NEUROLOGICAL
ALLIANCE
AUSTRALIA

Submission to the Australian Bureau of Statistics 2026 Census topic review

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The Neurological Alliance Australia (NAA) is *an alliance of 15 not-for-profit peak or national patient organisations representing adults and children living with progressive neurological or neuromuscular diseases or neurological disorders in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and increased funding to support research. Members of the Alliance are: Dementia Australia, Brain Injury Australia, Emerge Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia, Spinal Muscular Atrophy Australia, Leukodystrophy Australia, the Childhood Dementia Initiative, the Mito Foundation and Polio Australia.*

Some NAA members are providers under the NDIS, offering support coordination, allied health and/or other supports. Most members provide information and navigation services funded through separate sources such as fundraising and philanthropy.

The Neurological Alliance Australia represents *nearly 2 million Australians living with the conditions represented by the members of the Alliance with an annual impact on the Australian economy of over $50 billion.*

RECOMMENDATION:

That a question be added to the 2026 census regarding diagnosis of a neurological condition.

The case for establishing a neurological data set for Australia

The NAA member organisations experience considerable data gaps for their specific disease group.

These peak bodies have, in the past, allocated scarce resources to the commissioning of consultants to provide basic demographic and economic impact data. These data are a key foundation for building a platform for planning and prioritising health policies, evaluating the effectiveness of intervention programs and initiatives and providing tailored supports and services to people living with these conditions, their carers and families. Many smaller peak bodies representing fewer patients and with less resources have to manage as best they can without accurate up-to-date data sets and reports or by extrapolating or making assumptions based on overseas studies.

The conditions represented by the NAA are expensive and may increase over time as they are commonly progressive – both to the individual and to the Australian economy. They cause a significant impact on a person's quality of life, their ability to work and to engage fully with their family, friends and the community.

Prevalence data are fundamental

Prevalence data are a fundamental building block for disease-related datasets. Prevalence refers to the number of individuals in a population who have a specific disease or condition at a particular point in time or over a specific period. These data are crucial for understanding the burden of disease in a population and for identifying patterns and trends in disease occurrence.

Prevalence data can also be used to estimate the risk of developing a disease, which is important for designing prevention and control strategies. In addition, prevalence data can help identify populations that are at higher risk of developing a particular disease or condition, which is useful for targeting interventions and resources.

Other important disease-related data that can be built upon prevalence data include incidence, mortality, and morbidity data. Incidence refers to the number of new cases of a disease that occur over a specific period, while mortality refers to the number of deaths caused by, or related to, a particular disease. Morbidity refers to the impact of a disease on an individual's health, including symptoms, complications, and disability.

Overall, prevalence data are a critical component of disease-related datasets, providing important insights into the burden of disease, risk factors, and patterns of disease occurrence.

Building on prevalence data

Minimal data sets that build on prevalence data might include basic demographic information such as condition incidence, hospitalisations, accidents and emergency presentations, contribution to deaths, burden of disease and economic impact.

The NAA believes that the Australian Institute of Health and Welfare (AIHW) is currently well placed to collect and report some of this information as it does for certain chronic neurological conditions such as dementia[1] (in adults) and epilepsy[2], however this information is not comprehensively and routinely collected for *all* neurological conditions.

Responding to the WHO Global Action Plan on Epilepsy and Other Neurological Conditions 2022-31

Notably, the recent World Health Organisation (WHO) Global Action Plan on Epilepsy and Other Neurological Conditions 2022-31[3] includes a focus on data and information systems, with a list of actions for Member States, namely:

Actions for Member States:

212. Integrate monitoring of neurological disorders into routine information systems and across all levels of care and identify, collate, routinely report and use core data, disaggregated by sex, age and other equity measures in order to improve neurological care service delivery, promotion and prevention strategies and provide an understanding of the social determinants of neurological disorders.

213. Analyse and publish data collected on the availability and evaluation of utilisation and coverage of services and effective treatments for neurological disorders to improve care and delivery of programmes.

In light of this 'call to action' from WHO and the significant data gap for neurological conditions in Australia, the NAA is very keen to progress work to address this gap.

Looking to the future

The NAA has commenced discussions with the AIHW to identify current national neurological data gaps and opportunities for monitoring neurological conditions,

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[1] https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/about

[2] https://www.aihw.gov.au/reports/chronic-disease/epilepsy-in-australia/contents/about

[3] https://www.who.int/news/item/28-04-2022-draft-intersectoral-global-action-plan-on-epilepsy-and-other-neurological-disorders-2022-2031

with a view to improving health outcomes for people living with neurological conditions and inform evidence-based policy.

The NAA proposes that a very specific question be included in the 2026 Census to identify chronic neurological conditions, such as:

Have you been diagnosed with one of these neurological conditions, please tick:

- Dementia
- Acquired Brain Injury
- Huntington's Disease
- Leukodystrophy
- Machado Joseph Disease
- Mitochondrial Disease
- Motor Neurone Disease
- Multiple Sclerosis
- Muscular Dystrophy
- Myalgic encephalomyelitis/chronic fatigue syndrome
- Parkinson's Disease
- Polio
- Spinal Muscular Atrophy
- Other

We also feel that online completion of the Census makes it much easier to add cascading questions such as this one.

Long-term health conditions

There are currently a set of questions in the census relating to long-term health conditions: https://www.abs.gov.au/articles/long-term-health-conditions. Respondents have the option to choose from a range of conditions including mental health condition, arthritis, asthma, diabetes, heart disease, cancer, lung condition, stroke, kidney disease and dementia.

A further consideration would be to add the neurological conditions set out above to the list of long-term health conditions people can choose from.

Prevalence data collected through the Census would provide a comprehensive underpinning for other burden of disease and economic impact studies.

The NAA thanks the ABS for the opportunity to provide input into its 2026 Census topic review.

For more information about this submission and the work of the Neurological Alliance Australia please contact:

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