

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 X <input type="checkbox"/> Ms <input type="checkbox"/> Dr <input type="checkbox"/> Other <input type="checkbox"/>
Organisation	Huntington's WA
First Name(s)	Rae
Surname	Walter
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
- 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

Huntington's WA (HWA) welcomes the opportunity to provide this submission to the Sustainable Health Review 2017.

Huntington's disease is an incurable, life-limiting hereditary neurodegenerative condition characterised by a triad of symptoms including cognitive disturbance, motor abnormalities and psychiatric features (Paulsen, Hoth & Steirman, 2005). Affecting both men and women, symptoms typically present during a significant life-phase in regards to childbearing, child-rearing and career development (Vamos et al., 2007). There is no cure and no proven therapy for altering the disease progression which leads to severe incapacitation over 15-25 years.

HWA provides state-wide support to individuals with Huntington's disease as well as carers, families and young people impacted by the disease. HWA is a not for profit organisation formed specifically to improve the quality of life for people with Huntington's disease and assists more than 150 Western Australian families impacted by the disease. This includes 70 young people who currently participate in our HD Youth program. With a 50/50 chance of inheriting Huntington's these young people are considered as being 'at risk' of Huntington's. During 2016-17, HWA also provided professional education to 160 health professionals about Huntington's disease.

With 27 new client referrals over the past 12 months and increasing needs being identified in Aboriginal communities, particularly in northwest communities, HWA anticipates the number of families being supported with Huntington's will increase significantly over the next five years.

HWA's approach is to view Huntington's disease as a life-long and family condition. HWA's interdisciplinary team of 9 practitioners (4.0 FTEs) is drawn from social work, mental health nursing, behavioural science, youth work and occupational therapy. Our team members share a common philosophy of practice in which the approach is to work in partnership with clients where:

- The lifelong enablement of people living with Huntington's disease is valued and fostered;
- People with Huntington's disease are empowered and their families actively engaged in the care and control of their health and wellbeing; and
- Optimal health and wellbeing is nurtured irrespective of a person's age, severity of impairment or place or residence.

Interagency Collaborations and Living Well with Huntington's disease: Community of Practice Framework.

The management of Huntington's Disease in WA is coordinated by key agencies that are members of the Metropolitan Huntington's Interagency Network and the South West Huntington's Network. In working together, our approach reflects the Ottawa Charter, viewing health as a positive concept that emphasises social and personal resources, as well as physical capacities. Health and wellbeing are seen as the interaction between biological, psychological, social and environmental factors. Membership of the metropolitan interagency networks includes HWA, Neurosciences Unit (North Metropolitan Health Service, Mental Health), Brightwater Care Group, Department of Communities (Disability Services) and MSWA. Membership of the South West Huntington's Network includes the group listed above as well as the Neurological Council of WA (Bunbury) and WACHS – South West, Dept. of Health.

Our collaborative approach is reflected in the *Living Well with Huntington's disease: Community of Practice Framework. A Guide for Practitioners and Providers* developed by the interagency groups and that:

- Embeds principles of care that support the lifelong enablement of people living with Huntington's disease and are aimed at facilitating optimal health and wellbeing from early childhood to the end of life, irrespective of a person's age, severity of impairment or place of residence; and
- Focuses on wellness and enablement that builds on individual strengths, capacity and personalised goals so that people achieve maximum independence, safety and participation at all stages of their Huntington's journey.

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It is recommended:

- *Living Well with Huntington's Disease: Community of Practice Framework. A Guide for Practitioners and Providers* is incorporated in relevant health pathways and resource material.

Case Study. The following Case Study illustrates the benefits of HWA's strong interagency connections.

The SW region of WA represents the second highest concentration of families living with Huntington's Disease in WA. Challenges associated with engaging, supporting and managing families with Huntington's in a regional environment have been well articulated by family members reliant on care coordination from centralised metropolitan services. The SW Huntington's Network first met formally in December 2010 and arose out of a need to improve responses for people with Huntington's after a particularly difficult situation demonstrated the need for improved agency responses. A combined consumer / service provider needs assessment workshop identified the following needs: increased local treatment and support options; reduction in the stress and trauma associated with crisis and acute admissions to public MH services; local clinical and professional services to have specialist up skilling in Huntington's specific treatment and therapy options; professional up skilling across the region to grow local treatment and support capacity; and the need for a coordinating network of service providers.

All identified needs have been implemented within the South West region resulting in significant benefits to consumers, carers and service providers. Evidence of the practical positive benefits has meant improved psychiatric response in emergencies verified through family feedback, agencies having more clarity and confidence in each other's role and responses ensuing duplication between agencies is minimised and time is not wasted, improved communication between agencies and understanding of each other's service responses; people impacted by Huntington's are kept engaged and families do "not fall between the cracks"; moving beyond meeting immediate needs to looking forward; continuing to improve responses and plan for "what is next"; improved management in response to mental health issues; a focus on minimising crisis by not seeing admission as the solution but as an early warning sign to which a response is needed; changes in professional skills resulting in people being better equipped to respond to individuals with Huntington's; and, contact between professionals being increased as well as enhanced through professional development.

Outcome. The Network recognises there are different impacts for families and professionals. In this regard, the network seeks to ensure there is a seamless response to meeting family needs as they move across the "system". To achieve this, seeking client input from families about what is different for them now compared with their previous experiences remains a priority.

Huntington's WA's Day Centre Enrichment Program

HWA's Day Centre Enrichment Program in Beechboro is operating at capacity. Designed to provide participants with physical, mental and social stimulation the program is aimed at maintaining a level of independence to support and prolong community living. Accordingly it is based on carefully selected activities that are stimulating and meaningful and that target cognitive, psychological and motor function. Our program is designed specifically to address current participants' challenges and to enhance and maintain their strengths. Broadly speaking the program targets the following domains:

Physical. Key areas targeted are balance, mobility, muscle strengthening and coordination. This approach is supported by research evidence that whilst the decline in physical functioning cannot be avoided by those experiencing symptomatic Huntington's disease, it can to some degree be slowed.

Mental. A decline in cognitive function is a characteristic of Huntington's disease. The Day Centre program provides activities focussed on sustaining cognitive functioning, particularly in those affected by the condition.

Social. The program also provides the means through which participants can establish and maintain social support networks. Activities are group orientated and sensitive to participants' interests. This ensures social activities that provide social engagement whilst having greater meaning and purpose.

Nutrition. A nutritionally balanced meal is also provided and designed to meet the dietary requirements of participants. Clients can trial use of adapted equipment and also seek the advice and support of speech therapists to assess feeding and swallowing abilities.

It is recommended the:

- Relevance of HWA's Day Centre Enrichment Program in assisting participants maintain a level of independence that supports and prolongs community living is recognised and utilised as a demonstration model concerning sustainable health approaches.

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Youth

Recognising Huntington's disease as a life-long and family condition where children of a parent who is gene positive have a 50/50 chance of inheriting the disease means early intervention is essential to ensuring positive health outcomes. Experiences of clinicians working with these young people indicates an increased risk of suicidal ideation, development of psychological disorders such as depression and anxiety at a relatively young age, and dependency on social services.

To ensure positive sustainable health outcomes for children and youth it is essential that children and young people are well supported.

Huntington's manifests many years before there is a confirmed diagnosis making it difficult for individuals/family members to understand the emotional/cognitive/behavioural changes affecting a family member. It is also becoming increasingly evident, largely as a result of specialised MRI brain imaging, that degeneration of brain regions precedes clinical onset of Huntington's and is more widespread than initially contemplated. Studies indicate a long period of dysfunction of neurons may occur within these brain regions prior to their death which results in clinical manifestation of the disease. This means there is a longer disease process than originally thought that may impact on the everyday quality of life for individuals, their families and carers.

Research around emotional health, well-being and psychological health in the context of families impacted by complex conditions involving deterioration and death has informed HWA's approach in developing a youth program. Our strategy is designed to help reduce the sense of isolation young people experience, assist youth in making informed decisions about their life, encourage and prepare youth for the challenges they face, provide positive role models and support and connect youth in the Huntington's community. Parents are also supported especially in regards to age appropriate discussions with their children about Huntington's.

Accommodation

Individuals living with progressive neurological disorders like Huntington's disease express a desire to remain in their homes and active in their communities for as long as possible (Giles & Lewin, 2008).

It has also been the experience of HWA's advisors that where some individuals have been living at home with little or no family support or where there is a potential for relationships to breakdown, that transferring to care accommodation where staff are well trained in and understand the progression of Huntington's, their community engagement and independence can significantly increase and assist in maintaining/strengthening family relationships.

Sustainable health approaches and relationship to NDIS

The extent of cognitive impairment that people with Huntington's have is not always apparent at initial face to face interviews. Thus, whilst this client group can have apparently logical conversations, in practice the ability to have insight into the consequences of their decisions can be impaired. This can ultimately result in negative outcomes with risks to an individual's vulnerability and safety - physically, financially and emotionally. Many people with Huntington's disease as well as other neurological illness navigate this situation by nominating an advocate in the early stages of their illness who understands their value systems and personal preferences. This is especially important for people with Huntington's disease due to the degenerative decline in cognition outlined above.

It is recommended:

- Due to the cognitive changes associated with Huntington's it is essential NDIS service assessors/providers are appropriately familiar with the condition and recognise the impact of cognitive impairment in determining support needs if people are going to maintain a level of independence that supports a sustainable health approach and prolongs community living.