



Submission to the Treasury Measuring What Matters consultation

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The Neurological Alliance Australia (NAA) is an alliance of 16 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, Polio Australia and the Fragile X Association of Australia Inc.

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 Treasury, through the Department of Health allocate \$550,000 to the Australian Institute of Health and Welfare to address the current neurological data gaps and opportunities, including:

- **\$400,000 for a scoping study leading to the development of a minimum data set for neurological and neuromuscular conditions in Australia.**
- **\$150,000 for a data report on neurological conditions in Australia that would report the latest available data.**

The case for establishing a neurological data set for Australia

The members of the NAA welcome this opportunity to make a submission to the Treasury’s Measuring What Matters consultation.

Our NAA member organisations experience considerable data gaps for their specific disease groups and the communities they represent. This was a major issue identified at a workshop of NAA members in August 2022.

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.

We believe that the establishment of this neurological data set will enable further metrics to be applied, specifically to those communities impacted by a variety of policy proposals and decisions.

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 dementia¹ (in adults) and epilepsy², 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 2022-31³ 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.*

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>

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

Representatives of the NAA met with the AIHW in November 2022 to discuss the current national neurological data gaps and opportunities for monitoring neurological conditions, with a view to improving health outcomes for people living with neurological conditions and inform evidence-based policy. The AIHW advised that there are two essential projects that must be undertaken to establish the current neurological data gaps and opportunities:

- A scoping study that comprises a short report reviewing and assessing Australian data sources for neurological conditions across the lifespan, including identifying gaps and opportunities for data improvements pertaining to the topics of interest; and
- A data report on neurological conditions in Australia that would report the latest available data.

A copy of the proposal developed for the NAA by the AIHW is set out in the attachment.

The outcome of these projects can then help to guide the future monitoring of neurological conditions by the AIHW. The AIHW have recently undertaken a similar project with the creation of the National Centre for Monitoring Dementia (NCMD) which was established to undertake a range of data improvement activities. This included scoping data gaps and opportunities, a comprehensive data report and the implementing an ongoing monitoring and reporting program for dementia in Australia.

Alignment to the consultation policy themes, descriptors and indicators

The NAA believes that the establishment of a neurological data set is directly related to the Measuring What Matters consultation policy themes, descriptors and indicators as set out in Table 1 of the consultation document under the “Health” heading (reproduced below).

Whilst it may be possible to measure these indicators in very broad terms, it will not be possible to effect improvements in health, aged care and disability care outcomes for people with chronic conditions, without the sound underpinning of data.

Healthy

A society in which people feel well and are in good physical and mental health now and into the future

- A society in which people are in good physical health.
- A society in which people are in good mental health.
- A society that ensures the health and development of its children.
- A society in which people are generally satisfied with their life.
- A society where people have enough time for family, friends, personal interests and their community.
- A society that values the contributions of all regardless of health or ability.

Conclusion

The NAA welcomes the opportunity to contribute to the Treasury Measuring What Matters consultation.

We believe that the establishment of a neurological data set will serve as a cornerstone for advancements in neurological research, clinical practice, personalised medicine and the provision of services and support. By harnessing the power of big data and applying sophisticated analytical techniques, we can pave the way for innovative treatments, improved patient outcomes, and a deeper understanding of the impact of these conditions on those diagnosed, their carers, family and friends and the broader community.

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

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