and encouraging proactive steps towards better Neurological health.

Component 3 **Financial Support Systems & Participation by Cohort**

C3-O-1 **Improve Access to the NDIS:**

Improve access to the NDIS for people diagnosed with Neurological Conditions to ensure early intervention support is applied at the earliest possible stage of the course of the Disease.

C3-O-2 **Enhanced System Integration:**

Mandate and facilitate the navigation between public health disability and aged care systems to ensure coordinated service delivery and improved outcomes for people affected by Neurological Conditions, regardless of the system they access..

C3-O-3 **Enhance Data Collection:**

Invest in comprehensive data systems that track detailed information on system usage and patient demographics to improve decision-making and targeted healthcare interventions.

Component 4 **Map Support Gaps & Unmet Needs**

C4-O-1 **Enhanced Diagnostic Communication:**

Establish clear guidelines and training programs for healthcare providers to improve their communication skills and ensure patients fully understand their diagnoses and treatment options.

C4-O-2 **Integrated Mental Health Support:**

Incorporate mental health services into Neurological departments by employing specialists and training staff to blend care approaches, providing comprehensive care for psychological and physical health needs.

C4-O-3 **Centralised Support Platform:**

Create a digital gateway listing all Neurological support services in Queensland to simplify patient access to necessary care, make information more accessible, and reduce fragmentation.

C4-O-4 **Community-Centric Neuro Wellness Hubs:**

Establish community-centric hubs, especially in rural and remote areas, to provide comprehensive resources and support services, enhancing access and community engagement while reducing service fragmentation.

C4-O-5



Rural Neurologist Incentives:

Provide incentives for Neurologists to work in rural areas and support the adoption of Telehealth technologies, improving access to Neurological Services in underserved regions.

C4-O-6 Navigating Support:

Establish a personalised centrally led but locally focused service that provides critical and timely over the phone or virtual support and advice for people at the point of diagnosis to help simplify the complex maze of health and support systems.

Component 5 Demographic Considerations

C5-O-1 Improved Research & Data:

Boost investment in research that maps the similarities and differences across diverse demographic and social determinants to understand the prevalence and impact of Neurological Conditions in Queensland.

C5-O-2 Enhanced Data Linking:

Link existing data to better identify and understand the specific needs of all populations, informing more effective and equitable healthcare strategies.

C5-O-3 Preventative Policies:

Focus on preventive health policies, health promotion, and education that address the different burdens of Neurological Conditions across age groups and sexes.

C5-O-4 Overall, Health Approach:

Explore interventions for Neurological Conditions that combine treatments for Comorbid Conditions, particularly for First Nations Peoples.

C5-O-5 **User-Friendly CALD Supports:**

Invest in culturally accessible entry points and navigation support for CALD people in Queensland with Neurological Conditions and their families.

C5-O-6 **Making Family Caregivers Visible:**

Recognise caregivers' significance as part of the healthcare team and provide them comprehensive support for their mental, physical, and overall well-being.

Component 6 **Neuro Response in Other States / Territories**

C6-O-1 **Queensland Leadership In Neurological Care:**

Develop a cross-Government and sector Neurological Care Framework as a critical pillar of Queensland's Public Health and Disability Plans, involving careful co-design with key stakeholders and incorporating the lived experiences of individuals affected by Neurological Conditions.

C6-O-2 **Leveraging NAA's Work & Insights:**

To position Queensland as the leader amongst States and Territories in addressing the challenges imposed by Neurological Conditions, they can utilise the NAA's work to

- Recognise Neurological Conditions as Chronic Diseases to ensure appropriate attention and resources.
- Develop a coordinated and co-designed response to Neurological care.
- Ensure quality data collection for informed decision-making and targeted interventions.

Component 7

Neuro Response Internationally

C7-O-1 **Dedicated Queensland Neuro Taskforce:**

Form a taskforce with key sector and Government stakeholders and people with lived experience to drive Neuro-specific actions across Queensland.

C7-O-2 **Develop Neuro Care Framework:**

Provide a comprehensive approach to Neurological care across the state, focusing on enhancing diagnostic communication skills, integrating services, improving access to specialist care, developing centralised resources, and using interdisciplinary teams.

Component 8

Benefits of Awareness, Early Diagnosis, & Targeted Response

C8-O-1 **Invest In Data Collection & Research:**

Conduct a large-scale Neurological survey to identify current gaps and inform service delivery and planning.

C8-O-2 **Targeted Public Awareness Campaigns:**

Educate the public about symptoms and encourage early diagnosis and better management of Neurological Conditions.

C8-O-3 **Innovative Communication Tools:**

Develop user-friendly interfaces for interaction and support, such as a centralised gateway, to significantly enhance the quality of life for people with Neurological Conditions, and their family / carers.