

# Movement Disorder Nurse Specialist (MDNS) Pilot

## Evaluation Report Addendum

### MDNS Pilot:

The MDNS pilot commenced in mid-2020 and concluded on 30 June 2024. The pilot was implemented through four Primary Health Networks (PHNs) - Western Victoria (WV), Hunter New England Central Coast (HNECC), Western New South Wales (WNSW), and Northern Territory (NT). The grant was to provide seed funding for PHNs to establish a sustainable service if the outcome of the pilot indicated an ongoing need. Over the life of the pilot, 896 patients accessed the service, and 21 nurses were upskilled.

### Purpose:

This addendum provides supplementary information to the MDNS pilot final evaluation report, which was provided to the department in December 2023. The independent evaluation conducted by Nous Group captured data up until 26 May 2023. This document provides a complete dataset until the pilot cessation date of 30 June 2024 and is intended to be read with the final evaluation report.

Table 1: Supplementary Data provided by the PHNs

PHN		As of last evaluation data collection (26 May 2023)	As of Cessation date (30 June 2024)
<b>HNECCPHN</b>			
Patients	Number of patients seen through the pilot	190	197
Nurses	Active nurses	1 nurse specialist and 3 nurses received formal training	1 nurse specialist
	<b>Total nurses upskilled</b>	<b>4</b>	<b>4</b>
<b>NTPHN</b>			
Patients	Number of patients seen through the pilot	170	249
Nurses	Active nurses	1 nurse specialist	1 nurse specialist
	<b>Total nurses upskilled</b>	<b>1 nurse specialist</b>	<b>1 nurse specialist</b>
<b>WVPHN</b>			
Patients	Number of patients seen through the pilot	160	160
Nurses	Active nurses	3 nurse specialists	3 nurse specialists
	<b>Total nurses upskilled</b>	<b>4 nurse specialists</b>	<b>4 nurse specialists</b>
<b>WNSWPHN</b>			
Patients	Number of patients seen through the pilot	376	471
Nurses	Active nurses	4 generalist nurses	2 generalist nurses
	<b>Total nurses upskilled</b>	<b>12 generalist nurses</b>	<b>12 generalist nurses</b>

The supplementary data provided by the PHNs highlighted common benefits and key themes across the regions. Building strong working relationships with allied health professionals and peak bodies was identified as a shared benefit across all PHNs. These relationships increased nurse awareness of scope and value of the multidisciplinary care teams and encouraged ongoing collaboration with specialists such as Neurologists and Geriatricians. Nurses were regularly given the opportunity to upskill and expand their professional knowledge which has long-term benefits in the wider community.

PHNs collectively noted that this pilot provided care for a cohort which was previously without specialised nurse services for people living with movement disorders. These patients were provided a space to create connections with healthcare professionals, to increase their health literacy and to offer a greater sense of purpose while living with these conditions.

Table 2: Summary of PHNs transition arrangements from 1 July 2024

*\*The following information has been provided by the PHNs*

PHN		Nurse workforce	Transition arrangements from July 2024
<b>Hunter New England and Central Coast (HNECC)</b>		1 movement disorder nurse specialist and 3 nurses with additional training	PHN funding private provider for 6 months, while sustainable long-term funding is identified. The nurse was employed as an MDNS, and patients continue to access services.
<b>PHN Reflections</b>	<b>Benefits realised</b>	<ul style="list-style-type: none"> <li>- Establishing the service within an allied health provider already working in Parkinson’s/movement disorder space provided an existing client base and good community partnerships from the start and increased nurse awareness of the scope and value of allied health practitioners.</li> <li>- Patients recognised that incorporating exercise into the management of their Parkinson’s has broader benefits to health, ageing and managing comorbidities such as cardiac health and diabetes.</li> <li>- Nurse benefits included: <ul style="list-style-type: none"> <li>o feeling valued by community and seeing positive outcomes such as an <u>increase</u> in client reported Quality of Life (QoL) as demonstrated through the evaluation.</li> <li>o the opportunity to upskill and work with a higher level of speciality and subject matter expertise including knowledge and skills in treatment modalities such as injectable and device assisted therapies.</li> <li>o establishing and developing strong working relationships and mentorships from the movement disorder clinic team through the Local Health District (LHD) and, key Parkinson’s stakeholder groups such as Parkinson’s NSW and local community and support groups across the New England Northwest region</li> </ul> </li> <li>- Benefits from the PHN perspective included: <ul style="list-style-type: none"> <li>o the freedom to be innovative and flexible, to trial new ways of working, models of care and activities to achieve goals in a way that is place based and fit for purpose.</li> </ul> </li> </ul>	

PHN		Nurse workforce	Transition arrangements from July 2024
		<ul style="list-style-type: none"> <li>o demonstrating hospital cost savings through effective primary care services.</li> </ul>	
	<b>Implementation challenges</b>	<ul style="list-style-type: none"> <li>- The main challenge for the service since the completion of the evaluation is developing sustainability once pilot funding ceases. The PHN, service provider and local community groups continue to increase awareness of Parkinson's Disease (PD) as the fastest growing neurological condition and advocate for investment in services to support early intervention and support for patients with PD.</li> </ul>	
	<b>Lessons learned</b>	<ul style="list-style-type: none"> <li>- While there was initial resistance from stakeholders to establishing this service outside the traditional tertiary sector the PHN and service provider have built strong relationships and trust with the LHD, gaining support for the service that has demonstrated strong integration with existing services and pathways.</li> <li>- Commissioning services through small private community focussed organisations who are innovative and progressive allows services to be person centred, responsive and agile when faced with changes and challenges.</li> </ul>	
<b>Northern Territory (NT)</b>		1 movement disorder nurse specialist	NTPHN will fund the MDNS Pilot until 30 June 2024. NT Government has not committed to funding the pilot beyond July 2025.
<b>PHN reflections</b>	<b>Benefits realised</b>	<ul style="list-style-type: none"> <li>- Patient feedback was obtained from 85 of the MDNS clients across the NT. The average level of satisfaction was an 8/10. Clients described the impact of this service, praising the nurse's dedication, responsiveness, and active listening. They also highlighted her extensive knowledge, effective communication skills and compassionate approach.</li> <li>- Development of a new model of care for specialist nursing support, including in-reach, remote outreach, and telehealth, provides access to high-quality nursing care, closer to home.</li> <li>- Through strengthening relationships with Parkinson's South Australia and Western Australia, a conduit was formed to transfer expert knowledge and best practice to the NT.</li> <li>- Working with acute hospital staff across the Top End supported best practice care, during admissions for clients with Movement Disorders.</li> <li>- Ongoing collaboration with Neurologists and Geriatricians at the Royal Darwin Hospital (RDH) and Palmerston Hospital assisted with creating guidelines and protocols for managing inpatients with PD.</li> </ul>	
	<b>Implementation challenges</b>	<ul style="list-style-type: none"> <li>- The increasing number of referrals and follow-up visits is making it difficult to program activities different from the clinical practice, such as specific training or in-service presentations. Additional administrative support for the role would be able to further develop activities different from access to specialist nursing care.</li> </ul>	

PHN		Nurse workforce	Transition arrangements from July 2024
	<b>Lessons learned</b>	<ul style="list-style-type: none"> <li>- There have been ongoing discussions between NT Health and NTPHN on continuous improvements to the service with the focus on making the service fit-for-purpose to meet the diverse and complex needs of the NT population, ensuring it is culturally safe and culturally appropriate to meet the needs of all people. The MDNS Nurse has conducted patient surveys to obtain feedback on their experience with the service, this feedback has informed continuous improvements.</li> <li>- Better engagement with other trial sites (community of practice) would have been beneficial for NT MDNS staff.</li> <li>- NT PHN has supported community engagement and health promotion activities in partnership with NT Health.</li> </ul>	
<b>Western NSW (WNSW)</b>		12 nurse generalists - 2 nurses engaged at cessation.	Model ceased in its current form – focus was on upskilling nurses and did not fund service delivery. MDNS specialists continue to be employed by NSW Health, as per model and provide specialist services.
<b>PHN reflections</b>	<b>Benefits realised</b>	<ul style="list-style-type: none"> <li>- Overall, having more nurses with specialist education that can be applied either through specialist or general roles benefits people living with movement disorders.</li> <li>- Advocacy for these patients and guidance on how to access the right support and knowing referral opportunities is key.</li> <li>- Benefits for people living with Parkinson have also been realised outside of the specialist appt model, including: <ul style="list-style-type: none"> <li>o health literacy for people living with movement disorders, along with family and carers through involvement in Parkinson’s Support Groups.</li> </ul> </li> <li>- Being able to offer creative environments (singing, dance, exercise) has allowed for connection, purpose, and social outlets for many patients, and having groups with people with varying diagnoses has increased support among community for people living with movement disorders.</li> <li>- Creating and connecting professionals is also key in sharing knowledge and approaches to supporting patients.</li> <li>- For the two nurses who have remained active, being able to immediately, and consistently utilise the specialist skills has allowed the benefits to be recognised and subsequently allowed the work to be embedded and recognised, which is vital for small communities.</li> <li>- The specialist knowledge has enabled the care previously offered through neurologists to be extended and more accessible for people living with movement disorders.</li> </ul>	

PHN		Nurse workforce	Transition arrangements from July 2024
	<b>Implementation challenges</b>	<ul style="list-style-type: none"> <li>- The WNSW pilot implementation experienced a number of challenges including the impact of COVID on nurse capacity to undertake additional activities, staff changes within the PHN Pilot team, as well as for a number of the nurses who had enrolled in the pilot. Since the Nous Evaluation completed, implementation was no further hindered, and consistency was maintained for active nurses.</li> <li>- One further nurse did undertake a placement; however, her role does not currently enable integration of active patient appointments, however the knowledge and professional contacts are beneficial for referral and health literacy purposes of her work in the <i>Aged Care Community Assessment Team</i>.</li> <li>- The further opportunity to develop Movement Disorder health pathways will also create a platform for clinicians to access up to date evidence-based clinical guidelines and local service mapping to more easily support patients diagnosed with movement disorders. This will be further embedded/promoted through the ongoing <i>Continuing Professional Development Opportunities</i> through the WNSW PHN education program.</li> </ul>	
	<b>Lessons learned</b>	<ul style="list-style-type: none"> <li>- A key lesson lies within workforce, funding or costing models, time, support, and leadership. All nurses who enrolled in the pilot were passionate and saw the need for the specialised skills.</li> <li>- The nurses who have been successful have been supported by their employer to give dedicated time to the role, were able to utilise their specialist skills and able to see the benefits of these.</li> <li>- For many who did not continue, it was an added extra task on top of already time poor roles and in areas of stretched workforce which impacted implementation.</li> <li>- Looking at more extensive recruitment processes for potential candidates and including mentoring throughout the process would be opportunities to further support clinicians to integrate and embed new skills into workflows.</li> <li>- Support from leadership is crucial as are opportunities to utilise skills immediately to see benefits and realise opportunities.</li> <li>- Consideration for broader education and upskilling for people at different clinical levels could also be considered, to enable greater understanding and support offered across the healthcare system (e.g., in aged care homes/respite/General Practitioners/Registered Nurses/Allied Health). This may provide patients with better support through all points of contact in the healthcare system.</li> </ul>	
<b>Western Victoria (WV)</b>		<p>4 movement disorder nurse specialists - 3 nurses engaged at cessation.</p> <p><i>(The Fourth nurse transitioned to the Local Health Network (LHN) as business as usual (BAU) prior to cessation)</i></p>	<p>WVPHN worked closely with each health service since November 2023 for the transition of funding arrangement from the MDNS pilot. All three health services have committed</p>

PHN		Nurse workforce	Transition arrangements from July 2024
			to the MDNS role beyond the pilot period via State government funding.
PHN reflections	Benefits realised	<ul style="list-style-type: none"> <li>- The MDNS pilot provided WV PHN an opportunity to strengthen care for a cohort of the community who had not received adequate support due to lack of access to specialised care.</li> <li>- Patients have shared that having support from the movement disorder (MD) nurses has been life changing.</li> <li>- The nurses agreed that existing soft skills were beneficial, however, the pilot enhanced their knowledge of patient centred care with an integrated approach.</li> <li>- The nurses worked closely with other allied health and medical teams through a multidisciplinary approach within each health service.</li> <li>- One of the MD nurse specialists is currently completing additional studies to become a <i>Movement Disorder Nurse Practitioner</i>.</li> </ul>	
	Implementation challenges	<ul style="list-style-type: none"> <li>- The main implementation challenge since the evaluation concluded has been supporting health services with the transition of funding from the department to alternate sources of funding.</li> </ul>	
	Lessons learned	<ul style="list-style-type: none"> <li>- A co-design approach during the pre-project phase, where trial models of care could be created and discussed would have saved time during the project's initial delivery.</li> </ul>	