

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 checked="" type="checkbox"/> Ms <input type="checkbox"/> Dr <input type="checkbox"/> Other <input type="checkbox"/>
Organisation	Muscular Dystrophy WA
First Name(s)	Hayley
Surname	Lethlean
Contact Details	[REDACTED]

Publication of Submissions

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

- I do not want my submission published
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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).

Muscular dystrophy and neuromuscular conditions are a collective group of more than 60 types of rare, complex, genetic degenerative conditions affecting around 2,500 Western Australians. In line with the WA Rare Diseases Strategic Framework 2015-18, rare diseases are a public health priority. Given there is no cure and the conditions are life-threatening and chronically debilitating, complex health care needs and multidisciplinary support of those living with muscular dystrophy is essential.

Muscular Dystrophy WA (MDWA) is a not for profit charitable organisation providing specialist support, linkages and increased capacity to those Western Australians individuals living with muscular dystrophy and neuromuscular conditions, their families, relatives and carers. We understand each member of our community deserves the opportunity to reach their potential and to achieve their goals, irrespective of their geographical location, their condition, their culture or their current capacity.

Success means our community are more connected and informed to make decisions about their own personal needs – both medical and lifestyle, and are more integrated with specialist and mainstream service provision and support networks in their local area to enable them to live a fuller life.

The not-for-profit community sector provides support and advocacy for the interests and wellbeing of Western Australians, and the value of this sector should not be underestimated by government. As a collective, this sector brings a strength of social cohesion and community purpose to its activities, and demonstrates empathy for those which it serves. It is our belief that this sector may offer government cost-efficiencies and may also provide vital opportunities for improved health and social outcomes through linkages and multi-disciplinary service delivery.

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

Given the rare, chronic, and complex care needs associated with neuromuscular conditions, we know that an integrated and multi-disciplinary approach to the healthcare and social wellbeing of our community is essential. Our focus in this area includes:

A multidisciplinary coordinated care approach to the condition taking both psychosocial and clinical needs into consideration.

Currently within the paediatric environment, access to specialist coordinated neuromuscular clinics with a full multidisciplinary team is limited given there are only a limited number of neuromuscular clinics held annually – it is our knowledge that a number of patients are waitlisted and the key reason is actual clinical space and the number of specialists engaged during the coordination of the patient care. This is undesirable given the degenerative nature of the varying conditions and that best health and wellbeing outcomes can be better achieved with earlier intervention and prevention strategies.

Within the adult environment there is very limited coordinated care and this responsibility rests with the patient or their family/carers.

Opportunities:

- Engagement with MDWA as part of the coordinated care planning process of patients and implement a community in-reach nursing model to support the administration hospital environment – this may alleviate financial resources in the clinical environment. In addition this may provide the community with more coordinated and planned care support. This can be provided within a cohort nursing model alongside other conditions where there are patients which may share similar needs (e.g. other neurological conditions)

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- Engagement with MDWA for key specialist physician support through fellowship & scholarship programs – more HR resources to assist in the clinics and less costs to the health system. These fellowships can align to research studies in partnership with other entities e.g. Telethon Kids Institute and Universities.
- Investment and integration with the development of the MDWA prototype personalised online support ecosystem which will address both the medical and lifestyle needs of the neuromuscular community. Improved quality of life outcomes for our community will in turn lead to less hospitalisation and greater social connections within their local environment.

Support during various transition phases of their condition both from age of patient and the degeneration of the condition:

There is limited support in the transition from the paediatric environment to the adult environment for neuromuscular patients within the health care system and as such patients and their parents/carers are often overwhelmed and daunted during this phase of transition. In addition, this is often the time when the disease progression is significant and psychosocial support is critical. The added burden during this phase is often associated with greater social isolation and increased mental health care needs.

Opportunities:

- Engage and invest in the not for profit sector and those specialised organisations involved along the patient pathway journey to develop a formalised patient-support pathway which will include a coordinated care plan for patients during their condition journey. This can be done as a cohort investment in partnership with other like organisations and engaging university students or graduates as part of the development.
- As above, a greater investment in community outreach nursing models in the not for profit sector will enable a more planned and coordinated care approach to the patient and support them through transition.
- Invest and improve IT systems to enable patient information to be shared across the Primary, Secondary and Tertiary healthcare environments and with those key partners who provide support during the patient journey. Greater investment in options like tele-health support and education will enable integration across sectors and organisations.

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;

With patients who have complex care needs, access to quality allied health services and therapies that integrate into the primary healthcare system and across the disability sector is essential. While there is some integration across sectors, this remains fragmented, and the planning and support systems across sectors are so significantly different, this creates confusion and a fractured pathway for the patient.

Opportunity:

- It is well documented that coordinated care planning delivers better health outcomes and provides social and emotional support for the community. The patient journey management upon discharge is critical in long-term preventative care and engagement and integration with the not for profit sector to enable a collaborative approach to the patient care needs will deliver greater support for the community.

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The value of quality of life outcomes and integration of care beyond just the medical needs - putting the community at the centre of the decision making process and solutions, both within research and medical advances is limited.

Opportunity:

The importance of the health system to proactively seek opportunities to influence community wellbeing by engaging patients and their family as part of health care planning and the pathways of the development of clinical trials and pharmacological approval processes. The not for profit sector and patient representative groups like MDWA are an integral link during these processes and may provide an avenue for greater voice and input by the community during the planning and delivery process.

Ways to encourage and drive digital innovation, the use of new technology, research and data to support patient centred care and improved performance:

There is currently no collaborative accessible, reliable suite of information that is simple to read and understand, which addresses the holistic needs of Australians living with the multidisciplinary complex care needs of the neuromuscular community. This is true for those individuals living with the condition, their families and their informal supports. It can be noted that this is indeed true for most genetic and chronic conditions. In most instances all information is tailored to individual components of patient care needs rather than as a holistic whole of life care plan.

Through recent Australian surveys, it became evident that the neuromuscular community is overwhelmed by the lack of clear, consistent information that is age, diagnostic stage, cultural and condition specific, leading to further confusion of individuals and their families. It is also evident that the limited information available does not aid choice and control. It often uses complex clinical language and does not provide holistic support for social and emotional well-being of the individual, nor does it address integration with mainstream communities, services and activities.

Opportunity:

Muscular Dystrophy WA is working on an exciting innovative technology system which will provide a personalised online support ecosystem for both the medical and lifestyle needs of our community. Through access to this personalised online integrated, accessible and multi-language information support system individuals, families and carers living with muscular dystrophy are enabled to be more connected, resourced and supported giving them the opportunities and capabilities to overcome barriers limiting their preferred lifestyle.

Importantly, the project will link communities with mainstream services in their own geographic region and will bring together communities to embrace diversity and their individual challenges living with these conditions. This ecosystem will include a medical component and lifestyle component and it is predicted this system could integrate through data plates across public sectors.

MDWA welcomes the opportunity for a further conversation with the Health Department in seeking opportunities for this prototype ecosystem to be expanded upon and rolled out across other chronic conditions and health issues.

Opportunities to drive partnerships across sectors and all levels of government to reduce duplication and to deliver integrated and coordinated care;

- Partnerships with the not for profit sector are critical and better integration across multiple organisations is essential. While there may be legal limitations around patient data sharing across

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multi sectors and organisations, it is critical the government invests in appropriate IT infrastructure to ensure this is resolved. An environment where patient data is safely and securely centralised and available across sectors, networks and organisations that provide vital support during that patient's pathway will ensure significant benefit to the patient and cost saving to government. Partnerships and sharing significantly reduces duplication and enables improved care for the patient – we encourage cohort funding models where red tape is reduced and community outcomes are increased.

- Government authorities play a vital role in building the capacity of the not for profit community sector and their ability to respond to community needs. With this in mind, government must ensure the integral process of grant funding and service agreements processes and acquittal are streamlined, longer term and with KPIS and outcomes linked to the holistic patient journey through the health system.

Any further opportunities concerning patient centred service delivery and the sustainability of the WA health system.

- Currently the neuromuscular community does not have equitable access to clinical trials across Australia and no clinical trials are currently taking place in Western Australia for this community. This does not permit equitable access nor equitable outcomes for our community and limits their opportunities for access to future treatments. In a State where ground-breaking treatment options have been discovered and developed, it is critical our community is given the opportunities for access to these treatments. While we appreciate the costs of personalised medicine development is significant, there too are significant costs saving to the health system given investment into these treatments will reduce the long-term burden of these chronic conditions on the system. Critically important, it is also undervalued how much treatments of this type may lead to improved quality of life outcomes for the patients.
- Ensure greater inter-departmental liaison for streamlining processes and red tape to support the patients in the health system that cross into other sectors – disability, mental health, education, planning, community and housing. Systems, processes, timing, funding allocation are more often than not significantly variant across all these sectors, and as an individual trying to navigate all these systems is complex. Departments must collaborate and share all the above to save costs and put the patient - rather than the government system - at the centre of their health and life journey.
- Given costs continue to rise and the burden on the health system and state budget is being stretched, both government and other sectors need to work more transparently and collaborative to share infrastructure and the patient support. An increasing challenge facing both the public and community sectors is sustainable service delivery and this is significantly influencing the ongoing viability of organisations in community sector. Short-term contracting arrangements and regular transitions between service providers can have a profound and damaging effect on services users and must be considered by public authorities when planning new or replacement services.

People living with muscular dystrophy deserve equitable access to a wide range of services across the tertiary, secondary and primary sectors of health that are integrated and patient centred. As like many other community organisations, Muscular Dystrophy WA is part of this patient centred approach and we welcome all future opportunities to be included in the patient pathway journey through these systems.