

Public Submission Cover Sheet

Please complete this sheet and submit with any attachments to the Sustainable Health Review Secretariat

Your Personal Details

This information will be used only for contacting you in relation to this submission

Title	Mr <input type="checkbox"/> Miss <input type="checkbox"/> Mrs <input type="checkbox"/> Ms <input type="checkbox"/> Dr <input type="checkbox"/> Other <input checked="" type="checkbox"/>
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Publication of Submissions

Please note all Public Submissions will be published unless otherwise selected below

- I do not want my submission published
- I would like my submission to be published but remain anonymous

Submission Guidance

You are encouraged to address the following question:

In the context of the Sustainable Health Review Terms of Reference listed below, what is needed to develop a more sustainable, patient centred health system in WA?

- Leveraging existing investment in Primary, Secondary and Tertiary healthcare, as well as new initiatives to improve patient centred service delivery, pathways and transition;
- The mix of services provided across the system, including gaps in service provision, sub-acute, step-down, community and other out-of-hospital services across WA to deliver care in the most appropriate setting and to maximise health outcomes and value to the public;
- Ways to encourage and drive digital innovation, the use of new technology, research and data to support patient centred care and improved performance;
- Opportunities to drive partnerships across sectors and all levels of government to reduce duplication and to deliver integrated and coordinated care;
- Ways to drive improvements in safety and quality for patients, value and financial sustainability, including cost drivers, allocative and technical efficiencies;
- The key enablers of new efficiencies and change, including, research, productivity, teaching and training, culture, leadership development, procurement and improved performance monitoring;
- Any further opportunities concerning patient centred service delivery and the sustainability of the WA health system.

Submissions Response Field

Please type your response into the field below. Alternatively you may provide your submissions as a separate attachment (Suggested Maximum 5 pages).

Leveraging existing investment in Primary, Secondary and Tertiary healthcare, as well as new initiatives to improve patient centred service delivery, pathways and transition

CENTRE FOR NEUROLOGICAL SUPPORT

It is estimated about one in six consultations in primary health care relates to a nervous system or neurological symptom of some kind and about one in five emergency admissions to hospital are due to a neurological illness; however, many of these cases are managed entirely within the community (Action on Neurology, 2005).

The number of neurological conditions is unknown with many estimates suggesting around 600 neurological diagnoses, with the symptoms impacting upon a person's physical, emotional, psychological and social functioning (WHO, 2006). Given the anticipated increase in neurological need and the changing focus to the "community" as the setting for support and care (Department of Health Strategic Intent, 2015-2020), knowledge is needed to determine the most appropriate service delivery model for WA.

Most people with a neurological condition may have a normal life expectancy and require anywhere between 20-50 years of community care (Middleton 2014). This poses a challenge for Australia over the coming decades; coupled with the ageing population, there is likely to be an unprecedented rise in both the number of individuals facing these challenges and the costs and burden associated with care. A patient with a neurological condition spends roughly three hours per year with an acute based health professional. The other 8757 hours the person manages their own condition with community support, thus community based support networks and meaningful social connectivity is crucial (Simons, 2008).

The Centre for Neurological Support (CNS) based at The Niche on the QEII campus in Nedlands is an integration point for people living with the impact of a neurological condition throughout Western Australia. The centre provides accommodation for 14 neurological organisations. The Centre also offers, shared conference and forum spaces that are used for support groups, seminars and governance activities. The Neurological Council of WA located at the CNS negotiated funding for tele-health equipment which is made available to all. It is a recognised hub of neurological activity and support that creates a sense of connectivity and a culture which can positively influence the neurological community. Through a collaborative approach the CNS collective provide specialist support and competency to their communities of interest e.g. Muscular Dystrophy, Huntington's, Parkinson's, Motor Neurone Disease, Stroke, alongside the generic service of Neurocare that provides support for those for whom diagnosis is unclear or there is no specialist organisation. This partnership reflects the principles of equity of access and equity of outcome as outlined in the Sustainable Health Review.

This submission sets out to reinforce the work and structure of the neurological organisations based at the CNS. As a collective, the CNS offers a unique touch point for the community. The services provided by the neurological organisations at the CNS include information and resources, referral pathways, professional education and development, advocacy, emotional support, coordinated care planning, early intervention programs, home visits, tele-health support and education, telephone service, referrals,

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nursing, in-reach to hospitals, support groups, transport and volunteers in a wide variety of areas. As a result of the support and services outlined above, patients and families living with neurological conditions are better educated and informed to adopt a proactive approach to their own self-management

The strengths of neurological service provision can easily be demonstrated with some organisations reporting outcomes to the WA Department of health as their funding body, with other organisations relying solely on fundraising and donations. The strengths of the CNS as a place where neurological expertise and support is delivered in an environment that shares common goals, values and outcomes to deliver essential neurological support in the community cannot be underestimated. This environment opens up opportunities to drive partnerships, reduce duplication and to deliver integrated coordinated care that facilitates effective collaboration and care for individuals and families across agencies and services.

The organisations at the CNS maximise health outcomes and value to the public through shared knowledge with health professionals in hospitals and aged care facilities, education of GP's to assist in the diagnostic process, in-reach to multi-disciplinary teams and Neurology clinics, youth programs, cultural competency training, carer and family integrated co-ordinated support.

As the WA population continues to grow, the number of people with neurological conditions will continue to rise. In order to maximise value for money, and contribute to a sustainable health system, consideration should be given to investment in data infrastructure such as integrated IT and technology in order to accurately reflect population needs and outcomes. More broadly, integrated IT and technology across primary, secondary and tertiary health is required to avoid duplication, provide holistic information and speed of access to information with a view to improving the patient experience while avoiding unnecessary spending.

Improved data infrastructure across primary, secondary and tertiary health will also contribute to improve discharged planning. The organisations based at the CNS perform a vital role of support in the community. Poor discharge planning can create significant challenges for an individual not equipped with appropriate knowledge or referral pathways once discharged from hospital. An improved system of referrals, inter-agency sharing of patient records, communication, awareness and education will all contribute to a more fluid and positive experience, inevitably preventing further re-admissions and burden on the hospital system. Community based organisations provide education and information to enable patients to adopt a proactive approach to their own self-management, this could be further improved through a more positive and connected experience across primary, secondary and tertiary systems. It is also vital that patient reported outcomes are valued and included in part of their care planning. The opportunities of an effective and integrated IT system that utilise the specialist knowledge and data collected by CNS organisations cannot be under estimated.

Greater acknowledgement of the benefits of in-reach from community based organisations to care in the management of patients receiving or presenting for treatment in secondary and tertiary care would further improve the communication and fragmentation across primary, secondary and tertiary health. In-reach for neurological organisations based at the CNS would assist with support during the diagnosis

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process which for neurological patients can be a lengthy process, while also assisting with discharge planning. The outcomes would be reflected in unplanned hospital admissions, length of stay at hospital, hospital readmission, cost-effectiveness as well as patient satisfaction and improved quality of life.

As mentioned, the CNS is a key connecting location through which the organisations as a collective deliver outstanding services to the neurological community. While some organisations based at CNS have a regional footprint, there is a gap of service to patients living with neurological conditions in regional WA. While Tele-health can be further explored and utilised and is a growing resource used by the CNS organisations, consideration needs to be given to isolated communities where connectivity is unavailable.

The expertise and important work of neurological organisations could be greater utilised by disability services, particularly in providing information and guidance to NDIS planning. A more open approach to in-put from health funded or non-disability funded organisations during the NDIS planning process could greatly enhance the quality of planning, avoiding crisis periods when plans fail to deliver the services required for neurological conditions, particularly rapidly degenerative conditions. It is also critical there is improved alignment across various government departments (e.g. with health, mental health, disability, housing, communities) to remove duplication of processes and to assist the patient journey through stages of their condition.

Recognition of accommodation needs for young people in need of residential care is a significant gap that requires addressing. Specialist understanding needs to be acknowledged to identify options for those under 65 years with Neurological conditions to prevent from having to utilise aged care facilities. Diversity in accommodation options such as community housing approach or well supported small group housing would present better outcomes and greater quality of life for these individuals.

The Centre for Neurological Support is a WA lotteries facility and will soon be the recipient of an \$850,000 refurbishment grant to support the maintenance of a contemporary and fit for purpose facility. In recent years the organisations have a robust collaborative approach and work together to be more involved in health reform innovation and activity. There is a relationship and connectivity with research and University projects for the benefit of shared knowledge, keeping abreast of current research developments while also sharing and maintaining evidence based practice.

The WA State Government's Sustainable Health Review priorities for the delivery of high quality, patient-centred sustainable health care across WA should consider the chronic disease impact of neurological conditions on the health system. A recognition of the work carried out by organisations at the CNS and how these organisations could potentially have an even greater contribution in supporting families in the community while easing the burden on the hospital and GP settings should be considered as factors for improved health outcomes and patient experience. We welcome an opportunity for a collaborative conversation with WA Department of Health and all the CNS organisations to investigate opportunities to explore greater improvement to the WA Health system.

(References available on request)