

# Response ID ANON-VV54-Y1X7-E

Submitted to Public Consultation on the refresh of the National Strategic Framework for Chronic Conditions  
Submitted on 2024-03-19 17:20:52

## Introduction

## Privacy Notice

## Demographics

1 Which stakeholder group best describes you? Please tick all that apply.

National not for profit non-government organisation

## Part 1: Overview of the Framework

2 Have you engaged with and used the Framework, and if so, how? Please tick all that apply. There is also the option to include any other information about your engagement with the Framework in the 'Other' open-text response box.

An organisation that I am engaged with shared the document with me, To guide the development of policies, programs and/or projects for the organisation I represent

(Optional) Other::

The Neurological Alliance Australia (NAA) was established in 2010 to give a strong, collective voice to promote and advocate for improved quality of life for people living with these conditions and increased funding to support research.

Since that time, the NAA has grown to include 21 not-for-profit peak or national patient organisations representing millions of adults and children living with progressive neurological or neuromuscular conditions or neurological disorders in Australia, their families and carers.

The Alliance aims to promote shared issues and concerns for the improved quality of life for people living with these conditions and funding to support research into the prevention, treatment, better management and ultimately a cure for these conditions.

The Framework takes a very broad approach to chronic conditions and as such, does not address the specific needs of the neurological communities.

## Part 1: Overview of the Framework

3 The Vision of the Framework (Vision) is: "All Australians live healthier lives through effective prevention and management of chronic conditions."

Question 3A - To what extent do you agree the Vision is still relevant?:  
Somewhat agree

(Optional): Please provide further comments about your response, including any suggested amendments to the Vision.:

In the case of neurological conditions, not all can be prevented and early recognition of symptoms, detection and diagnosis is vital to minimising or delaying disease progression and resulting disability. Suggested amendment, "All Australians live healthier lives through effective prevention, detection, diagnosis, access to treatment and management of chronic conditions."

## Part 1: Overview of the Framework

4 Please provide a score from 0-10 to demonstrate how important you think each of the enablers are (with 0 being not at all important and 10 being very important).

Question 4A - 1. Governance and leadership — supports evidence-based shared decision-making and encourages collaboration to enhance health system performance.:  
10

Question 4A - 2. Health workforce — a suitably trained, resourced and distributed workforce is supported to work to its full scope of practice and is responsive to change.:  
10

Question 4A - 3. Health literacy — people are supported to understand information about health and health care and appropriate health care settings, to apply that information to their lives and to use it to make decisions and take actions relating to their health.:  
10

Question 4A - 4. Research — quality health research accompanied by the translation of research into practice and knowledge exchange strengthens the evidence base and improves health outcomes.:  
10

Question 4A - 5. Data and information — the use of consistent, quality data and real-time data sharing enables monitoring and quality improvement to achieve better health outcomes.:

10

Question 4A - 6. Technology — supports more effective and accessible prevention and management strategies and offers avenues for new and improved technologically driven initiatives.:

10

Question 4A - 7. Resources — adequate allocation, appropriate distribution and efficient use of resources, including funding, to address identified health needs over the long-term.:

10

(Optional): Are there any other enablers you think should be included in the Framework?:

Other enablers:

Community Engagement and Participation: Involving communities, patients, caregivers, and stakeholders in the planning, implementation, and evaluation of initiatives fosters ownership, relevance, and sustainability. Community engagement ensures that interventions are culturally appropriate, accessible, and responsive to local needs.

Monitoring, Evaluation, and Continuous Improvement: Establishing robust monitoring and evaluation mechanisms allows for tracking progress, identifying gaps, and adapting strategies based on feedback and evidence. Regular review and refinement of the framework ensure its relevance, effectiveness, and sustainability over time.

## Part 2: Objectives of the Framework

5 Please discuss which, if any, of the above determinants of health have most significantly impacted you or the work of your organisation. Additionally, are there any other determinants of health that you think the Framework should focus on? If yes, please note them.

(Optional)::

Genetic Predisposition: Genetic factors play a significant role in the susceptibility to certain neurological conditions. Understanding genetic predispositions can inform risk assessment, early detection, and personalised treatment strategies.

## Part 2: Objectives of the Framework

6 To what extent do you agree with the following statements?

Question 6A - Australians with chronic conditions can easily access primary care services, including regular care with a GP and/or allied health providers.:  
Somewhat disagree

Question 6A - Australians with chronic conditions can easily access specialty healthcare services when required.:  
Somewhat disagree

(Optional): Please provide further comments about any of your responses to the previous statements.:

Australians with neurological conditions face barriers to access associated with:

- geographical barriers where thin markets operate in rural, regional and remote communities
- specialised neurological care such as disease specific clinicians, including specialist nurses and allied health professionals who are specialist in neurological conditions.

## Part 2: Objectives of the Framework

7 To what extent do you agree with the following statement?

Question 7A - I have access to health information and data, and use this to help make decisions regarding the prevention, diagnosis, treatment and management of chronic conditions.:  
Somewhat disagree

(Optional): Please provide further comments about your response, and if appropriate, provide examples of ways you have or have not used information and data.:

From a peak body perspective, most of the Neuro Alliance members have considerable data gaps for their specific disease group. These peak bodies have in the past allocated scarce resources to commissioning consultants to provide demographic and economic impact data. This data is a key foundation for building a platform for planning and prioritising health policies and evaluating the effectiveness of intervention programs and initiatives. Smaller peak bodies representing fewer patients with less resources have to manage without accurate up-to-date data sets and reports or by making assumptions based on overseas studies.

Minimal data sets might include basic information such as condition prevalence, incidence, hospitalisations, accidents and emergency presentations, contribution to deaths, burden of disease and economic impact. The AIHW is best placed to collect and report this information as it does for the other chronic conditions such as dementia (in adults) and epilepsy

## Part 2: Objectives of the Framework

## 8 To what extent do you agree with the following statements?

Question 8A - 1. Australians living with chronic conditions, including myself, friends/family, patients, or members of the organisation I represent if applicable, are recognised in the Framework.:

Disagree

Question 8A - 2. The Framework is representative of the diversity of population groups in Australia.:

Somewhat disagree

Question 8A - 3. The Framework recognises the individual needs of the many different groups in Australia.:

Somewhat disagree

Question 8A - 4. The Framework provides guidance about how the prevention and management of chronic conditions can be tailored to the needs of different population groups.:

Disagree

(Optional): Please provide further comments about any of your responses to the previous statements.:

Neurological conditions are not identified or mentioned at all in the consultation paper.

Despite "neurological conditions" being identified as one of the top five burdens of disease reported in the AIHW Burden of Disease study published in Dec 2023.

Also despite the WHO issuing a "call to action" to member states (including Australia) in 2022 through its Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Conditions.

The consultation does not mention this IGAP report.

There is no national data set for neurological conditions.

Based on overseas data, there are approximately 1 in 6 Australians living with neurological conditions with an annual impact on the Australian economy of over \$100 billion

They represent around 14% of NDIS participants.

## Part 2: Objectives of the Framework

9 Please provide information known to you on the experiences of people with chronic conditions in the above, or additional, priority population groups including any challenges and barriers in accessing prevention and/or treatment services that you think may be of relevance to the refresh of the Framework.

(Optional)::

Disparities in healthcare access and quality can disproportionately affect racial and ethnic minority groups. Factors such as socioeconomic status, cultural beliefs, language barriers and discrimination can hinder access to neuro care. Individuals with neuro conditions in low-income groups struggle to afford medications, specialist visits and diagnostic tests. LGBTQ+ individuals face discrimination when disclosing their diagnosis and may not disclose their sexual orientation or gender identity to healthcare professionals, leading to suboptimal care and treatment outcomes. Alzheimers and Parkinsons are more prevalent among the elderly with barriers of mobility, cognitive decline, limited social support networks, making it challenging to access preventive services and adhere to treatment regimens. Those with disabilities experience compounded barriers to neuro care due to accessibility issues, communication challenges, and healthcare discrimination.

## Part 3: Focus on the Future

10 Potential barriers for people with chronic conditions are shown below. Which of these barriers do you believe significantly impact Australians living with chronic conditions (including yourself if applicable)? Please select all that apply.

Difficulty in finding an appropriate healthcare provider or facility, Long wait lists, Lack of coordinated care and communication between health professionals, Lack of information sharing and exchange between healthcare providers, Financial cost of healthcare, Limited awareness and understanding of chronic conditions and/or prevention by patients and/or carers, Limited understanding of the healthcare system by patients and/or carers, Limited knowledge of some chronic conditions by healthcare professionals, Stigma associated with chronic conditions and risk factors, Not being able to attend appointments due to geographical location/transport, Difficulty using technology to receive or navigate healthcare services, Lack of health promotion education and prevention activities, Limited availability of publicly funded health programs, Lack of access to research and data

(Optional): Are there any other barriers that you would like to draw attention to?:

A "whole of disease journey", person-centered approach is needed to ensure people get access to the right services and support at the right time. There is an urgent need to improve the interface between the Aged Care, Health and Disability sectors to improve care, health and wellbeing.

People living with neurological conditions need to access the health, disability and aged care sectors as their condition progresses.

Referral services between sectors need to operate effectively and movement of people between these sectors needs to be realistic, measured and safe.

## Part 3: Focus on the Future

11 Do you support this description of the inter-relationship between the Framework and condition specific Action Plans and Strategies?

Yes

(Optional): Please elaborate on your response.:

There is currently no Action Plan for neurological conditions.

The WHO issued a "call to action" to member states (including Australia) in 2022 through its Intersectoral Global Action Plan (IGAP) on Epilepsy and Other Neurological Conditions.

The forward to the IGAP states "The plan's ambitious scope is designed to address the long-standing neglect of neurological disorders. Member States, national and international partners, and WHO must work together to realize the action plan's vision of a world in which brain health is valued and protected across the life course; neurological disorders are prevented, diagnosed and treated; premature mortality and morbidity are avoided; and people affected by neurological disorders have equal rights, opportunities, respect and autonomy." The consultation does not mention this IGAP report. A National Blueprint for Neurological Conditions is needed to address the specific needs of this cohort.

### Part 3: Focus on the Future

12 Do you support this approach?

Yes

(Optional): Please elaborate on your response.:

Priorities for neurological conditions:

They can arise from genetics, developmental issues, trauma, infections, autoimmune responses, or degenerative processes. Often the cause is unknown. A deep understanding of neurophysiology and expert multidisciplinary approach is essential.

They manifest in a wide range of often invisible symptoms, eg motor difficulties, sensory disturbances, cognitive impairments and emotional changes, making speedy diagnosis and treatment planning challenging.

Most are progressive and degenerative; they persist over time and worsen gradually requiring flexibility in care. Treatment options vary widely. Some benefit from medications, therapies, or surgical interventions, others have no treatment options.

They significantly impact a person's quality of life, eg limited mobility, independence, communication, cognition and social interactions and stigma.

Managing these conditions involves addressing the disease and physical symptoms and psychosocial aspects.

### Part 3: Focus on the Future

13 Do you believe a focus on these common issues is relevant, accurate and appropriate for Australians living with a chronic condition?

Yes

(Optional): Please elaborate on your response and/or include any other common issues across chronic conditions that you would like to note.:

Yes, these common issues are relevant, accurate and appropriate for people with neurological conditions.

In addition, people with neurological conditions need speedy and effective detection, diagnosis, and access to treatment as soon as possible to prevent or delay progression resulting in disability.

They also need "transition of care" not only through the health system, but also through the disability and aged care systems.

### Part 3: Focus on the Future

14 Please provide information on any opportunities for digitisation to enhance the prevention, treatment and management of chronic conditions.

(Optional)::

People living with neurological conditions have benefited from enhanced health-related technology and digitisation in recent years. Expanded use of telehealth and the use of e-scripts are good examples, though the use of e-scripts is, at best, patchy as some hospitals and clinics have incompatible software systems. A similar problem exists in the use of My Health Record which has the potential to alleviate the need for people to amass volumes of hard copy test results but many clinics and other providers are still not uploading this material.

The development of apps and online portals in recent years has helped some people living with neurological conditions to more carefully monitor their disease journey.

Artificial intelligence (AI) has significant potential to transform neurology by enhancing the speed and accuracy of detection, diagnosis and treatment. A significant body of research already exists on the use of these new digital techniques and biomarkers.

### Part 3: Focus on the Future

15 Please describe any impacts (positive or negative) of COVID-19 that you would like to highlight.

(Optional)::

For people living with neurological conditions:

Negative:

-fear of impact of COVID-19 and vaccines on their condition and treatment complications

- accessing trusted sources of information about COVID-19 and impact on their condition
  - visiting healthcare clinics and keeping appointments became problematic for those using immuno suppressing medications to treat their conditions for fear of exposure
  - increase in social isolation and loneliness
  - need to address the implications of impact of long COVID
- Positive:
- increase in use of telehealth
  - increase in use of virtual peer support

### Part 3: Focus on the Future

16 Which of the following statements are most important to you in terms of how the Australian Government enhances and uses the Framework in the future? Please select up to 5 options.

Greater promotion of the Framework to health professionals and researchers to increase awareness, Increased focus on how organisations can work together to improve the management of chronic conditions, Improve the collaboration between state and territory governments and the federal government, Refresh the content of the Framework to be better aligned with other state and territory, national and international policies, strategies and plans, Increased focus on the importance of lived experience in the Framework

### Part 4: Summary

17 In 1000 words (6000 characters) or less, please provide any additional feedback on the Framework including any other opportunities to improve the Framework.

(Optional): :