



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 x Dr <input type="checkbox"/> Other <input 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).

Parkinson's is a chronic, progressive, incurable, complex and disabling neurological condition.

Parkinson's WA (PWA) welcomes the opportunity to contribute to the State Governments Sustainable Health Review 2017.

Parkinson's WA has (for the last 19 years), through its Parkinson's Nurse Specialist Service, supported the key priorities of the WA Government; namely to ensure West Australians with Parkinson's, enjoy the best health care possible by putting them at the centre of our service.

To meet the demands of an ageing and increasing population during this period the Parkinson's Nurse Specialist Service has grown from one to six and a half full time equivalent (FTE) Parkinson's Nurse Specialists.

Four full time equivalent funded by Department of Health WA (DHWA) (Contract C06320) and two and a half FTE funded by Parkinson's WA.

The community based Parkinson's Nurse Specialists Service model ensures that the patients are the centre of service delivery. As referred to in the :

Global Declaration on Parkinson's 1997.(European Parkinson's Disease Association)

The Charter states that people with Parkinson's have the right to:

Have access to support services, Receive continuous care and Take part in managing the condition.

In 2008 the Department of Health Aged Care Network Parkinson's Disease Services Model of Care, (MOC) clearly identified the importance of referral to the Parkinson's Nurse Specialist by Specialist or by self referral.

The WA MOC has as its best practice framework for service delivery, the National Institute of Health and Clinical Excellence (NICE UK) Guidelines 2017.

The key to our success over nearly two decades is built on the provision of individualised support and education, not the; "one size fits all model". Parkinson's is frequently described as a "designer condition" as no two people with the condition exhibit the same signs and symptoms, have the same journey with the condition or the same medication regime. Each stage of the condition has its own unique interventions required.



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The Parkinson's Nurse Specialist service is built around providing individual support to: improve quality of life, maintain independence in their own homes and prevention of hospital admissions.

All of the above are of strategic importance to the DHWA as they provide significant cost savings.

Carers/partners take the life journey with the person with Parkinson's - they are an integral part of the support process. PWA provides carer/partner management programs.

The PNS Service focuses on education of the person with Parkinson's and the partner/carer to enable self management strategies, including integration of physical exercise on a regular basis as part of lifestyle.

Driving partnerships:

An early diagnosis is necessary to improve the impact and progression of the condition; this will enable early diagnosis strategies in the primary care sector.

To maximise the evidence based practice of General Practitioners, PWA promotes an online course: General Practitioners Guide to Parkinson's Disease, accredited with RACGPs and ACRRM.

PWA is working with the WA Primary Health Alliance, providing input into the Neurology – Parkinson's Disease HealthPathways WA.

The PNS have strong links with the Parkinson's focused clinics, within WA.

On completion of the PNS Nursing assessment, copies are provided to clients GP's and their Specialists, this ensures maximum continuity of care.

Referrals are made to: Occupational Therapists, Speech Pathologists, Social Workers, Psychologists and Physiotherapists.

The PNS advocate for the person with Parkinson's to ensure they are supported through ACROD/Carers Allowance/Companion Card/Mandatory Self Reporting/Equipment Grants/Enduring Power of Attorney/NDIS and Aged Care Packages.

If people with Parkinson's move into Residential Aged Care facilities or hospital for management of medications or a non-related issue, a key role of the PNS is to upskill the allied health professionals, in these facilities with the best practice management of people with Parkinson's.



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Digital innovation and research:

PWA continues to identify best practice models in the use of Telehealth and Skype. Telehealth can support regional consultations and Skype, if available, can be an excellent backup process instead of a face to face second PNS visit. Face time is also being included as an option to link regional family members into the PNS consultations.

Research both Internationally and Nationally supports the continued expansion of our Parkinson's support programs namely: dance, tai chi, singing and yoga. Self management strategies, including integration of physical exercise on a regular basis are promoted.

Improvements in safety and quality for patients:

Medication management: Medications to be used with caution for people with Parkinson's is an extremely important safety issue for people with Parkinson's and their carers/partners.

PWA provides education on this topic: to people with Parkinson's, allied health professionals and also to Pharmacists.

To ensure hospital staff adheres to best practice management of people with Parkinson's, information on "Guidelines for Hospitalisation" is provided to encourage correct management of people with Parkinson's when they are hospitalised for Parkinson's or comorbidity, e.g. Hip replacements.

The introduction of an Electronic Alert System into the WA Emergency Departments, linked to medical records and pharmacy would be beneficial. This will lead to reduced incidence of missed medications or drug interactions.

New efficiencies and continuous improvement:

PWA is driving the development of an on-line "One stop shop" for allied health professionals, to augment the face to face learning opportunities. This will be beneficial for nurses on shift work who cannot attend training sessions.

The allied health professionals will be able to gain valuable experience through 20 min up skilling E - learning opportunities.

Up skilling allied health professionals has a significant flow on effect. Every client they encounter will receive improved health support for the Parkinson's condition, and the allied health professional will be familiar with the best practice management pathway for the patient with Parkinson's.

PWA in conjunction with the Australian College of Nursing is preparing a Graduate Unit in Parkinson's Nursing Care. This will provide continuous up skilling for PNS and establish a significant career pathway for PNS.



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Regional support:

The South West of WA is supported through the Bunbury PNS Office, to provide community based support for people with Parkinson's and up skilling of allied health professionals in the best practice management of people with Parkinson's.

The regional centres including: Kalgoorlie, Narrogin, Northam, Broome, Jurien Bay/Moora, Port Hedland/Karratha, are provided with support on a six monthly basis.

This provision of services will improve health outcomes for regional Parkinson's communities and improve equity of outcome for all people living with Parkinson's.

Summary of recommendations

The research evidence indicates that the treatment and management of people with Parkinson's can be appropriately and effectively managed while a person lives independently in the community – by far the best outcome for the person, their partner/carer and the DHWA

1. Continue and expand the current DHWA funding for the Parkinson's WA Parkinson's Nurse Specialist Service, to meet the needs of the ageing and expanding population. This will require a gradual increase in PNS funding from the current 4 FTE to 10 FTE, over the next four years, to meet the needs in the metro area and regional WA.
2. Address the gaps in care for people with Parkinson's under 65 years regarding the provision of equipment and home modifications to enhance continued independence in their own homes
3. Fund a Counsellor to augment the Parkinson's Nurse Specialist Service to provide timely, appropriate advice and support to people with Parkinson's and the carers/partners, this will assist with prevention of unnecessary hospitalisation and extend independence in ones own home.
4. Recognise and understand the value adding to DHWA of PWA as a Not for Profit community based organisation, including provision of extensive resource material, point of contact, up skilling of allied health professionals and funding research in Parkinson's, conducted at WA research institutions.

Referenced material:

Deloitte Access Economics Living with Parkinson's Disease An Updated Economic Analysis, August 2015

Aged Care Network Parkinson's Disease Services WA Model of Care, May 2008

National Institute for Health and Care Excellence (NICE) Guidelines, July 2017

DHWA Service Agreement C06320 Parkinson's WA Parkinson's Nurse Specialists Report July 2017



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Relevant Parkinson's Nurse Specialist statistical data:

3400 Telephone consultations in the previous 12 months

1400 Home, Hospital, Aged care visits in the previous 12 months

1550 allied health professionals in hospital, Residential Aged Care Facilities universities and the community attended formal presentations on best practice management of people with Parkinson's, in the last 12 months

Annual DHWA Client Evaluation Survey April 2017:

94% rating of people with Parkinson's - "have a better understanding of the risk of falls" after a PNS visit

85% rating of people with Parkinson's - "having a visit from a PNS reduced their need to attend hospital"

94% of people with Parkinson's - "had an improved understanding of the importance of taking their medication on time after a PNS visit"

Background data:

Latest research in Parkinson's indicates that more than 100,000 people live with Parkinson's in Australia, 10,000 in WA.

The incidence of Parkinson's increased at an average rate of 3% per year over the 9 years to 2014.

It is estimated, the average growth in prevalence over the next 20 years will be 4%.

The prevalence of Parkinson's is higher than many cancers including: breast cancer, colorectal, stomach, liver and pancreatic cancer, lymphoma and leukaemia, kidney and bladder, uterine, cervical, ovarian and lung cancer.

In 2014 the cost of Parkinson's to the community was estimated at \$9.9b p.a. and for someone living with Parkinson's for 12 years, the average; lifetime financial cost is around \$161,300. which is on par with the average lifetime cost of cancer (\$145,000)

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