Evaluation of the Movement Disorder Nurse Specialist Pilot: Final evaluation report

Primary Health Care

28 November 2023



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This artwork was developed by Marcus Lee Design to reflect Nous Group's Reconciliation Action Plan and our aspirations for respectful and productive engagement with Aboriginal and Torres Strait Islander peoples and communities

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This is an accessible version of the final evaluation report of the evaluation of the movement disorder nurse specialist pilot. If there are any discrepancies between versions, the final evaluation report (non-accessible version) should be assumed to be the correct version.

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Executive summary

Neurological conditions including movement disorders are conditions that affect the brain, spinal cord and nerves that connect them. There are more than 600 diseases of the nervous system that together affect an estimated 10.6 million Australians. Of these, nearly 1.3 million Australians live with progressive neurological conditions such as Parkinson's disease and Huntington's disease.

It is well known that Australians living in regional, rural, and remote areas face challenges accessing health services. This is especially true for people living with neurological conditions including movement disorders – who often face limited access to specialist services, lack of appropriate support from primary care providers, and limited awareness of available interventions.

Recognising this challenge, in 2020 the Australian Government Department of Health and Aged Care (the Department) funded the Movement Disorder Nurse Specialist pilot (the MDNS pilot). The Department sought proposals from regional, rural, and remote Primary Health Networks (PHNs) to increase the capacity of nurses to care for people living with neurological conditions including movement disorders and improve access to specialised care for Australians living in regional, rural, and remote areas.

Funding was provided to four PHNs – Hunter New England and Central Coast PHN (HNECC PHN), Northern Territory PHN (NT PHN), Western NSW PHN (WNSW PHN) and Western Victoria PHN (WV PHN). Each PHN designed, developed and supported the delivery of a pilot model of care that addressed the unique needs of their communities.

Nous Group (Nous) was engaged by the Department to conduct a longitudinal national evaluation of the MDNS pilot. The evaluation triangulated data from literature; interviews, site visits and surveys; and a quantitative pilot minimum dataset. A realist lens was used to understand what worked, for who, and in what circumstances across the four pilot models.

Overall, the evaluation found that the MDNS pilot was appropriate and effective. As a result of the pilot, a total of 896 patients across the four PHN regions received specialist nursing care and support that had previously been unavailable or inaccessible. This includes 541 receiving direct care and an additional 355 that received support through patient support and exercise groups. The evaluation found the pilot delivered positive benefits to patients and carers, the nurses involved in the pilot, and the health system overall.

Patients involved in the pilot maintained their quality of life over the period of the evaluation. This is a positive result, given the progressive and degenerative nature of neurological conditions including movement disorders, and compares favourably to data reported in published literature where quality of life typically decreases over similar lengths of time.

Patients and carers reported several additional positive benefits of the pilot including increased access to specialist care; increased access to supportive care (such as those provided through the NDIS); greater understanding of neurological conditions including movement disorders; greater ability to self-manage and provide care at home; and greater coordination of care. The overwhelming majority of patients and carers were highly satisfied with the care and support provided through the pilot.

A total of 21 nurses received specialist training and upskilling through the pilot, and the majority of these nurses began delivering specialist nursing care during the evaluation period. Survey data indicates that the nurses began to stretch into advanced nursing practice during the pilot, and nurses reflected that they saw their skills, confidence, and capacity grow over the evaluation period. One PHN faced challenges with nurse retention – five of their nurses withdrew from the pilot during the evaluation period.

There are indications that the pilot built the overall capacity of the health workforce, supported greater collaboration at the system level, and delivered system efficiencies. As a result of the specialist nursing care that they were providing, nurses in some PHNs began to relieve pressure on other specialist neurological services – for example, providing elements of care in place of neurologists. In addition, service usage data collected through the evaluation suggests that the pilot reduced patient usage of other health services – self-reported data indicates that, when compared to the previous 12-months, patients involved in the pilot had fewer presentations to the Emergency Department, fewer planned and unplanned hospitalisations, and spent overall fewer days in hospital if they were hospitalised.

The pilot was cost effective when compared to some other interventions for patients with Parkinson's disease. This was based on comparing the cost-per quality-adjusted life years gained for the pilot, which was \$372,051 on average per patient, with other interventions including medication and deep brain stimulation.

The evaluation found that the pilot was effectively managed by the PHNs. PHNs were well placed to deliver on the overall objectives of the pilot – to improve health outcomes, to build the capacity of the workforce, and to address known service gaps – as these align with PHN priorities and areas of expertise.

The evaluation highlighted a number of factors that supported effective design and implementation of the pilot models. These include robust collaborative design and co-design processes to develop models; strong leadership and coordination from PHNs; clear commitment from nurse employers and managers to support nurses to complete training including clinical placements; connection with clinical expertise, mentorship and guidance such as through peak bodies; and clearly defined and identified referral pathways.

All PHNs faced challenges in implementation. The most obvious and universal was the impact of the COVID-19 pandemic, which delayed pilot implementation across all PHNs. Other challenges included providing appropriate support to nurses to keep them motivated and engaged in training; supporting nurses to build a new model of care; and building awareness of the service and referral pathways.

The evaluation found there is a clear need to continue to enhance access to specialist care and support for people living with neurological conditions including movement disorders in regional, rural, and remote areas of Australia. This need could be met through specialist nurse models, and / or other approaches – such as non-nurse models, or support provided through peak organisations. Effective models will be driven by local community need.

The evaluation describes the four different models, each specifically designed for the unique needs and strengths of the individual regions and communities they are located in. There are benefits and

challenges of each of the four models, and lessons have been learnt about how they can be effectively implemented and delivered.

The evaluation did not identify one "best fit" MDNS model to enhance access to specialist care for people living with neurological conditions including movement disorders in regional, rural, and remote locations. Instead, the evaluation found that the most appropriate models are those that are tailed to regional contexts and integrate with existing services. The evaluation found the following in relation to model design which could help PHNs or other funders contemplating funding a specialist service:

- Specialist nursing services, such as movement disorder nurse specialists, could be considered either primary or secondary care, and as such, collaboration is required between PHNs and other parts of the health system including Local Health Networks (LHNs).
- A generalist nurse with some additional specialist training could be beneficial to communities
 with a small number of nurses that need to support people with a variety of conditions. A
 movement disorder nurse specialist could be considered for larger communities where there are
 more people that experience movement disorders.
- A "hub-and-spoke" approach where there is one or more movement disorder nurse specialists in a major regional community supported by a networks of generalist nurses with some additional training in surrounding rural and remote communities – could help increase the geographical reach of a service.
- Neurological conditions often manifest as complex, chronic conditions that require involvement
 of healthcare staff from a range of disciplines. As such, a multidisciplinary model with a range of
 healthcare professionals could be beneficial in some communities depending on the availability
 of certain workforces.

The evaluation identified that the MDNS model could work in some circumstances to enhance access to services and outcomes for people living in regional, rural, and remote areas, but that it is not the only potential approach. A range of approaches – either independently or in combination – should be considered. These include telehealth options, disease-specific nurses, and multidisciplinary team care as well as interventions such as exercise programs, occupational therapy, medication interventions, and deep brain stimulation. These approaches could be used – either in combination with, or in place of, an MDNS model – to support people living with neurological conditions. The exact combination of approaches chosen should be determined based on local need and context, and account for other existing services and supports.

The evaluation faced challenges related to participant recruitment and data collection. Despite best efforts, there were very few respondents for some data collection activities – such as surveys of patients and carers, and surveys of nurse colleagues and line managers. As a result, care should be taken when considering evaluation insights based on the varying strength of evidence.

Based on the findings of the evaluation, six considerations are presented for shaping future policy decisions about specialist supports for people with neurological conditions, including movement disorders, living in regional, rural, and remote areas. These considerations are presented in Table 1.

The Department is currently working with the PHNs involved in the pilot to ensure patients currently receiving services have continuity of care.

	Table 1	Summary	of	considerations
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Number	Considerations
1	The MDNS model is one of a number of potential approaches that could be explored to enhance access to specialist care for people living with neurological conditions including movement disorders in regional, rural, and remote areas.
2	Future approaches should be designed to meet regional or local community needs and context – it is appropriate that PHNs and / or LHNs lead this work (and consider appropriate integration with existing services / care).
3	Clear guidance and advice – drawn from the results of this evaluation – should be provided to PHNs (or other organisations) wishing to establish similar MDNS models.
4	Should MDNS models be explored in the future, the model should be co-developed in partnership with service providers and communities.
5	Future MDNS models may wish to continue to focus on broader MDNS models, although disease-specific nurse models may be appropriate in certain local contexts.
6	Future MDNS models should enable PHNs (or other organisations) to collect relevant data and information to enable evaluations and continuous quality improvement.

Glossary of key terms

Key term	Definition		
Specialist care or specialist service	The term specialist care or specialist service are used in this report to refer to secondary and tertiary health services. This includes specialist medical services, for example a neurologist or geriatrician, and specialist nursing services.		
Specialist nurse	The term specialist nurse is mostly used in this report to refer to movement disorder nurse specialists. As such, the definition used for specialist nurses is taken from the Australasian Neuroscience Nurses' Association: Movement Disorder Chapter's Parkinson's Disease and Movement Disorder Nurse Specialist standards for practice. ¹ The standards define an experienced specialist nurse as someone having additional training and qualifications, for example a graduate certificate, Masters degree or Doctorate in nursing, in addition to a Pachelor of Nursing		
Movement disorder nurse specialist	A movement disorder nurse specialist is a specialist nurse, consistent with the above definition, with additional skills and accreditation in supporting patients with movement disorders. It includes Parkinson's disease nurse specialists, MS nurse specialists, and motor neurone disease (MND) nurse specialists.		
Generalist nurse	A generalist nurse is a nurse with a Bachelor of Nursing only. A generalist nurse may have some additional specialist knowledge or skills and may be working toward additional qualifications like a graduate certificate.		
Medical specialist	A medical specialist is a doctor who is an expert in a specific area of medicine. This includes neurologists and geriatricians.		
Parkinson's disease	Parkinson's disease is a neurological condition that causes problems with movement, mental health, sleep, and pain. The disease usually occurs in older people, but younger people can also be affected.		
Multiple sclerosis (MS)	MS is a neurological illness which causes damage to the nervous system. Symptoms can differ but usually include trouble with muscle control and vision, tiredness, pain, and changes in thinking.		

¹ Australasian Neuroscience Nurses' Association: Movement Disorder Chapter, Parkinson's Disease and Movement Disorder Nurse Specialists Standards for Practice, First Edition, 2017.

Key term	Definition
Motor neurone disease (MND)	MND is a neurological illness which affects the motor neurones. The disease gradually stops messages reaching the muscles leading the muscles to weaken, stiffen, and waste. This can affect how people walk, talk, eat, drink, and breathe.

1 Background and context

This section presents a background to the evaluation, information regarding neurological conditions including movement disorders in Australia, and context about the MDNS pilot.

1.1 Project overview

The then Australian Government Department of Health (now the Australian Government Department of Health and Aged Care) (the Department) engaged Nous to conduct an independent national evaluation of the movement disorder nurse specialist pilot (the MDNS pilot or the pilot).

The evaluation commenced in December 2020 with the collaborative design of the Evaluation Plan. The Evaluation Plan was finalised in October 2021, and evaluation data collection then commenced. Data collection ended in July 2023. The evaluation concluded in October 2023.

1.2 Project context

It is estimated that 10.6 million Australians live with neurological conditions

Neurological conditions affect the brain, spinal cord and nerves that connect them. There are more than 600 diseases of the nervous system,² including:

- Sudden onset conditions (e.g. acquired brain injury causing stroke, spinal cord injury).
- Intermittent conditions (e.g. epilepsy).
- Progressive conditions (e.g. motor neurone disease, multiple sclerosis, Parkinson's disease, and other neurodegenerative disorders).
- Stable conditions with or without age-related degeneration (e.g. polio or cerebral palsy).³

It is estimated that 10.6 million Australians live with these diseases with an annual cost of over \$31 billion to the Australian economy. The most common symptoms of neurological conditions are migraine and tension-type headache, affecting 4.5 and 7.9 million people respectively.

Nearly 1.3 million Australians live with progressive neurological conditions, with Alzheimer's disease and other dementias having the highest prevalence among such disorders, affecting nearly 250,000 Australians.⁴ Parkinson's disease is the second most prevalent neurodegenerative disorder, with the

² Australian Government Department of Health. (2020). What we're doing about neurological conditions. Retrieved at: <u>https://www.health.gov.au/health-topics/chronic-conditions/what-were-doing-about-chronic-conditions/what-were-doing-about-neurological-conditions</u>. Accessed 6 April 2021.

³ Neurological Alliance Australia. (2014). Palliative Care and Neurological Conditions. Retrieved at: <u>https://www.msaustralia.org.au/sites/default/files/Palliative%20Care%20NAA%20Position%20Statement.pdf</u>. Accessed 6 April 2021.

⁴ Mindgardens Neuroscience Network. (2019). Review of the burden of disease for neurological, mental health and substance use disorders in Australia. Retrieved at: <u>https://www.neura.edu.au/wp-content/uploads/2019/03/MINDGARDENS-WHITE-PAPER-FINAL-14th-March-</u> <u>2019.pdf</u>. Accessed 6 April 2021.

number of Australians living with the disease ranging from 81,000 to 212,000 (more definitive prevalence data is not available).⁵

Older people are increasingly likely to experience the impacts of neurological conditions. The burden of disease is a useful measure to describe the impact of living with illness and injury and dying prematurely. The burden for these conditions has continued to increase for those aged above 70 years, with a 22 per cent increase from 2010 to 2017.⁶

A subset of neurological conditions, the term "movement disorder" refers to a group of neurological conditions that cause abnormal increased movements.⁷ The International Parkinson and Movement Disorder Society (MDS) outline a spectrum of clinical disorders that fall under "movement disorders"; these are broadly described as "Parkinson's disease, related neurodegenerative and neurodevelopmental disorders, hyperkinetic movement disorders, and abnormalities in muscle tone and motor control".⁸

While this broad group contain conditions with various characteristics, disease trajectories and life expectancy, they are often neurodegenerative and require increasing care as the person's level of function decreases.

A summary of the prevalence and cost to the community of neurological conditions including movement disorders is presented in Figure 1.

⁵ Deloitte Access Economics. (2015) Living with Parkinson's Disease. Retrieved at:

https://www.parkinsonsvic.org.au/images/site/publications/Research/Living with Parkinsons_Disease.pdf. Accessed 16 March 2021; Ayton D, et al. (2018). Parkinson's disease prevalence and the association with rurality and agricultural determinants. Retrieved at: https://research.monash.edu/en/publications/parkinsons-disease-prevalence-and-the-association-with-rurality-a. Accessed 16 March 2021.

⁶ Mindgardens Neuroscience Network. (2019). Review of the burden of disease for neurological, mental health and substance use disorders in Australia. Retrieved at: <u>https://www.neura.edu.au/wp-content/uploads/2019/03/MINDGARDENS-WHITE-PAPER-FINAL-14th-March-</u> <u>2019.pdf</u>. Accessed 6 April 2021.

⁷ Mayo Clinic (2017). Movement Disorders. Retrieved at: <u>https://www.mayoclinic.org/diseases-conditions/movement-disorders/symptoms-</u> <u>causes/syc-20363893#:~:text=The%20term%20%22movement%20disorders%22%20refers,cause%0reduced%20or%20slow%20movements</u>. accessed 8 January 2021.

⁸ International Parkinson and Movement Disorder Society. (2021). About us. Retrieved at: <u>https://www.movementdisorders.org/MDS/About.htm</u>. Accessed 6 April 2021.

Figure 1 | Summary statistics of neurological conditions including movement disorders



There is limited access to specialist care for neurological conditions in regional, rural, and remote areas.

The health challenges faced by people living in regional, rural, and remote areas are well documented; Australians living in these areas have shorter lives, higher levels of disease and poorer access to, and use of, health services, on average, compared with people living in metropolitan areas.⁹ There is growing evidence to suggest that this is consistent with the experience of people living with movement disorders in these areas, especially for people with Parkinson's disease, in which there is higher prevalence reported in regional, rural, and remote parts of Australia compared to metropolitan areas.¹⁰

Currently, available information on the experience of people with movement disorders living in regional, rural, and remote areas is mostly limited to Parkinson's disease. The literature that does exist highlights that people living with Parkinson's disease in these areas report worse overall health-related quality of life than city dwellers.¹¹ The literature also highlights significant differences in the presentation, management, and use of health services between patients accessing regional and urban Parkinson's disease clinics. Compared to patients with Parkinson's disease from urban clinics, patients in regional clinics were significantly older and diagnosed at a later age with a

⁹ Australian Institute of Health and Welfare. (2022). Rural and remote health. Retrieved at: <u>https://www.aihw.gov.au/reports/rural-remote-australians/rural-remote-health/contents/summary</u>. Accessed 22 August 2023.

¹⁰ Soh, S., et al. (2012). Rural living and health-related quality of life in Australians with Parkinson's disease. Retrieved at: <u>https://www.researchgate.net/publication/233907866 Rural living and health-</u> <u>related quality of life in Australians with Parkinson's disease</u>. Accessed 20 January 2021.

¹¹ Soh, S., et al. Op. Cit.

shorter duration of treatment. Patients from regional clinics also reported a poorer understanding of their illnesses.¹²

These quality of life outcomes are likely to be common across other neurological conditions including movement disorders in regional, rural, and remote Australia. These poorer outcomes may be explained by:

- Limited access to specialist services: Specialist services, including specialist medical and specialist nursing services, are extremely limited in regional, rural, and remote areas with people often having to travel long distances to receive support and care in regional centres or metropolitan areas.¹³ This contributes to long waiting times for initial neurological review.¹⁴
- Lack of appropriate support from a general practitioner (GP): Many people access nonspecialist services from local generalist health practitioners who have limited awareness and understanding of best practice management of movement disorders. The literature shows that support from neurologists is perceived by GPs to be very good in cities, but poor in remote areas; GPs in remote areas also have limited confidence in their ability to treat neurodegenerative conditions (especially in their later stages), resulting in limited access to appropriate condition-specific care.¹⁵
- Limited awareness of interventions: There is a lack of awareness and information regarding beneficial local services for people with neurological conditions and their carers. In particular, there is limited awareness of the range of services offered by allied health professionals in regional, rural, and remote areas.¹⁶ This is reflected in the fact that people with Parkinson's disease in urban areas utilise more and desire greater access to allied health services than those in regional areas.¹⁷

Movement disorder nurse specialists can play a vital role in improving quality of life for people living with neurological conditions including movement disorders.

Movement disorder nurse specialists offer an opportunity to enhance quality of life outcomes for those living in regional, rural, and remote areas. The role was first established in Australia in 1997 and was modelled on the Parkinson's disease nurse specialist (PDNS) roles in the United Kingdom.¹⁸

¹² Lubomski, M., et al. (2013). A cross-sectional study of clinical management, and provision of health services and their utilisation, by patients with Parkinson's disease in urban and regional Victoria. Retrieved at:

https://www.sciencedirect.com/science/article/abs/pii/S0967586812002986. Accessed 20 January 2021.

¹³ Duncan, GF and Rositano, P. (2011). Parkinson's disease in regional Australia. Rural and remote health (11): 1658.

¹⁴Harding C., et al. (2017). "Going at half speed": Parkinson's disease in rural and regional Australia. Retrieved at: <u>http://www.ruralhealth.org.au/14nrhc/sites/default/files/Harding%2C%20Catherine%20PPTs%20C7.pdf</u>. Accessed 20 January 2021.

¹⁵ Peters, C., et al. (2006). Prevalence of Parkinson's disease in metropolitan and rural Queensland: a general practice survey. Retrieved at: <u>https://pubmed.ncbi.nlm.nih.gov/16540321/</u>. Accessed 20 January 2021.

¹⁶ Duncan, GF and Rositano, P. (2011). Parkinson's disease in regional Australia. Rural and remote health (11): 1658.

¹⁷ Lubomski, M., et al. (2013). A cross-sectional study of clinical management, and provision of health services and their utilisation, by patients with Parkinson's disease in urban and regional Victoria. Retrieved at:

https://www.sciencedirect.com/science/article/abs/pii/S0967586812002986. Accessed 20 January 2021.

¹⁸ McLeod, J. (2010). The Evolution of Movement Disorders Specialist Nurses Role in WA, Connections, Royal College of Nursing Australia, 13(14).

The PDNS role in the UK was established in the National Health Service (NHS) in 1989 to allow the provision of specialised nursing services in clinical, educational and professional aspects of Parkinson's disease care. Since then, PDNS positions have expanded throughout the UK and globally; today, the PDNS status is officially recognised in the UK where training is formally provided with support from the UK Parkinson's Disease Society and Parkinson's Disease Nurse Specialist Association.¹⁹ Around 80 per cent of people living with Parkinson's disease in the UK have access to specialist nurses.²⁰

In Australia, movement disorder nurse specialist positions have more slowly expanded. In 2021, there were 61 specialist Parkinson's nurses in Australia.²¹ This compares to the latest data from the UK in 2011 where there were 264 nurses²² in the UK. According to the Australasian Neurological Nurses Association (ANNA), most of these Parkinson's disease and movement disorder nurse specialists (PDMDNS) are in NSW and Victoria, in metropolitan areas.

Overseas, nurse specialist roles also exist for neurological conditions other than Parkinson's disease such as Huntington's disease nurse specialists in New Zealand²³ and MND nurse specialists in the UK.²⁴ Despite diversity within Australia and overseas, there are recurring themes around key roles and responsibilities of these roles:

- Education for patients and carers. Movement disorder nurse specialists provide information and knowledge to patients and their families about the neurological condition, its treatment and impact on daily life. They also provide education about self-management strategies and advice regarding medication management.²⁵
- Education for providers. Movement disorder nurse specialists provide condition-specific education to healthcare professionals in generalist roles to enable enhanced support for patients, including medication-related education.²⁶
- **Care coordination.** Movement disorder nurse specialists are often seen as a key contact for patients and their families, acting as a link to the rest of the team involved in patient care. Movement disorder nurse specialists often cooperate closely with neurologists and

26 Ibid.

¹⁹ Bhidaysiri, R., Boonpang K., Jitkritsadakul O., et al. (2016). Understanding the role of the Parkinson's disease nurse specialist in the delivery of apomorphine therapy. Retrieved at: <u>https://www.anna.asn.au/wp-content/uploads/Understanding-the-role-of-the-Parkinsons-disease-nurse-specialist.pdf</u>. Accessed 20 January 2021.

²⁰ Dodd, A. (2014). Churchill Fellowship: Best Practice Models for people living with Parkinson's Disease. Retrieved from

https://www.churchilltrust.com.au/media/fellows/To study innovative care models A Dodd 2013.pdf. Accessed 6 April 2021.

²¹ Williams, S., Tsui, D., Zeppel, M. (2021). 2020 Annual Demographic Survey of Parkinson's Disease and Movement Disorder Nurse Specialists. Australian Journal of Neuroscience.

²² Emma Tenison, Alice James, Louise Ebenezer, and Emily J. Henderson (2022) A Narrative Review of Specialist Parkinson's Nurses: Evolution, Evidence and Expectation. Geriatrics (Basel). doi: 10.3390/geriatrics7020046

²³ Bourke, D., Finucane, G., Dysart, J., et al. (2012). The appointment of a Huntington's Disease Nurse Specialist has reduced admission rates and improved admission quality. Retrieved from: <u>https://content.iospress.com/articles/journal-of-huntingtons-disease/jhd120003</u>. Accessed 20 January 2021.

²⁴ Hobson, E., Baird, W., Bradburn, M., et al. (2017). The TiM system: developing a novel telehealth service to improve access to specialist care in motor nuerone disease using user-centred design.

²⁵ Bramble, M., V. Carroll, and R. Rossiter, Evidence based models that support best practice nursing services for people with Parkinson's disease in regional NSW: An integrative literature review. 2018, Australia: Charles Sturt University.

communicate information between clinicians and patients. They also make and receive referrals to other health and social care professionals, ensuring integrated care is delivered for patients.²⁷

- **Regular monitoring and assessment**. Movement disorder nurse specialists play a critical role in regular monitoring and consistent assessment of people with neurological conditions, measuring symptom changes, quality of life and caregiver burden.²⁸
- Emotional and psychosocial support. Movement disorder nurse specialists provide psychological and emotional support as they guide and support patients and their families adjust to living with the neurological condition.²⁹

1.3 Introduction to the MDNS pilot

In response to these challenges and to address known gaps, the then Australian Government Department of Health (now the Australian Government Department of Health and Aged Care) committed \$6.4 million over five years from 2019-20 to 2023-24 through the MDNS pilot. Funding was provided to PHNs to design and fund a service in their local areas.

The objective of the pilot was to improve access to quality specialised nursing care for people living with neurological conditions, including movement disorders; and increase the capacity of nurses to care for people living with neurological conditions including movement disorders. Regional, rural, and remote locations were targeted through the pilot.

The pilot had three intended objectives:

- 1. Improve health outcomes for people living with movement disorders across Australia.
- 2. Enhance education and training opportunities for nurses to better care for people living with movement disorders.
- 3. Build the knowledge base, including through sharing lessons learnt across PHNs and through a targeted evaluation.³⁰

Funding was made available in early 2020 for up to 15 sites. Four PHNs were ultimately successful in their applications:

- Hunter New England and Central Coast PHN (HNECC PHN).
- Northern Territory PHN (NT PHN).
- Western NSW PHN (WNSW PHN).
- Western Victoria PHN (WV PHN).

²⁷ Hellqvist, C., and Bertero, C. (2015). Support supplied by Parkinson's disease specialist nurses to Parkinson's disease patients and their spouses. Retrieved from: <u>https://www.sciencedirect.com/science/article/pii/S0897189715000555</u>. Accessed 20 January 2021.

²⁸ Bramble, M., V. Carroll, and R. Rossiter, Evidence based models that support best practice nursing services for people with Parkinson's disease in regional NSW: An integrative literature review. 2018, Australia: Charles Sturt University.

²⁹ Ibid.

³⁰ Australian Government Department of Health. 2020. Primary Heath Care Quality and Coordination Program: Movement Disorder Nurse Specialist Pilot Grant Opportunity Guidelines (GO2386).

In line with the stated objectives of the MDNS pilot, the Department engaged Nous to conduct a targeted national evaluation of the MDNS pilot. The Evaluation Plan for the evaluation was developed across 2021, with data collection occurring from late 2021 to mid-2023. The final report was delivered in October 2023 (this report).

2 Evaluation approach

This section presents information on the overall approach to the evaluation. It includes sub-sections that detail:

- Aims of the evaluation.
- Good practice principles.
- Evaluation framework and conceptual approach, including the theory of change and program logic that was developed for the evaluation.
- Key evaluation questions that guided data collection and analysis.
- Key data collection activities and analysis approaches.
- Evaluation limitations.

2.1 Evaluation aim

The overall aim of the evaluation was to determine the most appropriate and evidence-based models for improving access to specialist care and quality of life for people living with neurological conditions, including movement disorders, in regional, rural, and remote locations.

2.2 Good practice principles

A set of good practice principles underpinned the evaluation. This ensured that the evaluation was:

- **Respectful and empathetic**. The evaluation designed, conducted, and reported activities in a manner that respected the rights, dignity, entitlements and knowledge of different stakeholder groups.
- **Balanced.** The evaluation balanced feasibility, appropriateness, and rigour to ensure the effectiveness of the evaluation activities, whilst maintaining fidelity to key findings.
- **Robust.** The evaluation was methodologically robust and delivered valid and evidence-informed findings.
- **Practical.** The insights from the evaluation were framed with an eye to inform ongoing pilot delivery, potential future scale up and roll out, and policy development.
- Grounded in lived experience. The evaluation leveraged the experiences of those directly
 participating in the pilot models including nurses, people living with neurological conditions
 including movement disorders, their carers, and other system stakeholders to ensure that
 evaluation activities and outcomes reflected an understanding of day-to-day experience and
 practice, and that considerations for future directions were feasible and appropriate from a
 broad range of perspectives.
- Efficient. The evaluation made the best use of available data to optimise the efficiency of evaluation activities.

• **Collaborative and consultative.** The evaluation included sustained engagement with key stakeholders including those with neurological conditions including movement disorders, their families, and carers.

2.3 Evaluation framework

An overview of the framework for the evaluation is presented in Figure 2. The evaluation's approach applied a realist lens to develop an understanding of what worked, for whom, and in what context. The realist lens recognised that each PHN developed a model to meet the unique needs and circumstances of their local communities.

Overall evaluation question	What are the most appropriate evidence-based models for improving access to specialist care and quality of life for people living with neurological conditions including movement disorders in regional, rural, and remote communities?		
Rigorous approach and framework	The evaluation will apply a realist lens to understand context, mechanisms of change and outcomes across diverse models in regional, rural, and remote areas		
	 Process, outcome and economic components incorporating formative and summative insights 		
	 Program logics were used to understand the service delivery models and activities, agree on shared outcomes and identify data required to support the evaluation 		
	 Key evaluation questions were examined by triangulating in-depth qualitative and quantitative research 		
Documented approach	The Evaluation Plan and Project Plan formally documented the evaluation approach and framework, to support evaluation fidelity and consistency.		
Data collection via three	 Literature and policy: desktop review of academic and grey literature including documents provided by the Department and PHNs Consultations: 		
streams	 Interviews with key stakeholders 		
	Pilot PHN region visits		
	 Multi-stakeholder workshops 		
	3. Data analytics:		
	 Surveys of specialist nurses, their line managers and colleagues, and those receiving care under the pilot including families and carers 		
	Pilot minimum data set		

Figure 2 | Evaluation framework

Overall evaluation question	What are the most appropriate evidence-based models for improving access to specialist care and quality of life for people living with neurological conditions including movement disorders in regional, rural, and remote communities?
Mixed methods to analyse data	 Literature and policy Mapping of key features in PHN service delivery models Evidence synthesis Consultations Thematic analysis Constant comparative analysis Data analytics Descriptive and inferential statistics Derived quality of life years Cost effectiveness analysis Regression analysis
Data sources will be triangulated for reporting	 Realist lens: What worked, for whom and in what context? Patient outcomes Staff outcomes System outcomes
Comprehensive formative and summative reports	 Progress report 1: April 2021 Progress report 2: April 2022 Interim evaluation report: June 2023 Final evaluation report: October 2023

2.3.1 Evaluation components

The evaluation incorporated process, outcomes and economic components, as detailed in Table 2. These components have been used to shape data analysis and reporting of findings.

Table 2 | Process, outcomes and economic components of the evaluation

Process	The evaluation investigated how implementation of the pilot models was delivered, including planning, sustainability, quality, and satisfaction. The results of the process evaluation should be used by the Department and the four participating PHNs to consider how implementation could be adapted or changed should pilot models be considered for scale up and broader roll out.
Outcomes	The evaluation assessed short and medium-term outcomes at the patient, staff, and system level. It investigated whether and to what extent the pilot

	models contributed to factors such as enhanced access to specialised nursing care, improved continuity of care and management of complex needs, and improved quality of life.
Economic	The evaluation explored the cost-effectiveness of the different delivery models for government, providers, and those living with neurological conditions including movement disorders, and their families and carers. It investigated the cost per quality-adjusted life years gained, the total cost of each pilot model and how money was disbursed (for example program delivery, administration costs).

The evaluation delivered both formative and summative insights, as detailed in Table 3.

Table 3 | Formative and summative insights

Formative	Formative evaluations are conducted during program development and early program delivery. They are useful to understand the effectiveness of design and early implementation and can help support continuous improvement.
	The formative results were reported in progress reports at key stages of the evaluation, and were used by the Department and the four participating PHNs to understand and address any challenges or opportunities that arose during implementation and explore opportunities to improve as implementation progressed.
Summative	Summative evaluations are conducted once a program is well established. They are useful for understanding the extent to which a program is achieving its intended outcomes.
	The summative results of the evaluation may be used to determine whether and how the pilot models contribute to patient, staff, and system outcomes, and whether the pilot models (or elements of the models) should be expanded, modified, or ceased.

2.3.2 Key evaluation questions

Seven key evaluation questions (KEQs, presented in Table 4) guided and structured data collection and analysis. Detailed KEQs are presented in Appendix B.

Table 4 | High-level key evaluation questions

Overall evaluation question	What are the most appropriate and evidence-based models for improving access to specialist care and quality of life for people living with neurological conditions including movement disorders in regional, rural, and remote locations?	Type of evaluation question
KEQ 1	What are the pilot movement disorder nurse specialist models and how well have they been designed and delivered across PHNs?	Process evaluation
KEQ 2	How do the pilot models impact access to specialised nursing care and quality of life for people living with neurological conditions including movement disorders?	Outcomes evaluation
KEQ 3	How do the pilot models impact the upskilling and experience of the nurse workforce to provide specialised care?	Outcomes evaluation
KEQ 4	How do the pilot models impact delivery of specialised care at the system level?	Outcomes evaluation
KEQ 5	How cost effective are the different delivery models for government, providers, and patients?	Economic evaluation
KEQ 6	What lessons have been learned through the pilot that could support scalability and further roll out?	Learning for continuous improvement
KEQ 7	What evidence-based models of care to support those living with neurological conditions including movement disorders could be considered in future in regional, rural, and remote areas?	Learning for continuous improvement

2.3.3 Theory of change and program logic

A theory of change describes, at a high level, how program activities will lead to intended outcomes. In the case of the pilot, the theory of change is that increasing the availability of, and enhancing support for, specialist nurses will improve access to specialist care and enhance quality of life for those living with neurological conditions including movement disorders in regional, rural, and remote communities.

The theory of change is: Increasing the availability of, and enhancing support for, specialist nurses will improve access to specialist care and enhance quality of life for those living with neurological conditions including movement disorders in regional, rural, and remote communities.

The program logic provides more detail to the theory of change, and represents visually the links between activities, outputs, and outcomes. The program logic for the pilot (Figure 3) helped to

identify and shape output and outcome measures to collect data on and monitor throughout the evaluation. The program logic was tested and refined with the Department and each of the PHNs during finalisation of the Evaluation Plan in 2021.

Figure 3 | Program logic

Context	Inputs	Activities	Outputs	
Access to movement specialists for people in regional, rural, and remote	Department of Health funding of \$6.4m from 2019- 20 to 2023-24	Hunter New England and Central Coast: Single specialist nurse with three	Patient Who is receiving services? What frequency and dose? What is the eligibility criteria? What are the barriers and enablers for receiving services?	
areas has historically been low due to workforce capability constraints	Department coordination of PHN grant application process	nurse being upskilled and additional tools including screening tool for Aboriginal people		
Australian Government commitment for a MDNS pilot in regional, rural, and remote areas	Guidelines for the pilot to enable flexible execution across four PHNs	Northern Territory: A single full-time nurse will participate in multidisciplinary team care and provide education and support to patientsStaff Who is providing What education, support are they What clinical supe provided? What are the bar enablers for servWestern NSW: Model of care to involve upskilling and supporting 12 existing nurses within the regionStaff Who is providing What education, support are they What clinical supe provided? What are the bar enablers for servSystem What is the impact	Staff Who is providing services? What education, training	
The pilot aims to strengthen health care outcomes	PHNs within regional, rural, and remote areas have developed and implemented an integrated nurse-led model of care suited to the particular needs and circumstances of their region		support are they receiving? What clinical supervision is provided? What are the barriers and enablers for service delivery?	
and improving the quality, efficiency and availability of				
care and services in the community			System What is the impact on	
		Western Victoria: Model of care designed to support four nurses and build local specialist knowledge in clinical support, provide care coordination, and increased access to care	coordination and integration o primary and ambulatory health care? How do the pilot models integrate with other health services and health professionals?	

Outcomes					
Short-term Medium-term Long-term					
Potential patient outcomes	Patients in regional and rural areas have access to services	Patients have high satisfaction	Patients receive high quality care in the most appropriate		
	Improved continuity of care and management of complex chronic needs Carers are supported		Improved quality of life (QALY / DALY)		
Potential staff outcomes	Nurses receive appropriate education and training (accreditation)	Nurses report high engagement and satisfaction	Nurses are equipped and empowered to provide high quality care		
Potential system outcomes Improved sharing of practice across PHNs (building the knowledge base)		Build regional workforce capability Service delivery is cost-	Reduce impact on other health services (e.g. hospital admissions, primary care interactions		

2.4 Ethical oversight

The evaluation team gained approval from the Hunter New England Human Research Ethics Committee (HNE HREC) to engage with people with neurological conditions including movement disorders, and their families and carers, through consultations, surveys, and the use of de-identified service data (reference number 2021 / ETH11091). The evaluation was determined by HNE HREC to meet the requirements of the National Statement on Ethical Conduct in Human Research 2007 (the National Statement).

The NT PHN pilot model included potential engagement with Aboriginal and Torres Strait Islander Australians living with neurological conditions including movement disorders, their families, carers, and communities. The evaluation received ethical review and approval from the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (reference number 2022-4361). This review was considered under the National Mutual Acceptance (NMA) scheme.

2.5 Data sources and key activities

As noted in the evaluation framework, the evaluation collected data through three streams:

- Literature and policy. Desktop review of academic and grey literature including documents provided by the Department, PHNs and other key stakeholders (such as peak bodies).
- **Consultations.** Interviews with key stakeholders including representatives from the Department, PHNs, academics and peak bodies; in-person or virtual visits to each of the PHN regions including consultations with nurses, patients, and carers; and multistakeholder workshops to present, test and refine emerging insights and recommendations.
- Data analytics. Surveys sent to pilot nurses, their line managers and colleagues, and those receiving care and support under the pilot (including families and carers); collection of a pilot minimum dataset by the PHNs and nurses.

Table 5 provides an overview of the data sources, key activities, and analysis approach. Further detail is provided in Appendix C.

Independent evaluation of the WNSW PHN model

WNSW PHN commissioned a separate PHN-specific evaluation of their pilot model, led by an independent academic. The evaluation team worked closely with the independent academic during the development of the Evaluation Plan to agree opportunities to align evaluation approaches and reduce respondent burden. This included an agreement from WNSW PHN to share patient-related data (such as experience and outcomes measures) and nurse-related data (such as satisfaction with participation in the pilot) with the national evaluation. As a result, no patient-level data from WNSW PHN was collected by the national evaluation.

The academic delivered a realist evaluation report to the PHN in September 2023. The report captured insights from most of the nurses involved in the pilot and PHN representatives. Relevant insights from the independent evaluation have been incorporated into this report.

Information or data source	Description	Collection approach	Analysis approach
Literature and policy review	 Completed 2021, updated 2022 and 2023. Covered academic and grey literature, and documents provided by the Department and PHNs. Focused on: Nature of movement disorders, the evidence for available treatments and services, and the context in which the model was being piloted. Overview of the pilot models. 	Desktop search for relevant academic and grey literature. Targeted document request sent to the Department and PHNs. Updated requests sent to the Department and PHNs in 2022 and 2023.	Thematic analysis.
Interviews with key stakeholders	 Completed in 2021, 2022 and 2023. Stakeholders engaged including: Representatives from PHNs. Representatives from the Department including Office of the Chief Nursing and Midwifery Officer and Health Workforce Division. Peak bodies including Fight Parkinson's (formerly Parkinson's Victoria); Parkinson's Australia; the Australasian Neuroscience Nurses Association; MS Australia; Huntington's Disease Network of Australia. 	One-on-one or small group interviews. Semi-structured interviews with consultation guides.	Thematic analysis.

Table 5 | Overview of information and data collection and analysis

Information or data source	Description	Collection approach	Analysis approach	
Visits to PHN pilot regions	 Completed between March and May 2023. Visits to two PHNs were completed in person (HNECC PHN and NT PHN) and two virtually (WNSW PHN and WV PHN). Stakeholders engaged including: People living with neurological conditions including movement disorders, their families, and carers. Pilot nurses. Note that the evaluation was not able to contact many of the nurses in WNSW PHN. The evaluation was also not able to contact two of the nurses from HNECC PHN that received scholarships through the pilot. Nurse line managers and colleagues. Other health system stakeholders such as neurological specialists and representatives from local health networks. 	One-on-one or small group interviews. Semi-structured interviews with consultation guides.	Thematic analysis.	
Multistakeholder workshop	 Completed in August 2023. Designed to provide an opportunity to present, test and refine initial insights and emerging recommendations. 	Facilitated workshop.	Thematic analysis.	

Information or data source	Description	Collection approach	Analysis approach
	 People from the Department that attended represented the Health Resourcing division, the Primary and Community Care Group. 		
Nurse survey	 First cycle completed April / May 2022. Nine nurses completed the survey. Second cycle completed April / May 2023. Five nurses completed the survey, one of them had not completed the first survey. Survey collected data including: Demographic information including about nursing experience. Information about the activities and training they have done. Information about their skills and capabilities. Assessment of advanced nursing practices using the Australian Advanced Practice Nursing Appraisal Tool. 	Online survey hosted on Alchemer platform. Nurses emailed link to survey. Evaluation team directly followed up with nurses. PHN representatives followed up with nurses.	Descriptive statistics. Thematic analysis of qualitative responses.
Nurse line manager and colleague survey	 First cycle completed April / May 2022. One line manager or colleague completed the survey. Second cycle completed April / May 2023. None responded in 2023. 	Online survey hosted on Alchemer platform. Surveys were emailed to PHN representatives who emailed them	Descriptive statistics. Thematic analysis of qualitative responses.

Information or data source	Description	Collection approach	Analysis approach
Patient survey	 Survey collected data including: Demographic information. Assessment of the nurse's capabilities including against the Australian Advanced Practice Nursing Appraisal Tool. Barriers and enablers to success in the program. First cycle completed April / May 2022. Sixteen patients completed the survey. Second cycle completed April / May 2023. Seven patients completed the survey. Survey collected data including: 	to known colleagues of the participating nurses. Online survey hosted on Alchemer platform. Surveys were emailed to patients that consented to participate in the evaluation and had provided email	Descriptive statistics. Thematic analysis of qualitative responses.
	 Survey collected data including: Information about their condition. Ability to manage their condition. Satisfaction and experience with the service. 	addresses. These patients completed the survey online. A number of other patients that had consented to participate were called by the evaluation team and completed the survey over the phone.	
Carer survey	 First cycle completed April / May 2022. Five carers completed the survey. Second cycle completed April / May 2023. Three carers completed the survey. Survey collected data including: Level of carer burden. 	Online survey hosted on Alchemer platform. Surveys were emailed to carers that consented to participate in the evaluation and had provided email	Descriptive statistics. Thematic analysis of qualitative responses.

Information or data source	Description	Collection approach	Analysis approach
	• Satisfaction with the service.	addresses. These carers completed the survey online. A number of other carers that had consented to participate were called by the evaluation team and completed the survey over the phone.	
Patient outcomes data (pilot minimum data set)	 Completed by the nurse at baseline (entry into the evaluation) and annually for patients who consented to provide data to the evaluation. Collected data including: Patient characteristics. Quality of life using the 36-item Short Form Survey (SF-36). Charlson Comorbidity Index. 	Nurses recruited patients to participate in the evaluation, seeking consent. Nurse collected outcomes data from patients and provided this, de-identified, to the evaluation team. Data was collected at two time points: at the beginning of the nurse working with the patient and 12-months follow-up.	Converted quality of life responses into a single quality of life score and six domain scores using the SF-6D (See Appendix C for further details). Converted responses to comorbidity questionnaire to index using Dr Mary Charlson's approach (See Appendix C for further details). Descriptive statistics. Performed non-parametric one- way ANOVA test on data. Conducted a cost effectiveness analysis, combining the change in costs to change in outcomes, generating an incremental cost effectiveness ratio measuring the

Information or data source	Description	Collection approach	Analysis approach
			cost per quality-adjusted life-years gained. Performed bootstrapping analysis to estimate the uncertainty of the estimates.
Service interaction data	 Completed by the nurse at baseline (entry into the evaluation) and annually for patients who consented to provide data to the evaluation. Collected data including: Self-reported hospital service use in the previous 12-months. Presentations to Emergency Departments. Planned admissions and length of stay. Unplanned admissions and length of stay. 	Data was collected at the same time as patient outcome data. Collection approach described above.	Descriptive statistics. Data was converted into costs using unit costs for Emergency Department presentations and hospital bed days (See Appendix C for further details).
Administrative data from primary health networks (PHN)	 Completed by the PHNs annually. Included spending information, and nurse education and training information. 	PHNs data in a spreadsheet to the evaluation team.	Descriptive statistics.

2.6 Evaluation limitations

There are a number of limitations to be considered when interpreting the findings from the evaluation.

The evaluation team received data for a sub-set of people that received care and support through the pilot

Not all patients who received care and support during the pilot consented to provide data to the evaluation. As a result, the consenting population, and those that provided data, may not represent the whole population that was involved in this study.

Table 6 presents the total population of people receiving care and support during the pilot, the number of patients who initially provided consent, and the number of patients lost to follow-up.

In a long-term evaluation like this, it is common to lose patients to follow-up. The reasons are varied. For the evaluation of the MDNS pilot, reasons for loss to follow up include: patients becoming more unwell and losing contact with the nurse; patients moving into aged care; patients moving from the service area; patients choosing to disengage with either the nurse or the evaluation project.

PHN	Total patients receiving regular care or support	Consenting patients	Baseline	Follow-up	Lost to follow-up
HNECC	140	49	40	23	17
NT	170	25	25	23	2
WNSW ³¹	86	0	0	0	0
WV	145	84	84	53	31
Total	541	158	149	99	50

Table 6 | Number of patients at baseline and follow-up

The study collected demographic information from patients who provided data at baseline, and so it is possible to understand whether there are substantial differences between the baseline cohort

³¹ A separate evaluation was funded for WNSW PHN. To reduce reporting burden, the national evaluation did not collect patient data from this region. As a result of delays and issues with this evaluation, no patient data is available for the Western NSW region.

and the cohort that remained in the evaluation (i.e., not lost to follow-up). Table 7 presents the characteristics of these cohorts, indicating that the cohort at baseline is similar to the cohort that remained at the end of the evaluation The only substantial difference between the two is distribution of age, with a slight increase in the proportion of people over 60 remaining in the cohort.

Based on the information available, it is not expected that the patients who were not able to be followed-up would impact the evaluation results. However, the evaluation team notes there could be unobserved characteristics that bias the results.

Category	Baseline	Lost to follow-up	Remain in evaluation
Gender: Female	66 (44%)	23 (46%)	43 (43%)
Gender: Male	83 (56%)	27 (54%)	56 (57%)
Language spoken at home: English	147 (99%)	50 (100%)	97 (98%)
Language spoken at home: Another language	2 (1%)	0 (0%)	2 (2%)
Country of birth: Australia	120 (86%)	40 (93%)	80 (84%)
Country of birth: Other country	19 (14%)	3 (7%)	16 (16%)
Age: under 50	3 (2%)	1 (2%)	2 (2%)
Age: 51-60	11 (7%)	6 (13%)	5 (5%)
Age: 61-70	29 (19%)	7 (15%)	22 (22%)
Age: 71-80	80 (54%)	27 (51%)	53 (54%)

Table 7	Demographic	information of	of patients a	it baseline a	nd follow-up ³²

³² Note: The overall number of patients that provided data at baseline on their demographics is 149. However, there is missing data for some demographic information, so numbers may not all add to 149.

Category	Baseline	Lost to follow-up	Remain in evaluation
Age: over 80	26 (17%)	9 (19%)	17 (17%)

A lack of control group means it is difficult to attribute changes solely to the pilot

Due to the design of the pilot and of the evaluation, the evaluation includes no counterfactual cohort (i.e., no matched or similar cohort of patients in other PHNs who did not receive care and support from a movement disorder nurse specialist).

In place of a counterfactual cohort, the evaluation understood change over time through:

- Collecting self-reported service use and quality of life before and during involvement in the pilot, and exploring change over time (i.e., pre-post).
- Comparing observed results to similar results published in the literature.

Due to these limitations, care should be taken when interpreting the evaluation findings. The impact of these limitations is discussed in further detail in the findings section.

Service data was self-reported and only collected for some services

Limitations related to patient service use data that should be considered include:

- Service use data was based on patient self-report and recollection, which introduces a risk of recall bias (i.e., patients did not accurately recall service usage).
- Patient reasons for hospitalisation were not available from the service use data, and it may be that patients' hospitalisations were different pre-pilot and during the evaluation (with resulting impact on cost calculations).
- Data was only collected on hospital service use. Use of primary care services, aged care services, NDIS services and outpatient or community health services was not collected. This includes information on the costs of healthcare borne by the patients themselves.
- As noted above, there was no counterfactual to allow the calculation of incremental costeffectiveness ratios.

There were low survey response rates

The evaluation team distributed four surveys in 2022 and 2023. Response rates to each of these surveys were low despite best efforts and follow-up from the evaluation team (patient survey: n=16 in 2022 and 5 in 2023 of 541; carer survey: n=5 in 2022 and 3 in 2023; nurse survey: n=9 in 2022 and 5 in 2023 of 21; nurse colleague survey: n=1 in 2022 and 0 in 2023).

Caution is encouraged when drawing conclusions from the survey data alone. Wherever survey data is presented, the evaluation team has provided additional data or information (including qualitative evidence) to triangulate the finding.

There was limited data available for the WNSW PHN model, as compared to other models

As noted above, WNSW PHN separately commissioned a PHN-specific evaluation from an independent academic. At the start of the evaluation, the national evaluation team agreed an approach with the independent academic and the Department to share data and insights across the two evaluations, in order to minimise respondent burden.

Under this agreement the WNSW PHN pilot would not collect direct patient data for the national evaluation. Rather, the independent academic would access routinely collected patient reported experience measures (PREMs) and patient reported outcome measures (PROMs) and use these to understand patient outcomes.

Due to a number of factors, the PHN-specific evaluation proceeded slower than anticipated. As a result, PREMs and PROMs were not available, and the national evaluation team does not have patient-level data to report for WNSW PHN.

In addition to patient-level data, the national evaluation found it challenging to connect and engage with WNSW PHN nurses, despite best efforts.

3 Evaluation findings

This section presents findings from the evaluation of the MDNS pilot. It includes sub-sections that detail:

- Process evaluation findings describing what was delivered under the MDNS pilot and how well the pilot was delivered.
- Outcome evaluation findings describing the outcomes that were delivered for patients and carers, nurses, and the broader health system under the MDNS pilot.
- Economic evaluation findings discussing the cost effectiveness of the MDNS pilot.
- Learning for continuous improvement describing what was learned from the MDNS pilot that could be used to enhance or support future program design and implementation.

3.1 Findings from the process evaluation

Summary of findings from the process evaluation

This sub-section presents findings from the process evaluation in order to answer the following key evaluation question:

• KEQ 1: What are the pilot movement disorder nurse specialist models and how well have they been designed and delivered across PHNs?

Key findings from the process evaluation about the design of the models and the recruitment of nurses and patients:

- The MDNS pilot successfully supported four PHNs to develop and deliver new models of care.
- 896 patients received care and support, including 541 patients that received care directly and an additional 355 that received support through patient support and exercise groups.
- A total of 21 nurses have been supported and upskilled through the MDNS pilot.
- Of these 21 nurses, nine remain actively engaged in the pilot and a further four in WNSW and three in HNECC continue to use the skills they have learnt.

Key findings from the process evaluation about the role of nurses across the PHN models and activities delivered:

- The level of nurse specialisation varied across the pilot models, which impacted the care and support that nurses were able to provide in each PHN region.
- The disease or disorder focus of nurses varied across the pilot models some nurses were broad movement disorder nurse specialists, whereas others had a disease-specific focus.
- Nurse employment status varied across PHNs, which had a direct impact on the success of the models and the challenges faced by the nurses.
- Nurses spent the majority of time with patients providing patient and carer education, completing neurological assessments, and supporting care coordination.
Summary of findings from the process evaluation

- Nurses spent the majority of time overall delivering direct care and participating in professional development.
- All nurses participating in the MDNS pilot undertook education and upskilling.

Key findings from the process evaluation about the organisation and administration of the pilot include:

- The initial roll out of the MDNS pilot was delayed due to the COVID-19 pandemic.
- Collaborative processes were a critically important element of model design, however PHNs noted that effective collaborative processes require significant investment of time.
- It was appropriate and effective to direct funding for the MDNS pilot through PHNs.
- The Department effectively managed PHNs to support them to deliver the MDNS pilot.
- The evaluation identified factors at the PHN, service delivery organisation and nurse-levels that contributed to successful design and implementation of the pilot models.

3.1.1 Insights about the design of the models and the recruitment of nurses and patients

The MDNS pilot successfully supported four PHNs to develop and deliver new models of care

The MDNS pilot successfully supported four PHNs to develop and deliver new models to enhance access to care and support for people living with neurological conditions including movement disorders in regional, rural, and remote areas.

The pilot was launched in January 2020 as a targeted grant opportunity funded by the then Australian Government Department of Health. The pilot was funded under the Primary Health Care Development Program, which broadly aims to strengthen health care outcomes through facilitating access to, and improving the quality, efficiency and availability of health and medical services in the community.

The pilot aimed to improve access to quality specialised nursing care for people living with neurological conditions, including movement disorders, and increase the capacity of nurses to care for people living with neurological conditions including movement disorders. Regional, rural, and remote locations were specifically targeted in the pilot.

The grant opportunity provided funding for the employment of movement disorder nurse specialists in up to 15 regional, rural, and remote sites. Pilot locations were intended to focus on attracting specialist nurses in a community setting and upskilling nurses in primary care (for example those working in general practice). Funding was provided from the Department to PHNs.³³

Four PHNs were successful in applying for and receiving funding under the grant opportunity:

³³ Australian Government Department of Health. 22 January 2020. Primary Health Care Quality and Coordination Program: Movement Disorder Nurse Specialist Pilot Grant Opportunity Guidelines (GO2386).

- Hunter New England and Central Coast PHN (HNECC PHN).
- Northern Territory PHN (NT PHN).
- Western NSW PHN (WNSW PHN).
- Western Victoria PHN (WV PHN).

Each PHN received a different amount of funding, aligned with their original grant application, and intended activities.

Since 2020, each of the four PHNs have successfully developed and delivered a new nurse-led model of care that is aligned with the original aim and intent of the grant opportunity guidelines. Each of these are new models that provided additional care and support that was not otherwise available in the PHN regions. There is no indication that these models of care would have been developed without the support offered by the Department through the grant opportunity.

A summary of the four PHN models and their progress across the pilot delivery period is presented in Table 8. Further detailed case studies are presented in Appendix A.

Primary Health Network	Summary of model
HNECC PHN Total budget \$1,064,700 (ex. GST)	 The HNECC PHN model was developed through a comprehensive co- design process led by the PHN. The process involved a broad cross- section of stakeholders including representatives from the Local Health District, local primary health care providers, academics and researchers, peak bodies, and community members.
	 The model placed a single nurse in a private community-based allied health provider based in Tamworth, NSW.
	 The nurse provided care to patients and carers in Tamworth and surrounding communities.
	 The nurse employed had limited prior experience of and knowledge in neurological conditions including movement disorders. The model provided formal and informal training and upskilling opportunities to build nurse skills and confidence.
	 In addition to the single employed nurse, the model provided scholarships to three community-based nurses to enable them to complete formal training in movement disorders. There was no continued coordination of these nurses, and these nurses were not supported to (or expected to) design a new model of care.
	 The model intended to include a component of partnering with local Aboriginal Medical Services to increase care and support offered to First

Table 8 | Summary of PHN pilot models

Primary Health	Summary of model		
Network			
	 Nations Australians³⁴ living with neurological conditions including movement disorders. Due to challenges during the pilot implementation this partnership did not proceed. Through the model, the PHN facilitated additional training and upskilling of other health professionals including through organising a Parkinson's Symposium in Tamworth in November 2022, which was attended by 62 health professionals and 55 people with lived 		
	experience.		
NT PHN Total budget \$992,532 (ex. GST)	 The NT PHN model was developed through a comprehensive co-design process led by the PHN. The process involved a broad cross-section of stakeholders including representatives from NT Health, clinicians including neurologists, local primary health care providers, peak bodies, and community members. The co-design process took 6-months to complete. 		
	 The model placed a single nurse in the Community Allied Health Team (CAHT) within NT Health, based at Royal Darwin Hospital (RDH). 		
	 The nurse provided care to patients and carers across the entire Northern Territory – including Darwin. As a member of CAHT, the nurse travelled to and provided care and support to patients and carers in multiple remote and very remote communities. 		
	 The PHN received agreement from the Department to extend the service offering to metropolitan Darwin, even though the original grant opportunity specified that services were to be offered only to those living in regional, rural, and remote areas. 		
	 The nurse employed had extensive prior experience of and knowledge in neurological conditions including movement disorders. The PHN did not need to provide additional training or upskilling opportunities to enable the nurse to commence work. Throughout the pilot, the nurse was provided with training and upskilling opportunities (such as participation at conferences). 		
	 The nurse provided care and support to First Nations patients and carers as part of routine service delivery. 		
WNSW PHN Total budget	• The WNSW PHN model was developed in partnership with academic researchers and peak bodies, building from a successful prior research trial in NSW.		

³⁴ This report uses the term First Nations and First Nations Australians as this aligns with terminology used by the Australian Government Department of Health and Aged Care, First Nations Health Division. These terms should be understood to encompass all Aboriginal and Torres Strait Islander Australians.

Primary Health Network	Summary of model
\$430,800 (ex. GST)	• The model was originally overseen by a Steering Committee including representatives from the PHN, Local Health Districts, and peak and representative bodies. The role of the Steering Committee diminished over the course of the pilot.
	 There was an explicit agreement that the WNSW PHN model would initially focus on upskilling and training in Parkinson's disease. This was based on there being a higher prevalence of Parkinson's disease compared to other movement disorders, the lack of access to specialised services in the region, and the risk and common occurrence of people being hospitalised due to misadministration of Parkinson's disease medication.
	 The intention was that the focus of nurses would broaden during the pilot phase and into the future (should the model continue beyond the end of the pilot).
	 The model provided training to 12 community-based nurses across the WNSW PHN region. The nurses were employed in a variety of settings including within Local Health Districts, general practice and other primary care providers.
	 The nurses that were recruited had varying levels of previous experience ranging from no prior experience or skills in neurological conditions including movement disorders to some nurses who had previously worked in neurological clinics.
	 The nurses provided care to patients and carers that were based in their individual communities.
	• The model was set up so that the nurses would continue to work in their substantive roles, providing care and support to people living with neurological conditions including movement disorders when this was appropriate. It was never intended that the nurses would be full-time movement disorder nurse specialists.
	 The model included an informal community of practice, facilitated by the PHN, that enabled the nurses to share experiences and support each other.
	 The PHN facilitated links to academia, experts, and peak and representative bodies (such as Parkinson's NSW and the Australasian Neuroscience Nurses Association (ANNA)) to provide additional support, mentorship and clinical supervision and advice.
	 The PHN commissioned an independent researcher to complete a separate PHN-specific evaluation of the model.

Primary Health Network	Summary of model
WV PHN Total budget	• The WV PHN model was developed by the PHN based on the PHN understanding of local community needs and context and drawing from qualitative and quantitative data collected by the PHN.
\$1,975,788 (ex. GST)	 The model placed four nurses in government-run health services across the Western Victoria PHN region – Wimmera Health Care Group (Horsham), Grampians Community Health (Stawell), South West Healthcare (Warrnambool) and Rural Northwest Healthcare (Warracknabeal).
	 Three of the nurses were employed by LHNs, working in either a hospital outpatient clinic or community service, and the fourth nurse was placed in a community health setting.
	 The nurses provided care to patients and carers within their local communities, including in surrounding towns.
	 The nurses employed had limited prior experience of and knowledge in neurological conditions including movement disorders. The model provided formal and informal training and upskilling opportunities to build nurse skills and confidence, including through a formal link with Fight Parkinson's (formerly Parkinson's Victoria).

896 patients received care and support through the MDNS pilot

Nurses are providing care directly to 541 patients. The nurses are also supporting an additional 355 patients through patient support and exercise groups.

Table 9 presents a summary of patients receiving care and support across each PHN. The total patients receiving regular care or support is based on data self-reported by the nurses in September 2023 with the exception of WNSW which is based on data provided in April 2022. The total patients seen through support groups or exercise classes is based on data self-reported by the nurses in September 2023.

PHN	Total patients receiving regular care or support	Patients seen through support groups or exercise classes
HNECC	140	50
NT	170	0
WNSW	86	290
WV	145	15

Table 9 | Summary of patient receiving care and support across each PHN

PHN	Total patients receiving regular care or support	Patients seen through support groups or exercise classes
Total	541	355

Table 10 presents a demographic overview of the patients supported through the MDNS pilot. Note that this includes only those patients who consented to participate in the evaluation and provided data (149 patients in total), and as such demographic data should not be taken to be representative of the total patient cohort.³⁵

Table 10 || Demographic profile of patients receiving care and support under the MDNS pilot who had consented to share data with the evaluation^{36 37}

Category	HNECC	WV	NT	Total
Gender: Female	17	37	12	66
Gender: Male	23	47	13	83
Language spoken at home: English	40	83	24	147
Language spoken at home: Another language	*	*	*	2
Country of birth: Australia	36	65	19	120
Country of birth: Other country	4	9	6	19
Age: under 50	*	*	*	3
Age: 51-60	*	*	*	11

³⁵ Note that the evaluation received formal ethics review and approval to engage with First Nations Australians in the NT only. Given this, the evaluation did not collect First Nations status of patients in other PHN.

³⁶ Note that the overall number of patients that provided data at baseline on their demographics is 149 of the total 541 patients that received care and support from the nurses. However, there is missing data for some demographic information, so numbers may not all add to 149.

³⁷ Note that a * indicates data withheld due to small numbers to avoid a risk of identifying a patient.

Category	HNECC	wv	NT	Total
Age: 61-70	5	15	9	29
Age: 71-80	21	46	13	80
Age: over 80	9	15	2	26
Diagnosis: Parkinson's disease	40	62	22	124
Diagnosis: other	0	21	3	24

A total of 21 nurses have been supported and upskilled through the MDNS pilot

Attracting, recruiting, and upskilling nurses was at the core of the MDNS pilot – the grant opportunity guidelines note that pilot models should focus on attracting specialist nurses in a community setting and upskilling nurses in primary care.

The pilot was overall successful in meeting this objective. A total of 21 nurses have been supported and upskilled to date:

- Four nurses in HNECC PHN. One nurse who received training, developed a new model of care, and has been employed full-time as a movement disorder nurse specialist, and three community-based nurses who received scholarships to upskill in movement disorder care but did not become a movement disorder nurse specialist (nor design a new model of care). Of the three scholarship recipients, one worked at the local hospital, one in the office of a private neurologist and one in an aged care service.
- **One nurse in NT PHN**. A full-time, highly experienced movement disorder nurse specialist who did not require additional training.
- **Twelve nurses in WNSW PHN**. Each of these nurses are community-based nurses who received training in movement disorder care and support but did not become a movement disorder nurse specialist.
- Four nurses in WV PHN. Each of these nurses are full-time nurses who received training to become a movement disorder nurse specialist.

Of these 21 nurses, nine remain actively engaged in the pilot and an additional seven nurses are continuing to use their skills in various roles

The nurses that were recruited in HNECC PHN and NT PHN (one nurse in each PHN) remained in their roles and continue to provide care and support to patients and carers. Three of the four nurses in WV PHN and four of the nurses in WNSW PHN also remain in their roles.

In addition to these nine, the three nurses that received scholarships in HNECC PHN continue to use their newly gained skills as part of their employment.³⁸ Four of the nurses that are no longer actively engaged in the WNSW PHN pilot also reported continuing to use their skills.³⁹

These four nurses in WNSW PHN were engaged as part of the separate independent evaluation. They informed the evaluator they are continuing to identify opportunities to use the skills and knowledge about movement disorders they learnt through the pilot in various roles. One of the nurses is in a leadership role in an aged care service and seeking to establish referral pathways to care and support for their residents. Another nurse is helping to improve access to specialist services for patients with movement disorders as part of a small rural community health service.

WNSW PHN experienced a much higher rate of nurse dropouts than the other models (4 of 12 nurses (33 per cent)) remain actively involved in the pilot). WNSW PHN stakeholders and nurses engaged in the pilot reflected that there were multiple factors that led to nurses deciding not to continue with the pilot, including:

Perceived lack of support from organisations and line managers. The WNSW PHN model was
designed to provide education and training to already employed community-based nurses. There
was an expectation that nurses' organisations and line managers would support them to upskill
in movement disorder care and support – for example through providing time off for training,
supporting participation in mentorship programs, and allowing nurses to cordon off a portion of
time per week to see patients living with neurological conditions including movement disorders.

Some nurses in WNSW PHN reflected that they felt they were not provided with adequate support from their organisations, leaving them with little time to build and maintain their skills, and reducing their overall confidence in providing care and support to people living with neurological conditions including movement disorders.

- Lack of funding to support training and upskilling activities. The WNSW PHN model provided funding to cover the costs of formal nurse training and upskilling, however some nurses reflected that there were other, unforeseen costs that had not been considered. These include costs associated with travel for in-person training sessions and clinical placements, and the cost of backfilling the position when the nurse was participating in training (for example, the costs associated with locum relief). Without funding to cover these costs, some nurses were unable to complete necessary training and felt obliged to withdraw from the pilot.
- Changes in the WNSW PHN team managing the pilot in 2022. Many nurses had a strong personal relationship with the original WNSW PHN management team, who provided direct encouragement and support to the nurses. When the management team changed, some nurses reflected their impression that this encouragement and support reduced.
- Reduced support for the informal community of practice. WNSW PHN had initially established an informal community of practice for the nurses as a way to provide peer support and mentorship. As the pilot management team changed, some nurses reported their perception that

³⁸ Note that the HNECC PHN model never intended that these three nurses would remain engaged in the pilot long-term. These nurses were not supported to (nor expected to) develop their own models of care or implement a new service.

³⁹ In this instance, "no longer actively engaged" means the nurses have no ongoing connections with the pilot and are not working in roles where they are using the specialist movement disorder knowledge and skills they learned through the pilot.

the support for this community of practice also reduced. As a result, some nurses reflected without this support they felt more isolated and stressed, and less willing and able to dedicate time to their own training and education. PHN representatives reflected similar sentiments and noted that they found it challenging to engage nurses in meetings as the pilot progressed.

Responses from nurses that participated in the MDNS pilot:

- "We had that group [the community of practice] and then we didn't...it's really hard if you feel like you don't have that support network."
- "In terms of the MDNS, I have not done much at all as I have been busy with my current fulltime job, as well as there being no Parkinson patients within my current job."

3.1.2 Insights about the role of nurses across the PHN models and activities delivered

The level of nurse specialisation varied across the pilot models, which impacted the care and support that nurses were able to provide in each PHN region

The evaluation found that the level of specialisation of the nurses varied across PHN regions and fell along a spectrum from:

- Generalist nurse with some additional skills, such as in the WNSW PHN model. Nurses at this end of the spectrum were competent community-based nurses with some additional training and upskilling in neurological conditions including movement disorders. These nurses tended to focus on supporting early identification of patients with neurological conditions including movement disorders, connecting patients and carers with specialised neurological care, serving as a patient advocate in their interactions with neurological specialists, and providing patient and carer education and training.
- Specialist nurse with formal education and training in neurological conditions including
 movement disorders, such as the HNECC PHN and WV PHN models. Nurses towards the
 middle of the spectrum received formal training in neurological conditions including movement
 disorders and worked full-time as a movement disorder nurse specialist. In addition to the
 support provided by their colleagues at the more generalist end of the spectrum, these nurses
 tended to provide more specialist support such as advising on disease progression,
 coordinating care, running patient exercise groups, running patient and carer support groups,
 and building the skills and capabilities of other health workers.
- Highly specialised movement disorder nurse specialist, such as the NT PHN model. Nurses at this end of the spectrum had advanced training in neurological conditions including movement disorders and extensive clinical work experience. In addition to the support provided by their colleagues, these nurses tended to provide highly specialist support such as independently running neurological clinics, participating in multidisciplinary team care arrangements, collaborating with neurological specialists, and advising patients on treatment regimens.

Response from Department of Health and Aged Care representative:

• "It's not that one end of the spectrum is better than the other. At the end of the day, it has to be what's best for the community."

There are benefits and challenges of having nurses in regional, rural, and remote areas along the span of the spectrum. These are detailed in Table 11.

The evaluation did not find that future models should focus on nurses at any one point in the spectrum. Rather, multiple stakeholders highlighted that the level of specialisation should be driven by community needs and take into context factors such as incidence and prevalence data and availability of other specialist services.

Section 4 provides further detail on what regions may wish to consider when designing a model for their community.

Position along the spectrum	Benefits	Challenges
More generalist	 As demonstrated in the WNSW model, generalist nurses with some additional skills are less costly as they do not require as much further education and training to upskill and / or apply their skills. Generalist nurses with some additional skills working in more general nursing roles allow support and provision of care to a range of different patients beyond those that have neurological conditions. This is particularly important in regional, rural, and remote areas where there are a limited number of nurses to support a population with a broad range of healthcare needs. This model may be more sustainable in regional, rural, and remote area where there are workforce challenges including recruitment and retention of nurses. If a nurse with highly 	 Generalist nurses with some additional skills may take less pressure off other parts of the health system compared to more specialist nurses – for example, generalist nurses that are focused on disease identification, early intervention, patient education, and care coordination will need to refer to more specialist services such as neurologists. In regional, rural, and remote areas these services are often already overstretched. Under some models, generalist nurses may require additional support and coordination across a region to ensure they feel supported in their role and maintain their relevant knowledge and skills and to apply their learning to their ongoing care.

Table 11	Benefits and	challenges	along the	spectrum of	nurse s	pecialisation

Position along the spectrum	Benefits	Challenges
	specialist knowledge and skills were to move from the region, or retire, the community would lose an entire service. Providing only a small amount of additional training to another nurse in this scenario is easier and much more likely to be sustainable than recruiting or retraining a movement disorder nurse specialist.	
More specialist	 As demonstrated through the HNECC PHN, NT PHN and WV PHN models, more specialised nurses can improve patient outcomes and reduce hospitalisations. More specialist nurses can take pressure from other specialist services – such as neurologists and gerontologists. This may be particularly important in regional, rural, and remote areas where there can be limited specialist services, or access to these services via telehealth. 	 More specialist nurses require greater investment (including both time and finances) for education. Given their scope of practice, specialist nurses can be more expensive to retain compared to generalist nurses. More specialist nurses are likely more challenging to recruit to regional, rural, and remote areas, and may be more difficult to retain (given competition for these skills).

The disease or disorder focus of nurses varied across the pilot models – some nurses were broad movement disorder specialists, whereas others had a disease-specific focus

Similar to level of nurse specialisation, the disease or disorder focus of nurses varied across the PHN regions. Whilst the grant opportunity guidelines specified that the MDNS pilot was to improve access to specialist care for people living with neurological conditions, including movement disorders, in practice some models focused on specific diseases – for example:

- The HNECC PHN, WNSW PHN and WV PHN models all had an initial focus on Parkinson's disease, with an intent to broaden focus into the future. This condition focus was chosen due to known community needs and initial research on incidence and prevalence of Parkinson's disease in the community. In some PHNs, it may also have reflected the influence of peak bodies in the design of the pilot models.
- The NT PHN model had a broad focus on a selection of movement disorders. The PHN reflected that this broad area of focus was decided through the co-design process as participants

highlighted that it was unlikely that the NT would have high enough incidence and prevalence of a single specific movement disorder to justify a full-time disease-specific nurse.

Across the course of the pilot, taking into account patients in all PHN regions, the vast majority of patients who were supported were living with Parkinson's disease. Of those patients who provided data to the evaluation, 84 per cent (124 out of 148, with one patient not reporting a diagnosis, of the 541 patients that received care from the nurses) had a diagnosis of Parkinson's disease. This likely reflects the overall prevalence of Parkinson's disease in Australia (as compared to other movement disorders) as well as the explicit focus that some models had on supporting people living with Parkinson's disease.

As highlighted in Figure 4, stakeholders had differing opinions about nurse disease or disorder focus.

- Some stakeholders, for example representatives from peak bodies, argued for disease-specific
 nurses. These stakeholders highlighted the complexity of many neurological conditions
 including movement disorders particularly as a disease progresses and highlighted that
 disease-specific nurses were best placed to provide the highest quality care and support. These
 stakeholders also noted that disease-specific nurses are common in other areas of health, for
 example breast cancer nurses.
- Other stakeholders, for example representatives from the Department of Health and Aged Care
 and some nurses participating in the pilot, noted that nurses with broader specialisation had the
 ability to provide care to a greater number of patients. These stakeholders highlighted the
 commonalities between many neurological conditions including movement disorders –
 particularly in early stages of disease. Their perspective was that nurses with a broader
 knowledge base were valuable in regional, rural, and remote communities where there may be
 low incidence and prevalence of a specific disease, but higher overall incidence and prevalence
 of neurological conditions including movement disorders.

As with level of nurse specialisation, the evaluation found that decisions about disease focus should be made based on community need and context. For communities where there is a high prevalence of a specific movement disorder, disease-specific nurses could be considered.

Quote	Person quoted
"These diseases are really complex, particularly as the disease progresses. It's helpful to have someone that knows a lot, who can take pressure off the neurologist."	Peak body representative
"I don't provide advice on medications – I might say "before you do that, let's check with your neurologist". But I don't have that disease knowledge, I'm not an expert."	Nurse participating in the MDNS pilot

Figure 4 | Stakeholder views on nurse disease specialisation and area of focus

Quote	Person quoted
"It's a small community, I'll never have a full caseload of Parkinson's patients. I need to be able to provide care to as many people as possible."	Nurse participating in the MDNS pilot
"Maybe in some communities you do need a Parkinson's nurse, but in many others, there's not going to be those numbers. You'll need someone with a broader skill set."	Department of Health and Aged Care representative

Nurse employment status varied across PHNs, which had a direct impact on the success of the models and the challenges faced by the nurses

In three of the four PHNs (HNECC PHN, NT PHN, WV PHN), nurses were employed as full-time movement disorder nurse specialists.⁴⁰ As a result, these nurses reported that they had the time and support (from the PHN and their employing organisation) to focus on training and upskilling, to develop and implement a model of care, to provide care to the maximum number of patients and carers possible, and to engage in other important activities such as care coordination and upskilling other members of the health workforce.

However, stakeholders reflected that one trade-off with this employment model was that it limited the geographic scope of nurse services. Under this approach, there was a single nurse employed by an organisation in a community. This nurse could only reasonably be expected to provide care and support to patients and carers in that community and any close surrounding communities.

Efforts to expand geographic range – such as in the NT, where the nurse provided care and support in remote and very remote communities – meant that the nurse spent a significant portion of time travelling rather than providing direct care.

By contrast, many of the WNSW PHN nurses working in a community health setting were expected to utilise their skills and knowledge by providing care and support to patients with a movement disorder as part of their existing roles (further detail on employing organisations is provided in the case studies at Appendix A). Whilst the WNSW PHN model was able to provide additional education and training to more nurses – and thus reach more communities – using less funding, the evaluation highlighted a number of challenges with this employment status. This included the following:

• Some nurses found it difficult to secure time away from their substantive roles to provide care and support to people living with neurological conditions including movement disorders. Many nurses already had full caseloads, and they were not able to or supported to take on new patients.

⁴⁰ Note that the HNECC PHN model also included three nurses who received scholarships to upskill in movement disorders. The model did not intend that these nurses would remain engaged with the pilot in the long-term, nor that these nurses would be expected to develop and deliver a new model of care. Despite best efforts, the national evaluation was only able to engage with one of these three nurses.

- Some nurses found it difficult to gain support from their organisations and line managers to take time from their substantive roles to participate in training and upskilling. Many reported that their services were stretched, and they were not able to or supported to take time away from direct patient care.
- Some nurses did not feel that there were enough people living with neurological conditions including movement disorders in their local communities to enable them to maintain their currency of practice and feel confident.

Despite these challenges, nurses in WNSW PHN highlighted benefits of the employment model.

- The four nurses that are still actively engaged in the pilot are delivering direct care to 86 patients and providing other support to 290 patients (such as through patient support groups or exercise classes), despite the nurses only seeing patients with movement disorders part-time. These four nurses also reported a high level of satisfaction with their current experience with the pilot.⁴¹
- An additional four nurses that are no longer actively engaged in the pilot are also using the skills they gained through the pilot in a variety of roles.

Many of the WNSW PHN pilot nurses that were engaged as part of the national evaluation reported that the prevalence of movement disorders in their community was not high enough to justify a full-time, dedicated role. Where there is not a full-time case load, the WNSW PHN model uses finite nursing resources more efficiently to provide a more specialist service, while still providing care and support to patients without movement disorders living in regional, rural, and remote communities. Nurse reflections on employment status are presented in Figure 5.

Figure 5 | Nurse reflections on the appropriateness of employment status

Quote	Person quoted
"If I only see one patient every couple of weeks, it's hard to remain confident in my skills. I'm just not using them all that often."	Nurse participating in the MDNS pilot
"There aren't enough people out there in my community with movement disorders for me to be a full-time person. It just doesn't make sense."	Nurse participating in the MDNS pilot
"I'm a hearing nurse here, and if I shifted to being a full-time movement disorder nurse specialist then the hearing nurse role would just disappear. There would be no one in the community to provide this ongoing – and very much needed – support."	Nurse participating in the MDNS pilot

⁴¹ Note that this insight is drawn from the independent evaluation of the WNSW PHN pilot model.

Nurses spent the majority of time with patients providing patient and carer education, completing neurological assessments, and supporting care coordination

Service interaction data was collected by nurses in HNECC PHN, NT PHN and WV PHN each time they had an appointment / service interaction with a patient who consented to participate in the study Figure 6.⁴² Nurses recorded whether they provided one of five activities during the service interaction. A single service interaction could include multiple activities.





Whilst the exact proportions vary across each PHN, service interaction data indicates that approximately:

• In one in every three appointments, the nurse provided patient or carer education (for example around disease progression or medication management).

⁴² Note that, as agreed at the outset of the evaluation, service interaction data is not available for WNSW PHN nurses as it was anticipated that this data would be captured through the WNSW PHN independent evaluation.

⁴³ Note that this data is based on service interaction with patients that consented to participate in the study. Overall there are 1,896 service interactions and a total of 142 unique patients that had at least one service interaction recorded of a total of 541 patients that received care from the nurses. There were seven patients that had outcomes data collected at baseline but no service interactions recorded.

- In one in every four appointments, the nurse performed an assessment of the patient's symptoms or conducted diagnostic tests.
- In one in every five appointments, the nurses referred the patient to another service.

The nurse in NT PHN spent substantially more time providing treatment for the patient's movement disorder or symptoms than the nurses in HNECC PHN or WV PHN (approximately one in every five appointments, as compared to approximately one in every twenty appointments):

- This is likely related to the level of specialisation of the nurse in NT PHN who had extensive prior experience working with patients living with neurological conditions including movement disorders.
- The nurses in HNECC PHN and WV PHN reflected that the time spent on activities would likely change in coming years, as they became more comfortable in their roles and embedded their new skills. These nurses noted that the service interaction data reflected their activities during and soon after completing education.

Nurses spent the majority of time overall delivering direct care and participating in professional development

The survey of participating nurses asked nurses to estimate the proportion of time that they spent as a movement disorder nurse specialist completing select activities. The average of the responses from nurses are shown in Figure 7.⁴⁴ Note that as these are averages of the responses received across all nurses who completed the survey (n= 9 in 2022 and 5 in 2023 of 21 nurses), the total proportions do not add to 100 per cent.

⁴⁴ The survey specifically asked about proportion of time spent as a movement disorder nurse specialist, as the nurses in WNSW PHN were not employed full time.





Across all PHNs, nurses estimated that they spent the most amount of their time delivering direct care to patients and / or carers. This increased from 33 per cent of their time in 2022 to 45 per cent of their time in 2023 as the pilot progressed – likely reflecting a reduction in time needed for upskilling, growing caseloads, and an increase in nurse confidence.

Nurses estimated that they spent equal amounts of their time (between approximately 10 to 17 per cent of their time) upskilling or receiving education, coordinating care, and doing administrative activities.

These proportions are to be expected – especially the proportion of time spent on education – given the objective of the MDNS pilot was to upskill nurses in primary care and then support them to provide care to patients and carers.

In 2022, nurses estimated that they spent approximately one-fifth of their time (20 per cent) on "other" activities. Responses to the survey, and interviews with nurses and patients and carers, indicated that a significant proportion of "other" time was related to travel and to creating and designing their models of care. "Other" reduced to 5 per cent in 2023, likely reflecting that the models of care had been developed.

The proportion of time spent on travel is to be expected, given the explicit focus of the MDNS pilot on supporting patients and carers in regional, rural, and remote communities. Nurses from HNECC PHN, NT PHN and WV PHN all reported that they routinely visited patients or communities that were one-to-two hours travel time from the community in which they were based. Nurses in WNSW PHN did not report travelling to the same extent. Whilst many nurses reported that travel time was a burden – decreasing the amount of time they could dedicate to patient care, and introducing risk related to fatigue – they noted that travel time was required in regional, rural, and remote areas and provided a number of important benefits, including:

- Expanding the geographic scope of their service, so that patients and carers in surrounding communities could also access specialist care and support.
- Enhancing patient experience, as the nurse was able to see patients and carers in their homes.
- Potentially enhancing patient outcomes, as the nurses could gather additional information from home visits such as whether a patient needed specialised equipment for bathing (by looking to see whether the bathroom had been used), or whether a patient was eating (by looking to see whether they had food in their fridge).

Response from nurse participating in the MDNS pilot regarding travel time:

• "Patients love that I come to their home, and I get a fuller picture of what's going on in their lives."

Some nurses noted that if new models were to be designed in the future, travel time (and the impact of travel time on patient care and nurse satisfaction) should be considered and appropriately addressed. Some nurses highlighted opportunities to reduce travel time, including:

- Better leveraging telehealth and virtual care technology. Note, however, that many nurses
 cautioned that telehealth and virtual care would only work with patients who were comfortable
 with technology, and that it is not possible to complete many neurological assessments via
 telehealth or virtual care.
- Designing a "hub-and-spoke" model with a specialist nurse supporting more generalist nurses in surrounding communities. This approach is discussed further in Section 3.4.

There is limited published data available to enable comparisons to be made between the MDNS pilot and other nurses. The majority of published studies exploring how nurses spend their time focus on nurses working in hospital settings. One study from 2013 explored how community mental health nurses spent their time. The study found that nurses spent on average:

- 78 per cent of time performing clinical care.
- 12 per cent of time doing clinical organisation.
- 6 per cent of time doing administration.
- 4 per cent of time doing integration activities.⁴⁵

Whilst this study did include nurses in both metropolitan and regional, rural, and remote areas, it did not include the proportion of time that nurses in regional, rural, and remote areas spent

⁴⁵ Brenda M. Happell A B E, Cadeyrn J. Gaskin A B, Wendy Hoey C, Debra Nizette D and Kate Veach D, 2013, The activities that nurses working in community mental health perform: a geographical comparison. Australian Health Review 37(4) 453-457 https://doi.org/10.1071/AH13045

travelling. This study also did not focus on nurses who were participating in education, training, or upskilling – whereas the nurses in the MDNS pilot spent a significant proportion of their time in the early phases of the pilot engaged in these activities.

All nurses participating in the MDNS pilot undertook education and upskilling – nurses across the PHN regions are at different stages of progression

One of the explicit intended outcomes of the MDNS pilot was to enhance education and training opportunities for nurses to better care for people living with movement disorders. The pilot met this objective - all nurses across all PHN regions completed some form of education and upskilling during the evaluation period.

The package of education and training that was provided across PHN regions varied and included a combination of formal and informal education and training. Formal education and training for nurses included:

- Post graduate study in movement disorder nurse specialisation.
- Australian College of Nursing Parkinson's Care subject.
- Accreditation at using the MDS-Unified Parkinson's Disease Rating Scale tool.
- Industry clinical placements.

Some pilot models also provided membership to the ANNA Movement Disorder Chapter for four years.

Informal education and training included mentoring, participation in communities of practice, PHNsupported peer group learning (such as Project ECHO (Extension of Community Health Care Outcomes) learning), and support to participate in national and international conferences.

The level of training that nurses needed and were provided with varied across PHNs, based on both the pilot model and the existing level of experience of the nurses who were recruited (for example the nurse recruited into the NT PHN model was already highly specialist with post graduate training).

Data provided by the PHNs indicated that all the nurses in HNECC PHN, NT PHN and WV PHN have completed necessary education⁴⁶ – with informal education ongoing (such as on-the-ground training and informal mentorships). In WNSW PHN, the four nurses still actively engaged in the pilot only completed their clinical placements in October 2023.

3.1.3 Insights about the organisation and administration of the pilot

The initial roll out of the MDNS pilot was delayed due to the COVID-19 pandemic

⁴⁶ One nurse in WV PHN is still to complete their clinical placement.

Applications for the MDNS pilot grant opportunity opened in January 2020, and grant funding was made available in April 2020. This was just as the COVID-19 pandemic was beginning in Australia, with the Australian Government declaring a human biosecurity emergency on 18 March 2020.⁴⁷

Given this, PHNs reported that the initial roll out and implementation of the MDNS pilot was significantly delayed. Across 2020 and into 2021, PHNs and key implementation partners (such as state and territory health departments) diverted resources towards pandemic preparedness and response. As a result:

- PHNs and key implementation partners de-prioritised the MDNS pilot in favour of pandemic preparedness and response activities.
- Some nurses who had been recruited into PHN models were redirected towards pandemicrelated tasks, such as providing direct patient care or supporting vaccine roll-out.
- Some nurses who had been recruited into PHN models experienced burn-out as a result of the pandemic and were not able to dedicate necessary time to additional education and training.

Implementation of the MDNS pilot began in earnest in mid-to-late 2021. As reported in Evaluation Progress Report 2, as of April 2022 a total of 233 patients had received services across all four PHN regions. This accelerated over 2022 and 2023 – the number of patients receiving care directly from the nurses more than doubled between April 2022 and September 2023 (from 233 to 541, a 133 per cent increase).

Response from nurse participating in the MDNS pilot regarding capacity to participate in the MDNS pilot in 2020 and 2021:

• "We were asked to do so much [during COVID-19], I didn't have the mental or physical capacity to do anything else. There wasn't time."

Collaborative processes were a critically important element of model design, however PHNs noted that effective collaborative process require significant investment of time

Both HNECC PHN and NT PHN developed their models through formal co-design processes. NT PHN led this process independently, whilst HNECC PHN completed the co-design process with the support of an independent consultant.

Although WV PHN and WNSW PHN did not undertake formal co-design processes, representatives from both PHNs highlighted that the development of their model included robust community engagement. In WNSW PHN the PHN worked closely with an academic team from Charles Sturt University to engage with community and design a community-appropriate model.

Stakeholders reflected on the importance of collaborative design processes (Figure 8). These processes were vital to ensure that:

 ⁴⁷ Parliament of Australia. 2020. COVID-19 Legislative response – Human Biosecurity Emergency Declaration Explainer. Available from: <u>https://www.aph.gov.au/About Parliament/Parliamentary Departments/Parliamentary Library/FlagPost/2020/March/COVID-</u>
 <u>19 Biosecurity Emergency Declaration#:~:text=On%2018%20March%202020%20in,order%20to%20combat%20the%20outbreak</u>. Accessed:
 25 June 2023.

- Models met community needs and expectations. Collaborative design processes offered an opportunity to speak with a diverse group of stakeholders across PHN regions, to ensure that the model reflected local needs and desires.
- Models intersected with but did not duplicate existing services. Collaborative design processes brought together representatives from health services across PHN regions to ensure that the model that was designed would complement rather than duplicate existing services.
- Nurses and pilot models were set up for success from the start. Collaborative design processes ensured that models considered important factors such as referral pathways into the model and ensured that nurses and models could be effective from the start.
- Key stakeholders that were necessary for successful implementation had buy-in to the model and felt a sense of ownership. Collaborative design processes ensured that stakeholders felt they had a stake in the success of the model, and actively worked with the PHN and the nurses to guarantee success.

PHN stakeholders highlighted the importance of allocating appropriate time for successful collaborative design processes. Whilst the co-design processes in HNECC PHN and NT PHN took substantial time (between 6 and 12-months) PHNs were clear to emphasise the value of this time investment.

Although this process meant that services did not start immediately after grant funding had been provided, when services did start, they had the best chance of success. PHNs noted that if collaborative design processes are used to develop future models, the time taken to complete these models must be built into program and evaluation timelines and appropriate resources provided.

Quote	Person quoted
"The co-design process was pretty robust to be honestThere seemed to be a genuine commitment to co-design."	Co-design participant
"The community felt like they owned the position. There was good community buy-in and commitment."	Co-design participant
"The co-design process was invaluable. Getting community buy in was invaluable. Engaging people early on so that they felt listened to was really important.	PHN representative
We've since been able to call on those people that helped co- design the model to ensure that the model was working [and] to troubleshoot issues that were arising."	

Figure 8 | Stakeholder reflections on collaborative design processes

It was appropriate and effective to direct funding for the MDNS pilot through PHNs

Funding for the MDNS pilot was provided through the Primary Health Care Quality and Coordination Program, with funding available only to PHNs.

There are other mechanisms through which the Department could have met the objectives of the MDNS pilot such as partnering with state and territory health departments, providing funding to academic institutions to run pilot programs, or providing funding to peak organisations such as Parkinson's Australia.

The evaluation found that PHNs were an appropriate mechanism through which to direct funding for the MDNS pilot. PHNs provided a number of benefits, including:

- In-depth knowledge of local community needs. A core role of PHNs is to assess the health care
 needs of the community and commission health services to meet those needs.⁴⁸ By directing
 funding for the pilot through PHNs, the Department was able to build on this existing
 knowledge and ensure that pilot models were designed to meet known community needs and
 gaps in services.
- Strong connections with primary care and other health care providers to support
 collaborative design processes and delivery of the model. PHNs routinely work closely with
 primary care and health care providers in their local communities and could draw on these to
 support the success of models. Due to their role, PHNs have the authority to lead collaborative
 design processes and could serve as a bridge between key stakeholders that were needed for
 successful implementation such as between state and territory health departments, primary
 care providers, and aged care providers. Some PHNs (such as WNSW PHN and WV PHN) drew
 from these connections to build links between the nurses and peak bodies such as Parkinson's
 NSW and Fight Parkinson's.
- Expertise in program design and delivery. Many PHNs including the PHNs involved in the MDNS pilot – have extensive experience designing, commissioning, and managing new programs and services. The PHNs involved in the MDNS pilot had internal systems and resources – such as project management offices and dedicated staff resources – that supported model design and delivery.
- Ability to act as a central point of coordination, communication, and collaboration for all pilot nurses in the PHN region. In PHNs with more than one nurse (WNSW PHN and WV PHN), the PHNs were able to act as a central point of coordination, communication, and collaboration bringing together the nurses to share ideas, discuss challenges, and provide peer support. Given the nurses were working across multiple organisations such as multiple local health networks, or across various primary care providers it is appropriate that PHNs played this coordinating role (as opposed to coordination through state and territory departments of health).

It is possible that the coordination aspects of this role could be played by other stakeholders – such as peak organisations or academic bodies. However, PHNs provide added value in that

⁴⁸ Australian Government Department of Health and Aged Care. 2022. What Primary Health Networks Do. Available from: <u>https://www.health.gov.au/our-work/phn/what-PHNs-</u> <u>do#:~:text=Primary%20Health%20Networks%20(PHNs)%20assess.the%20primary%20health%20care%20system</u>. Accessed: 25 June 2023.

they are able to provide advice and support about more than just clinical service delivery including designing and planning a service model, and integration with other health services.

The evaluation further found that PHNs were overall effective at managing the delivery of the MDNS pilot. The majority of nurses spoke highly of the support that the PHN had provided to them – including to set up their model of care, to connect them with other nurses, and to help them address challenges when these arose. Other stakeholders with knowledge of the PHNs' role in pilot design and implementation also spoke highly of the support that had been provided.

WNSW PHN faced greater challenges delivering their model within the pilot than the other PHNs. In early 2022, a change in the way the PHN was managing the pilot and the PHN staff who were leading the pilot occurred. Nurses involved in the pilot reflected that this change decreased the intensity of the support provided to nurses and diluted the relationships that existed between the nurses and previous, local PHN staff who led the design and establishment of the pilot. The evaluation observed that after this PHN change, nurses began to disengage from the pilot. In addition, few nurses from WNSW PHN were able to be engaged for consultation through the evaluation.

Some PHNs reflected that their role in pilot management had diminished over time. These PHNs noted that their role was crucial in the design and early set up phase – to facilitate collaborative processes and support commissioning – but that as the pilot matured, it could be effectively managed by service delivery partners. This may be especially true for PHNs where state and territory health departments had been commissioned as the service providers (as opposed to placement of nurses in general practice or primary care).

Reflection from PHN representative regarding the role of the PHN:

• "We were asked to do so much [during COVID-19], I didn't have the mental or physical capacity to do anything else. There wasn't time."

The Department effectively managed PHNs to support them to deliver the MDNS pilot

The Department acted as the overall manager of the grant, working with the PHNs to support pilot development, roll out and ongoing implementation and was effective in this role.

PHN representatives spoke positively of the Department, including of the monthly cross-PHN meetings that the Department convened. These meetings enabled PHNs to provide updates on progress, and share challenges faced, and lessons learned. Some PHN representatives provided suggestions to enhance sharing of information between and across PHNs – these are discussed further in Section 3.2.3.

In addition, the evaluation noted the Department worked flexibly to respond to changes in context and support effective program delivery. This includes:

- Acknowledging and accepting delays in pilot delivery due to the COVID-19 pandemic.
- Working with PHNs to reallocate funding where needed for example, supporting PHNs to shift funding to future years to account for under-spending in early years (largely related to the COVID-19 pandemic).

- Working with PHNs to reallocate and reprogram funding where needed for example, allowing PHNs to use underspent funds for new purposes, aligned with the overall grant objectives.
- Reviewing and refining evaluation timelines to bring forward the delivery of the final report to ensure any decisions about continuation of the pilot would be made well before grant funding was scheduled to cease.

The evaluation identified factors at the PHN, service delivery organisation and nurse-levels that contributed to successful implementation of the pilot across the four PHN regions

The evaluation highlighted factors at the PHN, service delivery organisation, and nurse-level that contributed to successful design and implementation of the pilot models (Table 12).

Level	Factors that supported implementation
PHN-level	• Facilitating and agreeing clear expectations with service delivery partners at the start around how the model will fit into existing services. Through collaborative design processes, some PHNs clearly agreed and detailed how the new model would integrate with existing services. This made sure that roles, responsibilities, and expectations for nurse support were agreed up front.
	 Clear expectations were not set for some service delivery partners in WNSW PHN, which negatively impacted implementation. Some nurses in WNSW PHN reflected that expectation setting for their employers could have been more targeted and focused. These nurses felt that the organisations in which they were working could have more clearly articulated how the new movement disorder model would integrate with existing services. This would have helped provide these nurses with the time needed to put their new skills into practice. Prioritising raising awareness of the service including establishing referral pathways. Nurses across PHNs reflected that it was easier to establish a patient caseload where key stakeholders had been engaged early and so knew about the model, and where referral pathways into the model were
	clear. Many nurses noted that it was easier to establish referral pathways if the model was attached to a hospital, rather than being community-based. This setting meant that they were able to easily develop relationships with neurologists and allied health providers and could generate referrals through these pathways. Where nurses were community-based, they found that it was helpful to proactively build links with pre-existing support groups (such as Parkinson's disease support groups) as a way of raising awareness in the community and generating demand for services.

Table 12 | Factors supporting effective implementation

Level	Factors that supported implementation
	 The majority of nurses (with the exception of those based in general practice) found it challenging to build links with GPs. Nurses noted that GPs are time poor and may not have had capacity to fully engage with the service. Nurses suggested that PHNs could spend additional and focused time building awareness within general practice – such as through the Parkinson's Symposium that was run by HNECC PHN. Maintaining continuity in program oversight and coordination, especially where there was staff turnover. Two PHNs had a change in staff managing
	the pilot during the evaluation period. In one PHN, nurses continued to be engaged in the pilot and reported maintaining strong relationships with the PHN. In the other, nurses disengaged from the pilot.
Service delivery organisation- level	 Actively supporting nurses to attend and complete training, including clinical placements. Nurses that had greater success are those that had the full support of their employer and line manager to complete all required training early in the pilot. Whilst all nurses who were interviewed reported feeling supported by their employer, some reported that they found it difficult to complete training because there was limited financial support offered or there were no staff available to backfill their position whilst on leave. Note that the evaluation does not intend this to reflect a lack of commitment from employers to the pilot, but rather to highlight that each service delivery organisation has a number of priorities, and that the MDNS pilot may not have been the highest priority for a service at this time.
Nurse-level	 Selecting nurses that are comfortable working independently and in ambiguous environments. The MDNS pilot expected nurses across PHNs to independently establish a new model of care. Where nurses were successful, the evaluation noted that this was (in part) due to their personality and temperament. Successful nurses were comfortable setting up a new model of care (even when they had not done this before) and were happy to take the lead in promoting the service and building links with other health professionals. Guidance and support from PHNs or other organisations to nurses about how to set-up a new model of care and run a new service would support successful implementation. Some of the nurses interviewed reflected that this was not available to them but would have been helpful.

3.2 Findings from the outcomes evaluation

Summary of findings from the outcomes evaluation

This sub-section presents findings from the outcomes evaluation in order to answer the following key evaluation questions:

- KEQ 2: How do the pilot models impact on access to specialised nursing care and quality of life for people living with neurological conditions including movement disorders?
- KEQ 3: How do the pilot models impact the upskilling and experience of the nurse workforce to provide specialised care?
- KEQ 4: How do the pilot models impact delivery of specialised care at the system level?

Key findings from the outcomes evaluation about people living with neurological conditions including movement disorders:

- The pilot improved access to specialist nursing care for people living with movement disorders in regional, rural, and remote areas and is filling an identified service gap.
- Quality of life for patients participating in the trial was retained (no change) this is a positive result given the progressive nature of neurological conditions including movement disorders.
- Patients reported that they were satisfied with the quality of care they were receiving, and that their needs were being met.
- The pilot successfully supported patients with complex and chronic needs.
- Carers were also satisfied with the support they received through the pilot.

Key findings from the outcomes evaluation about nurses involved in the pilot:

- Nurses that were involved in the pilot increased their skills, knowledge, and confidence.
- Some nurses reported that they needed to see more patients, more regularly, to maintain their skills, knowledge, and currency of practice.
- Some nurses began to stretch into advanced practice nursing roles particularly related to delivery of clinical care and education.
- The majority of nurses are satisfied with their experience in the pilot.
- Some nurses are concerned that their workload is unsustainable, particularly given nurses now feel close to capacity.

Key findings from the outcomes evaluation about the delivery of specialised care at the system level:

- The nurses are supporting patients to experience more connected care by referring them to other services and supports.
- Data suggests that the pilots are reducing overall burden on the health system, including reducing hospitalisations and health service usage.
- There are indications that the pilots are contributing to uplift of the health workforce more broadly.

Summary of findings from the outcomes evaluation

• There is further opportunity to share information across PHNs involved in the pilot, as well as with other PHNs more broadly.

3.2.1 Outcomes about people living with neurological conditions uncluding movement disorders

The pilot improved access to specialist nursing care for people living with movement disorders in regional, rural and remote areas and is filling an identified service gap

As noted previously, there are currently 896 patients receiving care and support across all PHNs.

Patients, carers, and health system stakeholders all reported that as a result of the pilot patients were now able to access specialist nursing services that had previously been unavailable (Figure 9). This was either because there were no services in their community, services had no appointments or very long wait times, or because services were inaccessible due to travel times or discomfort with technology.

In some PHNs, it is likely that there is a greater need for services than can currently be accommodated:

- In NT PHN, the nurse has identified additional patients who would benefit from care, but who cannot currently be seen under the existing model and resourcing.
- In HNECC PHN, the nurse identified that they would soon be at capacity and would likely have to stop taking on additional patients.

Figure 9 | Stakeholder reflections on impact of the pilot on increasing access to specialised care

Patient and carer reflections	System stakeholder reflections
"Before the pilot, we'd contacted the peak body in South Australia, but all we really got was a newsletter and a request for donations."	"The role is filling a massive gap. Before this, none of these clients were receiving specialist care."
"Well [before the pilot] we had to go to Melbourne to see the neurologist, there was nothing here."	"If the nurse wasn't there, they'd just be getting lost in the system."
"What specialist services was I getting? Not a hell of a lot. Some people to help with shopping and housework but no nursing services."	"There was absolutely nothing here for people with Parkinson's disease before."

Patient and carer reflections	System stakeholder reflections
"I'd say most people in regional and remote areas aren't getting any care."	"The nurse is great. They're picking people up early in diagnosis and making sure they get channelled to me in the neurology clinic."

This qualitative data is complemented by quantitative data collected through the survey of patients and survey of nurses (Figure 10). As noted previously, there were low response rates to these surveys and therefore data presented here should be considered supportive of qualitative insights but not representative of the evaluation cohort.

Responses to the surveys indicate that:

- A majority of patients who responded to the survey (13 out of 18 respondents, of 541 total patients, (72 per cent)) agreed or strongly agreed that they were able to access specialised care for their neurological condition.⁴⁹
- Just under a majority of patients who responded to the survey (8 out of 18 respondents, of 541 total patients, (44 per cent)) agreed or strongly agreed that they didn't have to wait too long to access services that were appropriate to their needs.
- A majority of patients who responded to the survey (11 out of 18 respondents, of 541 total patients, (61 per cent)) agreed or strongly agreed that services were provided in a place that was easy for them to access.
- A majority of nurses who responded to the survey (7 out of 10 respondents, of 21 nurses, (70 per cent)) agreed or strongly agreed that the pilot had improved access to specialised care for movement disorders.

⁴⁹ Note that all questions in the patient survey were optional, so the denominator varies across questions.



Figure 10 | Response to selected patient and nurse survey questions

Quality of life for patients participating in the trial was retained (no change) – this is a positive result given the progressive nature of neurological conditions including movement disorders

Throughout the evaluation, nurses in three PHNs (HNECC PHN, NT PHN and WV PHN) collected quality of life information from patients who had consented to participate in the evaluation. The

evaluation used the 36-Item Short Form Health Survey (SF-36).⁵⁰ The evaluation used the standard SF-6D, developed by the University of Sheffield, to translate responses to the SF-36 survey to scores for six quality of life domain and a single health-related quality of life score.⁵¹

Table 13 presents the results from the evaluation including the average measures taken at baseline and follow-up. Only patients that provided complete data with no missing values at both time points are included (n=99 of 541 patients in total that received care from the nurses). Note that:

- A higher score for the overall quality of life measure indicates better health.
- For each domain, a higher score indicates poorer health.

On average, the quality-of-life score for patients involved in the evaluation was 0.01 points lower at follow-up as compared to baseline.⁵² This difference however was not significant (p=0.86) based on the non-parametric one-way ANOVA test at a confidence interval of 95 per cent. The difference for each of the quality-of-life domains was also not significantly different using the same test.

Domain	Result at baseline	Result at follow-up	Difference	Significance
Overall quality of life score	0.59	0.58	-0.01	0.93
Activities of daily living	2.71	2.73	0.02	0.97
Bodily pain	3.21	3.48	0.24	0.21
Mental health	2.69	2.66	-0.03	0.89
Physical functioning	4.30	4.23	-0.07	0.66
Social functioning	2.46	2.60	0.14	0.57
Vitality	3.48	3.44	-0.04	0.83

Table 13 | Quality of life results⁵³

Note: The six domains' scores are calculated using the SF-6D scoring.⁵⁴

⁵⁰ The SF-36 was developed by RAND Corporation as part of the Medical Outcomes Study (MOS). The SF-36 is available from: <u>https://www.rand.org/health-care/surveys_tools/mos/36-item-short-form.html</u>

⁵¹ University of Sheffield, Department of Economics, The SF-6D: An internationally adopted measure for valuing health and assessing the cost- effectiveness of health care interventions. Accessed on 18 June 2023. <u>https://www.sheffield.ac.uk/economics/research/impact-and-knowledge-exchange/sf6d</u>

⁵² Note that the evaluation plan intended that quality of life data would be collected at baseline (i.e. at the first appointment with the nurse) and then annually. Due to the reality of the delivery of the pilot (including initial delays with commencing service delivery, and the shortening of the evaluation period) and the reality of clinical service delivery (including that the nurses saw patients only when needed), not all follow-up scores were taken at 12-months post baseline. Some were collected sconer than 12-months and others later. The evaluation team analysed change in quality of life scores depending on time between measures and saw no association.

⁵³ Note that these calculations are based on complete data from 99 of 541 patients in total that received care from the nurses.

⁵⁴ The SF-6D is an internationally adopted measure for valuing health and assessing the cost-effectiveness of health interventions. References: Deverill, Roberts, Brazier (March 2022). The estimation of a preference-based single index measure for health from the SF-36. Journal of Health Economics. 21(2), pp. 271-292; O'Hagan, Roberts, Brazier, Kharroubi. (May 2007). Modelling SF-6D health state preference data using a nonparametric Bayesian method. Journal of Health Economics. 1;26(3). Pp. 597-612; Roberts, Brazier. (Sep 2004). The estimation of preference-based measure of health from the SF-12. Medical Care. 42(9). Pp. 851-9.

Table 14 presents the overall change in quality-of-life score stratified by PHN. Given the small number of patients in each region, it is difficult to draw definitive conclusions as to the impact of any individual model.⁵⁵ There was not a significant difference in any of the PHNs.

Primary Health Network	Number of patients with a score at baseline and follow-up	Baseline score	Follow-up score	Difference	Significance
HNECC PHN	23	0.60	0.61	0.01	0.51
NT	23	0.60	0.61	0.01	0.72
WV	53	0.57	0.56	-0.01	0.75

Table 14 | Overall change in quality-of-life scores by PHN⁵⁶

Whilst quality of life remained steady across the evaluation, the evaluation considers this a positive result. Neurological conditions including movement disorders are progressive illnesses, and it is expected that quality of life would decline over time.

As there was no control group available from this study, the evaluation has compared the results to control groups from other published studies. The evaluation found four randomised control trials for patients diagnosed with Parkinson's disease with health-related quality of life data collected and presented. Only studies with patients with Parkinson's disease were included because a majority of patients in this pilot had this diagnosis.

An additional three studies were found that are included in the cost-effectiveness comparison but are not included here. This is because these studies either presented the change in quality-of-life information for the control group in a way that could not be used as comparison or had control groups that received another type of treatment instead of routine medical care. Table 15 compares the evaluation data to the data from these studies.

The weighted average change in quality-of-life scores, weighted based on sample size, from these four studies was -0.024. This is a greater decrease in quality-of-life than the pilot, which was -0.01. This indicates the MDNS pilot was successful in maintaining patient quality of life and arresting any expected decline.

There was not sufficient data available from these studies on the uncertainty of the estimates to allow a statistical test of whether they are significantly different from the MDNS pilot data. Given the differences are similar, and based on the statistical testing from the studies, it is probable that

⁵⁵ Note that there was also limited differences when analysing outcomes by patient cohort. For some characteristics – such as diagnosis – there was not sufficient data to identify differences, given the vast majority of patients who provided data had Parkinson's disease. For other characteristics, including gender, age, quality-of-life score at baseline, and time since diagnosis, there were no significant differences in the results.

⁵⁶ Note that these calculations are based on complete data from 99 of 541 patients in total that received care from the nurses.

the MDNS pilot change in quality-of-life score was not significantly greater than the study data, depending on the statistical test used.

Study	Sample size	Starting value	Final value	Change in quality-of- life scores	Time period
Evaluation data	99	0.59	0.58	-0.01	12 months
2015 study in the Netherlands ⁵⁷	67	0.73	0.69	-0.04	6 months
2020 study in the UK ⁵⁸	236	0.669	0.626	-0.043	12 months
2012 study in the UK ⁵⁹	45	0.65	0.62	-0.03	20 weeks
2016 study in the UK ⁶⁰	178	0.48	0.49	0.01	12 months

Table 15 Comparison between evaluation data and dat	a from control groups from published
literature	

There are a number of factors that contribute to uncertainty around the outcomes analysis

Firstly, selection bias could have impacted the change in quality-of-life scores. Selection bias involves selecting people who are more likely to have positive outcomes. This is not usually done deliberately. Patients that recorded data at baseline may not be able to followed-up because their health had deteriorated. As a result, it is possible the average change in quality-of-life score is higher than it would have been if all patients were able to be followed-up.

Additionally, there are a number of differences in the studies used for comparison that could impact the findings.

• There are differences in the time period between observations. As part of this evaluation, the evaluation team analysed differences in changes in quality-of-life scores when scores were

⁵⁷ Sturkenboom, I. H., Hendriks, J. C., Graff, M. J., Adang, E. M., Munneke, M., Nijhuis-van der Sanden, M. W., & Bloem, B. R. (2015). Economic evaluation of occupational therapy in Parkinson's disease: A randomized controlled trial. Movement disorders: official journal of the Movement Disorder Society, 30(8), 1059–1067. https://doi.org/10.1002/mds.26217

⁵⁸ Xin, Y., Ashburn, A., Pickering, R.M. et al. Cost-effectiveness of the PDSAFE personalised physiotherapy intervention for fall prevention in Parkinson's: an economic evaluation alongside a randomised controlled trial. BMC Neurol 20, 295 (2020). https://doi.org/10.1186/s12883-020-01852-8

⁵⁹ Fletcher, E., Goodwin, V.A., Richards, S.H. et al. An exercise intervention to prevent falls in Parkinson's: an economic evaluation. BMC Health Serv Res 12, 426 (2012). https://doi.org/10.1186/1472-6963-12-426

⁶⁰ McIntosh, E., Gray, A., Daniels, J., Gill, S., Ives, N., Jenkinson, C., Mitchell, R., Pall, H., Patel, S., Quinn, N., Rick, C., Wheatley, K., Williams, A., & PD SURG Collaborators Group (2016). Cost-utility analysis of deep brain stimulation surgery plus best medical therapy versus best medical therapy in patients with Parkinson's: Economic evaluation alongside the PD SURG trial. Movement disorders: official journal of the Movement Disorder Society, 31(8), 1173–1182. https://doi.org/10.1002/mds.26423

taken at different time points. The evaluation team found there was no relationship between change in scores and time between observations. As such, it is unlikely these differences would impact the results.

- There are a number of differences in cohorts. There are many similarities between this evaluation and published studies including the average age and time since diagnosis. There were, however, a few differences including:
 - 2015 study in the US: a much higher proportion of females than this evaluation.
 - 2015 study in the Netherlands: patients, on average, received a diagnosis more recently.

Further information about these studies can be found at Appendix D.

Patients reported that they were satisfied with the quality of care they were receiving and that their needs were being met

Throughout the evaluation, patients reported that they were highly satisfied with the service provided by the movement disorder nurse specialist. This was particularly evident through interviews with patients and carers (Figure 11).

Figure 11 | Patient and carer reflections on satisfaction with care (qualitative data)

Patient and carer reflections

"Once [the nurse] has been involved it's been tremendous. I've felt lost at times, but my nurse provides encouragement, and it really helps."

"I have much less to worry about now than I did before."

"I honestly can't praise the program enough."

"The nurse has been amazing."

"The nurse has been a really good "go to", or buffer, to help us and guide us in the directions we needed to go."

"I think it gives you some light at the end of the tunnel. That you're not fighting this by yourself. If you need someone to talk to, the nurse is there."

"In big cities you might have great services, but out here in the country there's nothing. It's good to have someone at your door who knows what's what."

"This is ideal as far as I'm concerned. I'd be lost without it."

These qualitative insights are supported by patient survey data. Of those who responded to the survey – a small subset of the evaluation cohort – an overwhelming majority of patients agreed or

strongly agreed that they were satisfied with the service, that the service was meeting their needs, and that they had had a good experience with the nurse (Figure 12).





The pilot successfully supported patients with complex and chronic needs

There were a substantial number of patients in the pilot that experienced other chronic conditions and, as a result, had more complex healthcare needs. As part of the patient outcomes data collection, the nurses collected data on patient comorbidities. This data showed that 28.4 per cent (29 out of 102 patients of the total 541 patients) of patients that remained in the evaluation at follow up had at least one comorbidity, and 21 per cent (21 out of 102 patients of the total 541 patients) had at least two comorbidities.

Despite these complex and additional needs, survey data indicates that the nurses provided highquality supports that met those needs. Through the patient survey, a majority of patients that responded either agreed or strongly agreed that they were able to manage their other complex chronic needs (Figure 13).





Carers were also satisfied with the support they received through the pilot

responded to both surveys, their response to the 2023 survey is presented here.

In addition to providing direct care and support to people living with neurological conditions including movement disorders, across all PHNs the nurses also provided support to carers. The specific type of support provided varied across PHNs, but included:

- Providing carer education about neurological conditions including movement disorders, including advice on how carers can best support the person they are caring for.
- Offering mental health and psychosocial support for carers.
- Facilitating and supporting carer support groups, including through running classes for people living with neurological conditions including movement disorders so that carers had time to meet separately.
- Connecting carers with other formal services and supports that are available.
- Supporting carers to navigate the system and access other services and supports, such as through helping carers access Carer Gateway.

Figure 14 presents carer reflections on the impact of the pilot and the benefits that were provided.⁶¹

⁶¹ Note that the evaluation also distributed a survey to carers of people living with neurological conditions including movement disorders in 2022 and 2023. Given the extremely low response rates (n=5 in 2022 and n=3 in 2023), this data is not presented.

Figure 14 | Carer reflections on the impact of the MDNS pilot

Carer reflections

"Honestly I don't know what I'd do without the nurse."

"[The nurse] is chasing up respite services. Mum's getting really tired, and I'm there 7-days a week. It's too much. Me and mum need a break."

"[The nurse] was aware of the carer support services that were available. She knew what I could access, and she knew what services might be available to support the person I'm caring for."

"It's been a great benefit to patients and carers. Carers especially. Being able to link us in with the supports that we otherwise wouldn't have known about."

"It's really hard to put into words the impact it had when that position was created. Just knowing that there was something local. It was such a relief."

3.2.2 Outcomes about nurses involved in the pilot

Nurses that were involved in the pilot increased their skills, knowledge and confidence

One of the explicit objectives of the MDNS pilot was to enhance education and training opportunities for nurses to better care for people living with movement disorders. The evaluation found that this objective had been met.

All nurses that were involved in the pilot received formal training to build their skills in supporting people living with neurological conditions including movement disorders. As reported above, the majority of nurses remaining in the pilot have now completed this training – some nurses are still to complete their clinical placements.

Most of the nurses involved in the pilot were satisfied with the formal training that was provided and felt that it gave them the skills they needed to work with people living with neurological conditions including movement disorders.

Some nurses from WNSW PHN reflected that the level of training they received was more specialised than they needed for the care they were expected to deliver. Some of the nurses in WNSW PHN that are no longer actively involved in the pilot reported that the education and training that was expected of them was overly burdensome, and this was one of the reasons they chose to withdraw from the pilot and not complete the training. Given that the WNSW PHN model envisioned that nurses would not be employed as full-time movement disorder nurse specialists, it
is possible the level of education provided was more than these nurses would need to deliver in their role.

In addition to formal training, many of the nurses have benefited from informal upskilling and support, including:

- Engagement with the Australasian Neuroscience Nurses Association (ANNA) Movement
 Disorders Chapter. The WNSW PHN model included an explicit link with the Chapter, including
 mechanisms through which Chapter nurses provided guidance, advice, and mentorship. Nurses
 in the other PHNs were also connected with the Chapter and reflected on the benefits they
 received from being connected with a broader group of movement disorder nurses, many with
 extensive experience. The nurses involved in the pilot could turn to Chapter nurses for advice
 when needed, and many of the nurses also made use of resources developed by the Chapter to
 help them set up and embed their models.
- Engagement with peak bodies. The WV PHN model included an explicit link with Fight Parkinson's. The nurses in WV PHN participated in routine meetings with an expert representative from Fight Parkinson's, who provided them with advice and clinical oversight, and led them through case examples. The WNSW PHN model included a similar explicit link with Parkinson's NSW.
- Peer mentorship and support facilitated through the PHNs. The WNSW PHN and WV PHN models both included peer mentorship and support through an informal community of practice (WNSW PHN) and a Project ECHO approach (WV PHN). Nurses in these PHNs reflected the value they received from peer mentorship, including the important psychosocial support that peers provided.
- Informal conversations with colleagues and other health care professionals. Many of the
 nurses across all PHNs reflected the benefit they received from working alongside colleagues.
 For example, nurses working alongside allied health professionals grew in their knowledge and
 understanding of how allied health can support people living with neurological conditions
 including movement disorders.

During interviews and site visit the nurses, line managers and colleagues all reflected this increase in skills, knowledge, and confidence (Figure 15).

The evaluation spoke to the majority of nurse line managers in HNECC PHN, NT PHN and WV PHN, but not in WNSW PHN. Whilst the evaluation was able to speak to a small number of nurse colleagues across all PHNs during site visits, there was very limited uptake of the nurse colleague survey. As a result, care should be taken when reading and interpreting these insights.

Figure 15 | Nurse, line manager and colleague reflections on increase in skills, knowledge and confidence

Nurse reflections	Line manager and colleague reflections
"My knowledge has improved so much. I can't believe where I was and where I've gotten to.	"I've been able to see the nurses develop professionallythey've gone from a very

Nurse reflections	Line manager and colleague reflections
The improvement in my knowledge is mind- bending."	narrow understanding to a much broader scope of practice."
"It's been one of the most challenging but fulfilling periods of my career."	"The neurologist now says to me "if you've got any problems or questions, go ask [the nurse]."
"It's definitely improving my confidence."	"Initially it was a really steep learning curve, but they [the nurse] has really embraced it."
"As a clinician, it's given me a lot more confidence. People are now coming to me and looking for advice."	"[The nurse] has expert knowledge and skill. I can see them blossoming into the role."

Some nurses in WNSW PHN reported that that they needed to see more patients, more regularly, to maintain their skills, knowledge and currency of practice

As noted above, the WNSW PHN model was designed so that the nurses incorporated care for people living with neurological conditions including movement disorders into their day-to-day substantive roles. None of the nurses under the WNSW PHN model were full-time movement disorder nurse specialists.

As a result, some nurses in WNSW PHN and other system stakeholders reflected that these nurses were not seeing enough patients with neurological conditions including movement disorders, with enough regularity, to embed the skills they were learning. Stakeholders noted that building specialist skills and confidence requires formal training as well as clinical placements, ongoing clinical supervision, and the caseload to become competent and confident in providing patient care.

Due to challenges with engaging nurses in WNSW PHN, these insights should be considered reflective of those who engaged with the evaluation, and not representative of all nurses who participated in the pilot in WNSW PHN.

Reflection from a system stakeholder:

• "I see them more like local champions rather than specialist nurses."

Nurses in HNECC PHN, NT PHN and WV PHN began to stretch into advanced practice nursing roles – particularly related to delivery of clinical care and education

The survey of nurses included a section modelled on the Australian Advanced Practice Nursing Self-Appraisal Tool; a self-reported tool designed to understand the extent to which a nurse believes they are operating at an advanced level.⁶²

⁶² Gardner, G., Duffield, C., Gardner, A., and M. Batch. 2017. The Australian Advanced Practice Nursing Self-Appraisal Tool. DOI: 10.6084/m9.figshare.4669432

Definition of Advance Practice Nursing

The tool defines Advance Practice Nursing as:

"The experience, education and knowledge to practice at the full capacity of the registered nurse practice scope. It is a level and type of clinical practice that involves cognitive and practical integration of knowledge and skills from the clinical, health systems, education and research domains of the discipline and positions the advanced practice nurse as a leader in nursing and health care. Practice at this level is enabled through master level education."

The tool includes five domains of nursing practice:

- Domain 1: Clinical Care. Practice in this domain includes activities carried out on behalf of individual patients / clients focusing on specific needs, including procedures, assessments, interpretation of data, provision of physical care and counselling. Clinical Care also includes care coordination, care delivery, and guidance and direction to others relevant to a specific patient population.
- **Domain 2: Optimising Health Systems.** This domain includes activities that contribute to effective functioning of health systems and the institutional nursing service including role advocacy, promoting innovative patient care, and facilitating equitable, patient-centred health systems.
- **Domain 3: Education**. These are activities that involve enhancement of caregiver, student and public learning related to health and illness. This also includes aiding patients and families to manage illness and to promote wellness, informal staff development and formal presentations to healthcare professionals.
- **Domain 4: Research.** Activities that support a culture of practice that challenges the norm, that seeks better patient care through scientific inquiry and promote innovative problem solving to answer clinical questions. This includes conducting clinical research, identifying funding sources and using evidence to guide practice and policy.
- Domain 5: Leadership. Activities and attributes that allow for sharing and dissemination of knowledge beyond the individual's institutional setting. These activities promote nurses, nursing and healthcare and include disseminating nursing knowledge, serving in professional organisations, and acting as a consultant to individuals and groups. Leadership also includes setting directions and modelling standards towards optimising population and patient care outcomes.

Nurses self-reflected and reported against each of the domains from a scale of 0 (no time spent on these activities) to 4 (a great deal of time spent on these activities). The minimum mean score to indicate advance practice for each domain are:

- Domain 1 (Clinical care): 2
- Domain 2 (Optimising health systems): 2
- Domain 3 (Education): 2
- Domain 4 (Research): 1.7

• Domain 5 (Leadership): 1.7

Figure 16 presents nurse responses from 2022 and 2023 (n=4 of 21 nurses). These responses indicate that these nurses have moved toward advanced practice roles as the pilot has progressed. It also shows that the nurses that responded to both surveys are now working in advanced practice roles across almost all domains except Domain 4 (Research). Given the low response rate, these results should be considered illustrative and not representative of all nurses that participated in the pilot across all PHNs.

Note that none of the nurses from WNSW PHN responded to both surveys – so these results should be understood to reflect the experience of nurses in the other three PHNs only. As noted previously, many nurses in WNSW PHN reflected that they did not have the caseload to embed their new skills.



Figure 16 | Score in advanced practice nursing survey for all domains

The majority of nurses still actively involved are satisfied with their experience in the pilot

Qualitative and quantitative data indicates that the vast majority of nurses that are still actively involved in the pilot are satisfied with their experience. For those nurses that responded to the 2022 or 2023 survey (n=10 of 21 nurses across both surveys) (Figure 17):

- Two-thirds (6 out of 10, 60 per cent) reported that they felt happy and satisfied in their role.
- Two-thirds (6 out of 10, 60 per cent) reported that they would recommend others become movement disorder nurse specialists.⁶³

In interviews, many nurses still actively involved in the pilot expressed the satisfaction they were receiving from participating in the pilot. Across PHNs, nurses reported feeling a sense of accomplishment for completing the formal training, pride in working at a more advanced level, and joy at being able to provide additional specialist care and support to patients and carers that had not previously been able to access care.

Reflection from a nurse participating in the MDNS pilot:

• "I feel like I'm making a difference in someone's life... I can see in people's eyes that they have learnt something from me."



Figure 17 | Response to questions from the nurse survey

⁶³ Note that some nurses in WNSW PHN did not respond to the survey – it may be that the nurses that did not respond to the survey are those that had disengaged from the pilot. As a result, survey responses may be positively skewed.

Some nurses are finding it difficult to keep up with their workload, including the travel required

Some of the nurses, their colleagues, patients, and carers reported their concern that the nurses' workload may soon become unsustainable. In part, this concern related to being able to keep up with the number of referrals into the service, now there is greater awareness about the service. In part, this also reflects concerns regarding being able to sustain the travel required to see patients in large geographic areas.

This could have a number of different impacts on the success of the pilot models and on the care that could be offered to patients and carers:

- In HNECC PHN, NT PHN and WV PHN the majority of (although not all) nurses reported that they were quickly becoming close to capacity and would soon not be able to take on additional patients. Nurses in these PHNs reflected that there were many more people in their communities who would benefit from support from a movement disorder nurse specialist, but that this would not be able to be provided under the current models and with current resourcing.
- In WNSW PHN, some nurses reported that they needed additional support from their
 organisations and line managers to prioritise providing care for people living with neurological
 conditions including movement disorders. Many of these nurses reported feeling overwhelmed
 with the demands of ongoing education and training, and needing to provide specialist care,
 alongside the demands of their day-to-day role.

Stakeholders across all PHNs reflected concerns about the sustainability of the models, and urged PHNs to consider how the models could continue to be implemented into the future (Figure 18).

Quote	Person quoted
"I wouldn't change a lot about how the pilot is set up, there just needs to be more of me!"	Nurse participating in the MDNS pilot
"I think the model is working well, but I think it is probably coming to a point where it is unsustainable. Something needs to be done."	Nurse participating in the MDNS pilot
"I think the nurse is flat out – there definitely needs to be another one or two of them."	Patient
"The only concern I would have, is to worry about sustainability. The nurses need to be able to go on leave and not worry that their patients are being looked after."	Health system stakeholder

Figure 18 | Stakeholder reflections on the sustainability of the MDNS pilot models

3.2.3 Outcomes about the delivery of specialised care at the system level

The nurses are supporting greater connectivity across the health system and multidisciplinary care through facilitating patient referrals to other services and supports

Supporting care coordination and referrals to other services was a core component of the nurse role across multiple PHNs. Across the evaluation, nurses in HNECC PHN, NT PHN and WV PHN collected data on the proportion of service interactions that included patient referral to another service, and the type of service to which a patient was referred.

Service interaction data indicates that between 30 and 45 per cent of service interactions⁶⁴ involved referral to another service. Patients were referred to a range of other services, including:

- Allied health services including occupational therapists, physiotherapists, and speech pathologists (32 per cent of total referrals reported by nurses).
- Other health care services including GPs, neurologists, and other specialist nursing services (38 per cent of total referrals reported by nurses).
- Aged care and NDIS services (30 per cent of total referrals reported by nurses).

Service usage data was supported by qualitative data collected across the evaluation. Patients and carers routinely reflected that the nurse:

- Provided them with information about other services available in their region.
- Helped them to access these services, such as supporting them to register for NDIS or Carer Gateway.
- Advocated for their needs with other care providers.

Figure 19⁶⁵ includes service usage data and reflections from patients and carers.

⁶⁴ Note that this data is based on service interaction data collected from patients that consented to participate in the evaluation. Overall there were 1,896 service interactions and a total of 142 unique patients that had at least one service interaction recorded, from a total of 541 patients that received care from the nurses. There were seven patients that had outcomes data collected at baseline but no service interactions recorded.

⁶⁵ Note that data in Figure 19 is based on service interaction data collected from patients that consented to participate in the evaluation. Overall there were 1,896 service interactions and a total of 142 unique patients that had at least one service interaction recorded, from a total of 541 patients that received care from the nurses. There were seven patients that had outcomes data collected at baseline but no service interactions recorded.





Quote	Person quoted
It's very difficult to get help or for people to understand what mum's needs are. [The nurse] has been absolutely fabulous for being an advocate for what her aged care needs are and anyone else that is involved with her care.	Carer
She's got a good understanding of My Aged Care and the services that are available She has referred people through to the restorative care program where the person would benefit from physiotherapy, occupational therapy and speech.	Nurse participating in the MDNS pilot
She pointed us to a few other services we could look at, like dietician and movement chap We've been to the continence nurse in Hamilton. These were all services that [the nurse] spoke about.	Carer and patient

Data suggests that the pilots are reducing overall burden on the health system, including reducing hospitalisations and health service usage

Throughout the evaluation, the nurses collected data on patient usage of health services including Emergency Department presentations and hospitalisations. Note that data for the previous 12months was self-reported by patients and thus may be impacted by recall bias (that is, patients may misremember and over or under-report their health service usage).

Data indicates that across the pilot, as compared to the previous 12-months, patients on average:

- Had fewer Emergency Department presentations.
- Had fewer planned and unplanned hospital admissions.
- Spent fewer days in hospital for unplanned admissions and overall.

Planned admissions include visits to hospital for routine surgery and tests that require an admission. It is not expected that the MDNS pilot would have much impact on planned admissions or planned days in hospital because these are often required as part of effective routine healthcare for someone with a complex, chronic condition.

Figure 20 and Figure 21 present the results from this analysis. Given there are only a small number of patients admitted to hospital or presenting to an emergency department, a breakdown by PHN is not provided.





⁶⁶ Note: These calculations are based on complete data from 99 of 541 patients in total that received care from the nurses. Data was available for a total of 149 patients at entry into the evaluation, however follow up data was only available for 99 of these patients.





This service usage data aligns with qualitative data that was collected through interviews with patients, carers, nurses, and other health system stakeholders (Figure 22).

Figure 22	Stakeholder	reflections on	system	usage
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Quote	Person quoted
"Certainly, in our case, having the nurse reduced hospitalisations. If I didn't have the nurse to call, there are a number of times I would have called an ambulance."	Carer
"I had a man who avoided ED presentations – we did education on falls and liaised with the neurologist and the nurse. It was a win-win for everyone."	Health system stakeholder
"The patients can get answers to their questions by talking to the nurse rather than other specialists – and they can do that in their homes, in a safe environment."	Health system stakeholder
"It has definitely reduced the amount of clinic work I do. The nurse can liaise with me directly so that patients don't have to come and see me as soon or as often. I think it reduces a lot of patient and carer stress too."	Health system stakeholder

⁶⁷ Note: These calculations are based on complete data from 99 of 541 patients in total that received care from the nurses. Data was available for a total of 149 patients at entry into the evaluation, however follow up data was only available for 99 of these patients.

Stakeholders provided multiple possible explanations for the potential reduction in Emergency Department presentations and hospitalisations, including:

- Enhanced early intervention and preventative care, delivered by the nurses involved in the pilot. Nurses reflected that they were providing important preventative care such as around falls prevention which supported patients to live more confidently at home and may have reduced incidents that required them to attend the Emergency Department or be admitted to hospital.
- Easier access to specialist care when needed, through nurses involved in the pilot. This meant that patients and carers could access the information and support they needed via the nurses, rather than having to present to the Emergency Department or call an ambulance.
- Better patient and carer knowledge, as a result of education delivered by the nurses. This meant that some patients and carers were more comfortable and confident to self-manage challenges at home rather than present to the Emergency Department and potentially be admitted to hospital.
- Better health professional knowledge, as a result of upskilling delivered by the nurses. This meant that some health professionals were less likely to immediately send a patient to the Emergency Department or admit them to hospital following an Emergency Department presentation, and could instead send them home with a referral to the pilot nurses.

In addition to reduced service usage, some system stakeholders reflected that the nurses involved in the pilot may be relieving pressure on more specialist services. This was particularly emphasised under the NT PHN model, where the nurse was highly specialist and able to provide complex treatment and support. In the NT, neurologists and geriatricians reflected that as a result of the model and the work of the nurse they were able to reduce the number of times per year they saw individual patients – which in turn increased the number of appointments available to others.

There are indications that the pilots are contributing to uplift of the health workforce more broadly

As noted previously, the survey of participating nurses asked nurses to estimate the proportion of time that they spent as a movement disorder nurse specialist completing select activities.

Of all the nurses in all PHNs that responded to either survey about how they spent their time (n=7 of 21 nurses), nurses estimated that they spent on average approximately 10 per cent of their time teaching other healthcare professionals. This varied widely across nurses, ranging from 0 per cent of time for one nurse to 25 per cent of time for another. This variation is expected, as each nurse established their own model of care and independently decided where to focus their efforts.

Reflection from a nurse participating in the MDNS pilot:

• "I spend a lot of my time educating other health care professionals. In hospitals I do training. It's a really important part of my role."

In interviews nurses and other stakeholders, including other health care professionals, reflected their impression that the nurses were actively contributing to uplifting the skills of the broader

health workforce. This tended to be through informal means such as ad hoc education during dayto-day interactions (for example, when seeing patients as part of a multidisciplinary team) or planned in-service sessions for health professionals.

Some nurses highlighted the value that they received from providing education and training, reflecting the broader benefit they could see to the health system, and noted that as the pilot continued they planned to provide more education and training to other health workers.

There is further opportunity to share information across PHNs involved in the pilot, as well as with other PHNs more broadly

One of the system outcomes identified in the program logic was improved sharing of practice across PHNs. This is aligned with the grant opportunity guidelines, which include as an outcome:

• Build the knowledge base, including through sharing lessons learnt across PHNs and through a targeted evaluation.

There were efforts to share information including challenges faced and lessons learned across PHNs involved in the pilot, including through monthly meetings facilitated by the Department. Whilst PHNs appreciated these meetings, some representatives reflected that more could have been done to facilitate sharing of information.

Reflection from a PHN representative:

• "It's always good to have a formal support network set-up for projects like this. I think that was a missed opportunity."

The evaluation noted that there has been little to no sharing of lessons learned with PHNs outside the four involved in the pilot. One PHN representative noted that there were other PHNs across the country that had previously explored similar models, and it would have been good to draw from these PHNs as the pilot models were developed. Similarly, some PHN representatives highlighted that other PHNs face similar challenges providing services to people living with neurological conditions including movement disorders, and urged the Department to ensure that lessons learnt from the pilot and the evaluation were shared broadly.

Finally, many of the nurses reflected that there had been few opportunities for them to connect with their colleagues across the four PHNs. Some nurses reflected that there would have been benefit in facilitating meetings and connections, as a way of supporting peer learning and peer mentorship, and to share lessons learnt as the nurses each independently sent up a new model of care.

3.3 Findings from the cost effectiveness evaluation

Summary of findings from the cost-effectiveness evaluation

This sub-section presents findings from the cost-effectiveness evaluation in order to answer the following key evaluation question:

• KEQ 5: How cost effective are the different delivery models for government, providers, and patients?

Key findings from the cost effectiveness evaluation include:

- The average cost per quality-adjusted life-years gained of the pilot was comparable with other interventions.
- Available data indicates that hospital costs were lower during the pilot when compared to costs in the 12-month prior.

3.3.1 Insights about the cost effectiveness of the pilot

The incremental cost effectiveness ratio (ICER) for the pilot is \$372,051 per quality-adjusted life year (QALY) gained

The pilot resulted in higher costs but improved outcomes. The average cost per QALY gained was \$372,051. Table 16 provides the detailed breakdowns of the ICER calculation and Figure 23 describes the method used to estimate the cost-effectiveness of the pilot. These calculations are based on complete data from 99 of 541 patients in total that received care from the nurses.

Table 16 | Incremental cost, incremental QALYs gained and ICER68

Measure	Average	Standard error
Change in cost or incremental cost	\$5,287	2,196
Change in outcomes or incremental QALYs gained	0.01	0.01
ICER	\$372,051 per QALYs gained	131,855

Where an intervention has higher outcomes and higher costs (such as in this evaluation), decisionmakers need to decide what they are willing to pay for improved health outcomes.

In Australia, there is no set threshold for what value of ICER represents a cost-effective intervention. The best information available to determine the ICER investment threshold is for medications approved by the Pharmaceutical Benefits Advisory Committee (PBAC). According to a 2008 report of the Access to Medicines Working Group, the PBAC generally approves medicines with an ICER

⁶⁸ Note that these calculations are based on complete data from 99 of 541 patients in total that received care from the nurses.

between \$30,000 and \$70,000 per QALYs gained⁶⁹. There is much less information available on the appropriate threshold for services and healthcare interventions.

Figure 23 | Description of the methodology used to assess the cost-effectiveness of the pilot

Description of methodology used

Overview of methodology

Assessing the cost effectiveness of healthcare involves comparing the costs and outcomes of an intervention to the costs and outcomes of what would have happened without the intervention. This combined measure of costs and outcomes is known as an incremental cost effectiveness ratio (ICER).

An ICER is calculated by dividing the differences in costs, otherwise known as the incremental costs, of an intervention from a control by the differences in outcomes from a control, usually measured as quality of life. When the outcomes are measured as quality of life, the change in outcomes is also known as the incremental QALYs gained.

Calculating the change in outcomes

The outcomes data from the pilot used to calculate the ICER is shown in Section 3.2.1. The average change in outcomes is compared to data taken from a number of randomised control trials for interventions for people with Parkinson's disease. The weighted average of the data from these studies was used as an estimate of what the change in quality of life would have been for patients if the pilot had not been run. This is also shown in Section 3.2.1.

Calculating the change in costs

The costs used include the average per patient cost of delivering the pilot as well as the estimated avoided hospital costs. The estimated avoided hospital costs have been calculated using the resource use questionnaire. Patients provided an estimate of their 12-monthly hospital use before the pilot and during the pilot.

The control cost is assumed to be zero. This is because had the patients not received this intervention, they would have received nothing as an alternative.

The MDNS pilot is more cost effective than some interventions for people with Parkinson's disease and less cost effective than others

An alternative to using the threshold from the analysis of PBAC decisions is to compare the ICER found in this evaluation to other services or programs.

The evaluation team undertook a comprehensive literature review of economic evaluations undertaken for interventions for Parkinson's disease. Parkinson's disease was chosen because a large majority of patients included in the evaluation had Parkinson's disease. Results from a study were included if they provided an incremental cost-effectiveness ratio.

⁶⁹ Access to Medicines Working Group, Interim Report to Government, July 2008. Attachment A: The effects of statutory price reductions on the listing of new medicines. <u>https://www.pbs.gov.au/info/general/working-groups/amwg/amwg-interim-report-attachment-a#:~:text=While%20there%20is%20no%20single.with%20an%20ICER%20of%20%2430%2C000</u>.

Seven studies were identified that met the inclusion criteria. Table 17 provides an overview of each of the studies. Interventions fell into four categories:

- Exercise therapy.
- Deep brain stimulation.
- Occupational therapy.
- Medication.

Table 17 | Summary of studies included in the cost effectiveness comparison

Study	Study description	Type of intervention
Economic evaluation of a falls prevention exercise program among people with Parkinson's disease ⁷⁰	The study aimed to evaluate the cost effectiveness of a 6-month minimally supervised exercise program for individuals aged 40 and over with Parkinson's disease. Economic analysis was performed using data from a randomised, controlled trial of 231 participants.	Exercise therapy
Cost-utility analysis of deep brain stimulation surgery plus best medical therapy versus best medical therapy in patients with Parkinson's: Economic evaluation alongside the PD SURG trial ⁷¹	The study reports an economic evaluation of deep brain stimulation for people with Parkinson's disease.	Deep brain stimulation
Economic evaluation of a Tai Ji Quan intervention to reduce falls in people with Parkinson disease ⁷²	The study conducted a cost effectiveness analysis of Tai Ji Quan as an intervention for reducing falls in patients with mild-to-moderate Parkinson's disease, using data from a 9-month trial to compare it with resistance training and stretching.	Exercise therapy

⁷⁰ Farag, I., Sherrington, C., Hayes, A., Canning, C. G., Lord, S. R., Close, J. C., ... & Howard, K. (2016). Economic evaluation of a falls prevention exercise program among people with Parkinson's disease. Movement disorders, 31(1), 53-61.

⁷¹ McIntosh, E., Gray, A., Daniels, J., Gill, S., Ives, N., Jenkinson, C., ... & PD SURG Collaborators Group. (2016). Cost-utility analysis of deep brain stimulation surgery plus best medical therapy versus best medical therapy in patients with Parkinson's: Economic evaluation alongside the PD SURG trial. Movement Disorders, 31(8), 1173-1182.

⁷² Li, F., & Harmer, P. (2015). Economic Evaluation of a Tai Ji Quan Intervention to Reduce Falls in People with Parkinson Disease, Oregon, 2008-2011. Preventing chronic disease, 12, E120. https://doi.org/10.5888/pcd12.140413

Study	Study description	Type of intervention
Real life cost and quality of life associated with continuous intraduodenal levodopa infusion compared with oral treatment in Parkinson patients ⁷³	The study evaluated the costs and quality-of-life benefits of intraduodenal levodopa for treating advanced-stage Parkinson's disease comparing it with conventional oral medication over a one- year period.	Medication
Cost-effectiveness of the PDSAFE personalised physiotherapy intervention for fall prevention in Parkinson's: an economic evaluation alongside a randomised controlled trial ⁷⁴	PDSAFE is a training program aimed at preventing falls among people with Parkinson's disease.	Exercise therapy
Economic evaluation of occupational therapy in Parkinson's disease: a randomised controlled trial ⁷⁵	The study aimed to assess the cost effectiveness of home-based occupational therapy that involved 191 patients and 180 caregivers over a 6-month period.	Occupational therapy
An exercise intervention to prevent falls in Parkinson's: an economic evaluation ⁷⁶	The study aimed to understand the impact of an exercise intervention for people with Parkinson's disease.	Exercise therapy

Comparing the MDNS pilot results to these studies is not a direct comparison, however they provide an indication of what other funding bodies have decided to fund and thus could be considered cost-effective in certain circumstances. None of these interventions would be a direct substitute for specialist nursing. Patients could expect to receive both specialist nursing care and advanced medication therapies. Cost effectiveness data on interventions that may have been a

⁷³ Lundqvist, C., Beiske, A. G., Reiertsen, O., & Kristiansen, I. S. (2014). Real life cost and quality of life associated with continuous intraduodenal levodopa infusion compared with oral treatment in Parkinson patients. Journal of neurology, 261(12), 2438–2445. https://doi.org/10.1007/s00415-014-7515-4

⁷⁴ Xin, Y., Ashburn, A., Pickering, R.M. et al. Cost-effectiveness of the PDSAFE personalised physiotherapy intervention for fall prevention in Parkinson's: an economic evaluation alongside a randomised controlled trial. BMC Neurol 20, 295 (2020). https://doi.org/10.1186/s12883-020-01852-8

⁷⁵ Sturkenboom, I. H., Hendriks, J. C., Graff, M. J., Adang, E. M., Munneke, M., Nijhuis-van der Sanden, M. W., & Bloem, B. R. (2015). Economic evaluation of occupational therapy in Parkinson's disease: A randomized controlled trial. Movement disorders: official journal of the Movement Disorder Society, 30(8), 1059–1067. https://doi.org/10.1002/mds.26217

⁷⁶ Fletcher, E., Goodwin, V.A., Richards, S.H. et al. An exercise intervention to prevent falls in Parkinson's: an economic evaluation. BMC Health Serv Res 12, 426 (2012). https://doi.org/10.1186/1472-6963-12-426

substitute for the MDNS model, for example a multidisciplinary, team-based model, were not available.

Figure 24 provides a comparison between the cost-effectiveness of the MDNS pilot and the data from the published studies. This analysis shows the pilot is more cost effective than several interventions for people with Parkinson's disease including the medication and the deep brain stimulation interventions. The pilot is less cost effective than most of the data on exercise therapy and occupational therapy.





There was not sufficient, comparable data on the uncertainty of the cost-effectiveness from these studies to understand whether the differences between studies are statistically significant. Given the study on medication and deep brain stimulation are much less cost-effective than the MDNS pilot, it could be assumed these differences are significant depending on the test applied. Similarly, it is likely the two exercise therapy interventions with the largest differences in incremental QALYs gained are more cost effective than the MDNS pilot.

Appendix D provides more information about the comparative studies, their ICERs and how the studies compare to this pilot.

There is a significant amount of uncertainty in the cost effectiveness analysis and several factors that contribute to uncertainty around the estimates

Factors that contribute to uncertainty around cost effectiveness estimates include:

⁷⁷ Note: The cost effectiveness estimates for the MDNS pilot are based on complete data from 99 of 541 patients in total that received care from the nurses.

• The costs included do not capture all possible system costs. Additional costs not captured include primary care costs, private healthcare costs, NDIS costs and aged care costs, including costs to government and costs to individual patients. In the design of the evaluation, it was decided to focus on hospital costs as the most important costs to understanding the impact of the pilot.

While there is no data to suggest this, it is possible the pilot led to increased primary healthcare, aged care and NDIS costs that were not captured as part of the evaluation. Patients may have accessed more services because of better coordinated care from the pilot nurses and improved knowledge about the supports and services that were available in their region. This could have led to higher costs to both government and the individual. If these costs were incurred, this would have increased the ICER and reduced the cost effectiveness.

From a societal and productivity perspective, as the pilot was able to maintain the health of patients, it is possible patients were able to continue working, or contributing positively to society and the community in other ways, when they might otherwise not have been able to have their disease progressed and quality-of-life reduced. Similarly, it is possible carers may have been able to work more than they might otherwise have been able. Including the impact of productivity may have meant the pilot was more cost effective. This would have led to greater cost effectiveness; however, these costs are difficult to quantify.

- Recall bias could impact the data on costs. As the costs are based on patients' recollection of the services they used, it could be subject to bias. Patients with Parkinson's disease may have poorer recollection of the services they used as the disease progresses. This could mean the estimated avoided costs are higher than the estimates used which would have reduced cost effectiveness.
- Selection bias could have impacted the average QALYs gained. Selection bias involves selecting people who are more likely to have positive outcomes. This is not usually done deliberately. Patients that recorded data at baseline may not be able to followed-up because their health had deteriorated. As a result, it is possible the average QALYs gained is higher than it would have been if all patients were able to be followed-up.

Bootstrapping is a way to quantify some of this uncertainty. Bootstrapping uses a modelling technique to create a larger distribution of observations based on the sample data. Figure 25 provides this bootstrapped distribution. As can be seen, there is a significant amount of uncertainty in the data.

Based on the bootstrapping analysis, the ICER lies between \$113,615 and \$630,487 based on a confidence level of 95 per cent.





3.3.2 Insights about the cost effectiveness of each PHN model

As shown in Figure 26, all PHNs for which data was available had higher costs and improved outcomes. HNECC PHN and NT PHN models are more cost effective than the average, and more effective than the WV PHN model.

As shown in Table 18, these differences are mainly driven by the lower average QALYs gained through the WV PHN model, which results in a higher ICER. One of the reasons for this may be differences in the patient cohorts. On average, the WV PHN patients were older and had poorer quality of life at the beginning of the pilot.

⁷⁸ Note that these calculations are based on complete data from 99 of 541 patients in total that received care from the nurses.

Figure 26 | Incremental costs and QALYs gained for the pilot and other types of interventions for people with Parkinson's disease⁷⁹



Table 18	Cost effectiveness m	neasures and stand	ard errors and	key demographic	data for
patients t	hat remained in the	pilot ⁸⁰			

Measure	HNECC	wv	NT
Number of patients	23	23	53
Incremental cost	\$3,661 (7,951 SE)	\$6,279 (1,633SE)	\$4,671 (3,628 SE)
Incremental QALYs gained	0.03 (0.02 SE)	0.00 (0.01 SE)	0.02 (0.01 SE)
ICER	\$119,178 per QALYs gained (491,122 SE)	\$1,807,263 per QALYs gained (73,877 SE)	\$212,143 per QALYs gained (65,613 SE)
Starting quality of life value	0.60	0.57	0.60
Female	39 per cent	43 per cent	48 per cent
Born overseas	13 per cent	14 per cent	26 per cent
Age: under 60	4 per cent	9 per cent	4 per cent

⁷⁹ Note that these calculations are based on complete data from 99 of 541 patients in total that received care from the nurses. This includes 23 in HNECC PHN, 23 in WV PHN and 53 in NT PHN.

⁸⁰ Note that this data is based on patients that consented to participate in the study and provided responses to QALY questions and service interaction data. Overall, there are a total of 99 unique patients. Three patients had missing responses in the follow-up survey.

Measure	HNECC	wv	NT
Age: 61-70	13 per cent	19 per cent	39 per cent
Age: 71-80	57 per cent	55 per cent	48 per cent
Age: over 80	26 per cent	17 per cent	9 per cent
Diagnosed with Parkinson's disease	100 per cent	77 per cent	96 per cent

3.3.3 Insights about changes in hospital costs

In order to understand cost-effectiveness, the service use data discussed above (Section 3.2.3) was used to calculate a change in approximate hospital costs. Data was multiplied by a unit cost for an Emergency Department presentation and admitted days in hospital. These costs were obtained from various sources as detailed in Appendix C.

As noted above, patients who provided data to the evaluation at baseline and follow-up (n=99 of 541 patients) used fewer services during the pilot when compared to the 12-months prior. As shown in Figure 27, this reduced service usage equates to lower overall costs on the system – for the MDNS pilot this equated to approximately \$366 less per person, per year. However, this difference was not significant (p=0.59) based on the non-parametric one-way ANOVA test at a confidence interval of 95 per cent. The difference in Emergency Department costs, planned hospital costs and unplanned hospital costs was also not significant using the same test.

As previously discussed, the MDNS pilot was not expected to influence planned hospital use or costs as many of these admissions are an important part of effective, routine care for people with chronic conditions.



Figure 27 | Difference in hospital costs in the 12-months before and during the pilot by type for patients that provided data at baseline and follow-up⁸¹

Whilst the evaluation did not have a control group, the hospital costs of participating patients compares favourably to costs reported in published literature.

A study published in 2017 on the costs of living with Parkinson's disease over 12-months in Australia estimated hospital costs of between \$6,160 and \$30,061 per year for patients with Parkinson's disease. Based on inflation figures, these figures would be \$7,395 and \$43,218 in 2020-21 dollar values respectively.⁸²

Table 19 presents the average hospital costs for patients receiving care and support under the MDNS pilot, and the costs reported in the literature.

Table 19	Average	hospital	cost per	patient fo	or the	pilot	and from	literature ⁸³
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Patient cohort	Average cost (all based on 2020-21 dollar values)
Average hospital cost per patient in the 12-months before the MDNS pilot	\$4,527

⁸¹ Note: These calculations are based on complete data from 99 of 541 patients in total that received care from the nurses.

⁸² Shalika Bohingamu Mudiyanselage, Jennifer J. Watts, Julie Abimanyi-Ochom, Lisa Lane, Anna T. Murphy, Meg E. Morris, and Robert Iansek (2017) Cost of Living with Parkinson's Disease over 12 Months in Australia: A Prospective Cohort Study. Parkinson's Disease: 5932675. doi: 10.1155/2017/5932675

⁸³ Note that the figures from the study have been inflated to 2020-21 dollar values using the Reserve Bank of Australia's inflation calculator.

Patient cohort	Average cost (all based on 2020-21 dollar values)
Average hospital cost per patient in the 12-months during the MDNS pilot ⁸⁴	\$4,162
Average hospital costs for mild Parkinson's disease, as reported in 2017 comparison study	\$7,395
Average hospital costs for moderate Parkinson's disease, as reported in 2017 comparison study	\$43,218

Table 20 compares the demographics of the patients from the evaluation to those from the 2017 study. The patients engaged in the MDNS pilot were on average older and further along in disease trajectory (measured by time since diagnosis) than those from the 2017 study.

As a result, it could be expected that the pilot patients would have higher costs as compared to those from the 2017 study. However, the costs are lower and have reduced further through the pilot.

There are a number of potential reasons for the differences between the costs in this evaluation and the comparator study:

- The mostly likely reason is that the MDNS pilot evaluation analysed health care use for people living in regional and remote areas. It is possible that because those living in regional, rural and remote areas are not able to easily access the same number of health services, patients in the evaluation used less healthcare services.
- It is possible that there were differences in the way hospital costs were measured. While this
 evaluation and the study both used a resource use questionnaire, it is possible the
 questionnaire used in the published study captured additional information that was not
 captured in this evaluation.

Category	2017 comparative study: mild	2017 comparative study: moderate- severe	2017 comparative study: study population	MDNS pilot ⁸⁵
Number of patients	35	52	87	99

Table 20 | Comparison between patients that remained in the MDNS pilot and in the 2017 study

⁸⁴ Note that these calculations are based on complete data from 99 of 541 patients in total that received care from the nurses.

⁸⁵ Note that this data is based on complete data from 99 of 541 patients in total that received care from the nurses.

Category	2017 comparative study: mild	2017 comparative study: moderate- severe	2017 comparative study: study population	MDNS pilot ⁸⁵
Age: mean (years)	68.1	69.6	69.0	71.9
Age: 40-64	34 per cent	25 per cent	29 per cent	16 per cent
Age: 65 and over	66 per cent	75 per cent	71 per cent	84 per cent
Female	37 per cent	44 per cent	42 per cent	43 per cent
Disease duration (years)	2.7	8.2	6.0	9.0

3.3.4 Insights about differences in the expenditure of each PHN

The MDNS pilot grant opportunity guidelines invited PHNs to submit proposals for funding based on the intended features of their model. The Department did not specify a budget for models.

As a result, and as intended, each PHN received a different amount of funding for the pilot:

- WV PHN: \$1,975,788 (ex. GST)
- HNECC PHN: \$1,064,700 (ex. GST)
- NT PHN: \$992,532 (ex. GST)
- WNSW PHN: \$430,800 (ex. GST)

The varying amounts of funding were directly related to intended activities and design of the models - for example, the WV PHN model employed four, full-time nurses whereas the WNSW PHN model did not directly employ nurses, but rather intended funding be used to support education and training activities.

Figure 28 presents total spending across 2021-22 and 2022-23 by each PHN, including how this spending was distributed across categories. Note that data was self-reported by PHNs. This data indicates that:

- In three PHNs HNECC PHN, NT PHN and WV PHN the bulk of funding (ranging from 70 per cent to 89 per cent of total funding) was allocated to service delivery costs. PHNs reflected that this category included nurse salary and benefits, and payments to service delivery organisations to support roll out and implementation of the pilot models.
- One PHN WNSW PHN allocated no funding to service delivery costs, with the bulk of funding evenly split between operating model development costs and workforce development

costs. This aligns with the WNSW PHN model, which focused on upskilling nurses already working in the community.

• Across all PHNs, the proportion of funding allocated to administrative costs ranged from eight per cent to thirteen per cent.



Figure 28 | Spending by each PHN by spending category (2021-22 and 2022-23 combined)⁸⁶

As a result of these different budgets and expenditure, there is a different average cost per patient that received care and support as part of the pilot. The total costs each PHN reported in 2021-22 and 2022-23 combined were divided by the number of patients that received care and support throughout the pilot. This included patients that received care directly and those that received support from the nurses through patient support groups and exercise groups. Figure 29 shows the average per patient cost by PHN. WNSW PHN had the lowest average cost per patient while WV PHN had the highest.

⁸⁶ Note: Figures will not sum to the funding amounts provided on page 73 because this includes 2021-22 and 2022-23 only. It may also not sum to total funding amounts provided in appendices due to other expenditure not categorised in this figure.



Figure 29 | Average costs per patient by PHN (2021-22 and 2022-23 combined)

3.4 Findings related to learning from experience and best practice for continuous improvement

Summary of findings related to learning from experience and best practice for continuous improvement

This sub-section presents findings related to learning from experience and best practice for continuous improvement in order to answer the following key evaluation questions:

- KEQ 6: What lessons have been learned through the pilot that could support scalability and further roll out?
- KEQ 7: What evidence-based models of care to support those living with neurological conditions including movement disorders could be considered in future in regional, rural, and remote areas?

Key findings include:

- PHNs can work in partnership with state and territory departments of health to coordinate and co-commission specialist nurse services across their regions.
- Disease-specific nurse models have been trialled in Australia and overseas.
- Multidisciplinary teams including movement disorder nurse specialists could be considered, rather than stand-alone movement disorder nurse models of care.
- Future models could adopt a "hub-and-spoke" approach, building from identified strengths in the current models.

PHNs can work in partnership with state and territory departments of health to coordinate and co-commission specialist nurse services across their regions

One of the stated core roles of PHNs is to commission health services to meet the needs of people in their regions.⁸⁷ To achieve this, PHNs are expected to work in partnership with stakeholders across their regions – including state and territory departments of health and their service delivery organisations,⁸⁸ health care providers, and peak bodies – to understand needs and service gaps, and commission services to meet these gaps.

Both PHNs and state and territory health departments have flexibility to commission or deliver services that meet the needs of their local communities:

 PHNs receive some flexible funding from the Australian Government to commission services to meet service delivery gaps.⁸⁹

⁸⁷ Australian Government Department of Health and Aged Care, 2022. What Primary Health Networks do. Available from: <u>https://www.health.gov.au/our-work/phn/what-PHNs-</u>

do#:~:text=Primary%20Health%20Networks%20(PHNs)%20assess,the%20primary%20health%20care%20system. Accessed: 15 June 2023.

⁸⁸ Service delivery organisations have different names across different jurisdictions, such as Local Health Districts (LHDs) in NSW, Hospital and Health Services (HHSs) in Victoria and Queensland, and Local Health Networks (LHNs) in South Australia.

⁸⁹ Australian Government Department of Health, Primary Health Networks: Grant Programme Guidelines, p. 9

• State and territory health departments – and their service delivery organisations – are empowered to choose the mix of services that they will deliver for their communities.⁹⁰

Specialist nursing services, such as movement disorder nurse specialists, could be considered either primary or secondary care. To date both PHNs and state and territory health departments have independently commissioned similar services, including prior to the MDNS pilot. For example:

- In 2015, Murray PHN commissioned and funded a movement disorder nurse that was placed within Sunraysia Community Health Services.⁹¹
- A movement disorder nurse has recently been employed at Tamworth Hospital through Hunter New England Local Health District. This nurse complements the work being led by the nurse funded through the HNECC PHN model.

The evaluation found that close collaboration between PHNs, and other system stakeholders was a key enabler for success of the pilot models. Given this, health care providers must continue to work in collaboration to reduce duplication and overlap.

It is appropriate that PHNs take the lead in working with other key stakeholders to consider how specialist movement disorder nurse services can be provided in their regions, in a coordinated and cost-efficient manner. This may include PHNs commissioning services, state and territory health departments funding services, or PHNs and other stakeholders co-commissioning services.

This approach to coordination and co-commissioning aligns with federal and state and territory government priorities. The 2020-25 Addendum to the National Health Reform Agreement includes a priority to "improve local accountability and responsiveness to the needs of communities through continued operation and collaboration between Local Hospital Networks and Primary Health Networks."⁹² Such collaboration is already happening with regards to mental health and wellbeing services.⁹³

Disease-specific nurse models have been trialled in Australia and overseas

Specialist nurse positions for neurological conditions have existed for a number of years, both in Australia and globally. These positions tend to be focused on a specific condition – such as Parkinson's disease or multiple sclerosis – rather than broadly for neurological conditions including movement disorders.

Table 21 presents an overview of disease-specific nurse positions, including the current status of each in Australia. Whilst the evaluation found that broad movement disorder specialist nurses were an appropriate approach for the MDNS pilot, some stakeholders highlighted that it may be appropriate for some PHN regions to focus their efforts on a specific disease or condition, particularly where there is a high incidence and prevalence of a specific movement disorder. While

⁹⁰ National Health Reform Agreement, p. 46

⁹¹ Sunraysia Community Health Services, Media Release, New service for Movement Disorders now operating at SCHS, 28 August 2015. <u>https://www.schs.com.au/wp-content/uploads/20150828-Movement-Disorders-Nurse-1.pdf</u>

⁹² Addendum to the National Health Reform Agreement 2020-2025, p. 7

⁹³ Department of Health and Aged Care, Joint regional planning for integrated regional mental health and suicide prevention services: A compendium of resources to assist Local Health Networks and Primary Health Networks, 2018

there is unlikely to be the case load in regional, rural, or remote areas, there may be in some metropolitan areas.

Decisions must be made based on an understanding of community needs and context and should take into account any trade-offs that would be made through choosing one approach over another, for example broader movement disorder nurse specialists may be able to provide care and support to a wider range of patients, but this care and support would likely be less specialist (particularly as disease progresses).

Disease-specific nurse model	Current status
Parkinson's disease nurse specialist	 The Parkinson's disease nurse specialist role was established in the UK National Health Service in 1989. Around 80 per cent of people living with Parkinson's disease in the UK have access to specialist nurses.⁹⁴ The role provides clinical care to people with Parkinson's disease and education to other healthcare professionals. The role is officially recognised, and training is formally provided with support from the UK Parkinson's Disease Society and Parkinson's Disease Nurse Specialist Association.⁹⁵ There have been Parkinson's disease nurse specialist roles in Australia since 1997.⁹⁶ According to the Australasian Neuroscience Nurses Association, in 2021 there were 61 Parkinson's disease nurse specialists in Australia.⁹⁷ There are nurses in all states and territories (with the exception of the NT). Twenty-one per cent (13 out of 61) are based in regional areas, and 10 per cent are based in rural areas.
	 Around half of the nurses in Australia are employed through state-funded health services, 20 per cent through pharmaceutical companies, 8 per cent through consumer organisations, 7 per cent through private practices, 3 per cent through PHNs and 3 per cent through private hospitals.⁹⁸

Table 21 | Overview of disease-specific nurse models

⁹⁴ Dodd, A. (2014). Churchill Fellowship: Best Practice Models for people living with Parkinson's Disease. Retrieved from

https://www.churchilltrust.com.au/media/fellows/To study innovative care models A Dodd 2013.pdf. Accessed 6 April 2021.

⁹⁵ Bhidaysiri, R., Boonpang K., Jitkritsadakul O., et al. (2016). Understanding the role of the Parkinson's disease nurse specialist in the delivery of apomorphine therapy. Retrieved at: <u>https://www.anna.asn.au/wp-content/uploads/Understanding-the-role-of-the-Parkinsons-disease-nurse-specialist.pdf</u>. Accessed 20 January 2021.

⁹⁶ McLeod, J. (2010). The Evolution of Movement Disorders Specialist Nurses Role in WA, Connections, Royal College of Nursing Australia, 13(14).

⁹⁷ Williams, S., Tsui, D., Zeppel, M. (2021). 2020 Annual Demographic Survey of Parkinson's Disease and Movement Disorder Nurse Specialists. Australian Journal of Neuroscience.

⁹⁸ Ibid.

Disease-specific nurse model	Current status
	 A 2018 literature review found that Parkinson's disease nurse specialists could have a positive impact on patient quality of life.⁹⁹
Multiple sclerosis nurse specialists	 Multiple sclerosis nurse specialists (MS nurses) have been employed in Australia for a number of years. Initially, MS nurses were funded by and employed through pharmaceutical companies because of the need for nurses to assist patients with advanced medication therapies. According to a recent report by MS Australia, MS nurses are mostly based in public hospitals and community-based health services.¹⁰⁰ MS nurses provide education and advice to patients; counselling, compassion, and psychological support; and support with accessing and navigating other services.¹⁰¹ Most services are delivered either in a clinic or over the phone or via telehealth with some home visits.¹⁰² A recent report by MS Australia found that MS nurses reduced the need for more costly hospital care. This included reduced need to see a general practitioner or neurologist, reduced Emergency Department presentations and hospital admissions.¹⁰³
Huntington's disease specialist nurses	 There are a small number of Huntington's disease specialist nurses in Australia. A 2012 study investigated the impact of a Huntington's disease nurse specialist in Auckland. The nurse was based in a hospital and worked with patients and families to develop and implement biopsychosocial management plans and provide clinical education to patients and carers. The nurse also facilitated clinical appointments.¹⁰⁴ The study found a 51 per cent decrease in average monthly admissions for patients with Huntington's disease.

Multidisciplinary teams including movement disorder nurse specialists could be considered, rather than stand-alone movement disorder nurse models of care

⁹⁹ Marguerite Bramble, Vincent Carroll and Rachel Rossiter (2018) Evidence based models that support best practice nursing services for people with Parkinson's disease in regional NSW: An integrative literature review. Charles Sturt University and Mid North Coast Local Health District. p. 33

¹⁰⁰ MS Australia, MS Nurse Care in Australia, 2022, p. 28

 $^{^{101}}$ MS Australia, MS Nurse Care in Australia, 2022, p. 37

¹⁰² MS Australia, MS Nurse Care in Australia, 2022, p. 31

¹⁰³ MS Australia, MS Nurse Care in Australia, 2022, p. 10

¹⁰⁴ David Bourke, Gregory Funucane, Jo Dysart and Richard Roxburg (2021) The Appointment of a Huntington's Disease Nurse Specialist has Reduced Admission Rate and Improved Admission Quality. Journal of Huntington's Disease 1, 27-30. DOI 10.3233/JHD-2012-120003

Neurological conditions often manifest as complex, chronic conditions that require involvement of healthcare staff from a range of disciplines.¹⁰⁵ For example, the management of Parkinson's disease can require up to 20 different healthcare professionals including medical professionals, specialist nurses, physiotherapists, speech pathologists, occupational therapists, psychologists, and pharmacists.¹⁰⁶

Multidisciplinary care has shown to have a positive impact on people living with movement disorders. According to a 2017 review of the literature, involvement of a multidisciplinary team has shown to increase quality of life and motor function for people with Parkinson's disease and their caregivers.¹⁰⁷ Similarly, a 2020 systematic review of the literature on integrated care in Parkinson's disease found that integrated care for people with Parkinson's disease may improve patient-reported quality of life.¹⁰⁸

Whilst none of the four pilot models are strictly multidisciplinary team models, many either have direct access to allied health or medical professionals through their employer or are able to facilitate access through referrals. For example:

- **HNECC PHN.** The nurse is based at a private allied health practice. The nurse reflected that they can easily facilitate referrals to other allied health providers in the practice, such as occupational therapists and exercise physiologists.
- NT PHN. The nurse is part of the NT Health Community Allied Health Team (CAHT) and routinely works alongside allied health professionals to deliver multidisciplinary team care. The nurse routinely receives referrals from other allied health professionals and can easily refer to allied health if needed.
- WNSW PHN. Nurses in WNSW PHN are based across a variety of settings including in primary care, community care, and within hospitals. Some stakeholders including nurses reflected that it was easier for nurses based in hospitals to develop relationships with other health professionals, as compared to nurses based in primary care.
- WV PHN. Three nurses in WV PHN are based in hospitals, and one is based in a community health centre. As in WNSW PHN, stakeholders including nurses reflected that it was easier for the nurses based in hospitals to develop working relationships, including generating referrals. The nurse based in a community health centre reported that they found it initially difficult to build awareness of the service within hospitals and other health services.

Some of the models are moving to a more multidisciplinary approach:

¹⁰⁵ Bastiaan R Bloem, Emily J Henderson, Ray Dorsey, Michael S Okun, Njideka Okubadejo, Piu Chan, John Andrejack, Sirwan K L Darweesh, and Marten Munneke (2020) Integrated and patient-centred management of Parkinson's disease: a network model for reshaping chronic neurological care. Lancet Neurology. 19(7) 623-634. doi: 10.1016/S1474-4422(20)30064-8

¹⁰⁶ Stephen W Pedersen, Martin Suedmeyer, Louis W C Liu, Dirk Domagk, Alison Forbes, Lars Bergmann, Koray Onuk, Ashley Yegin, and Teus van Laar (2017) The role and structure of the multidisciplinary team in the management of advanced Parkinson's disease with a focus on the use of levodopa–carbidopa intestinal gel. Journal of Multidisciplinary Healthcare 10:13-27. doi: 10.2147/JMDH.S111369

¹⁰⁷ Ibid.

¹⁰⁸ Roopa Rajan, Laura Brennan, Bastiaan R. Bloem, Nabila Dahodwala, Joan Gardner, Jennifer G. Goldman, David A. Grimes, Robert Iansek, Norbert Kovács, Jennifer McGinley, Sotirios A. Parashos, Maria E.P. Piemonte, and Carsten Eggers (2020) Integrated Care in Parkinson's Disease: A Systematic Review and Meta-Analysis. Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/mds.28097

- One of the nurses in WNSW PHN operates as part of a multidisciplinary clinic with an occupational therapist and a physiotherapist.
- NT PHN are exploring using some unspent funds from the pilot to employ a speech pathologist to work alongside the nurse.

If the current models are reviewed and refreshed, and as future models are developed, PHNs and other stakeholders should actively consider how models can support and promote the delivery of holistic, multidisciplinary team care.

Future models could adopt a "hub-and-spoke" approach, building from identified strengths in the current models

A "hub-and-spoke" organisational design is one where service delivery is organised into a network consisting of an "anchor establishment" (the hub) which offers a full array of services, complemented by "secondary establishments" (the spokes) which offer more limited services. Spokes direct patients to the hub when and if more intense services are needed.¹⁰⁹

Throughout the evaluation, some stakeholders suggested that a "hub-and-spoke" design could be explored and trialled in future models. Under this design, the model would consist of:

- A central hub in a major regional or rural community, staffed by one or more movement disorder nurse specialists and likely involving other health professionals to provide multidisciplinary team care.
- A network of spokes in surrounding rural and remote communities, staffed by generalist community-based nurses with some additional training in neurological conditions including movement disorders.

Patients and carers in surrounding rural and remote communities would receive the majority of their care from generalist community-based nurses, who would be supported by the movement disorder nurse specialist based in the hub. Patients would be directed to the hub for more specialist care when needed.

Stakeholders noted that this approach would build on the strengths of a number of the current PHN pilot models – combining the specialist nurses that are a feature of the HNECC PHN, NT PHN and WV PHN with the geographic coverage of the WNSW PHN model.

Reflection from a nurse participating in the MDNS pilot:

• "I guess the next step would be to have me supporting a network of nurses in other communities – so I don't have to travel so far, and so patients still get care close to home."

Benefits of a hub-and-spoke model could include:

- Supporting the delivery of care across the spectrum of nurse specialisation.
- Increasing the geographic coverage of services.

¹⁰⁹ James Elrod and John Fortenberry (2017) The hub-and-spoke organisation design: an avenue for serving patients well. BMC Health Services Research 17(1) 457.

- Ensuring that patients and carers are able to access care as close to home as possible.
- Ensuring that more generalist nurses have the support and peer mentorship needed to build their confidence.
- Reducing overall travel required by more specialist nurses.

Comparable data is not available on these alternative models to determine whether they are more effective than this pilot

There is a small amount of information about the effectiveness of multidisciplinary care for people with Parkinson's disease that has been discussed above. There is not, however, any information on the cost effectiveness of the model. Similarly, there has not been any published literature on the effectiveness of hub-and-spoke models.

The lack of comparable information means making a conclusion about the most appropriate model of care for people with neurological conditions, including movement disorders, is not possible as part of this evaluation. As previously discussed, the most appropriate model, whether it is a specialist nurse, generalist nurse, or multidisciplinary team depends on the needs and strengths of communities. The Department, PHNs, LHNs and state and territory health departments should consider this when making investment decisions and introducing new models of care.

4 Considerations for future policy discussions

This section presents a set of considerations that may contribute to future policy discussions regarding the provision of specialist care and support for people living with neurological conditions in regional, rural, and remote areas of Australia.

The evaluation confirms that there was a need to enhance access to specialist care and support for people living with neurological conditions, including movement disorders, in the four PHN pilot regions. It is likely that similar needs exist in other PHN regions in regional, rural, and remote areas of Australia.

Based on the findings of the evaluation, six considerations for future policy decisions are presented. These considerations are summarised in Table 22.

The evaluation team notes that the Department is currently working with the four pilot PHNs to make decisions about the sustainability of these models continuing access to care and supports for patients and carers.

Number	Summary of considerations
1	The MDNS model is one of a number of potential approaches that could be explored to enhance access to specialist care for people living with neurological conditions including movement disorders in regional, rural, and remote areas.
2	Future approaches should be designed to meet regional or local community needs and context – it is appropriate that PHNs and / or LHNs lead this work (and consider appropriate integration with existing services / care).
3	Clear guidance and advice – drawn from the results of this evaluation – should be provided to PHNs (or other organisations) wishing to establish similar MDNS models.
4	Should MDNS models be explored in the future, the model should be co-developed in partnership with service providers and communities.
5	Future MDNS models may wish to continue to focus on broader MDNS models, although disease-specific nurse models may be appropriate in certain local contexts.
6	Future MDNS models should enable PHNs (or other organisations) to collect relevant data and information to enable evaluations and continuous quality improvement.

Table 22 | Summary of considerations

Consideration 1 | The MDNS model is one of a number of potential approaches that could be explored to enhance access to specialist care for people living with neurological conditions including movement disorders in regional, rural, and remote areas

This evaluation found that the MDNS model was overall effective at enhancing access to specialist care for people living with neurological conditions including movement disorders in regional, rural, and remote areas of Australia. Patients, carers and nurses engaged in the pilot, and other system stakeholders across all PHNs, consistently reported that the pilot was addressing an unmet need, and that patients and carers were accessing services that were previously unavailable.

As noted throughout this report, the evaluation faced challenges related to participant recruitment, data collection, and overall stakeholder engagement. Whilst the evaluation found many positive impacts of the MDNS model at the patient and carer, nurse, and system levels, these are drawn primarily from qualitative interviews from a select group of stakeholders. Future evaluations of the MDNS model – which take a different evaluation approach – may uncover different findings.

The evaluation further noted that there are a number of potential other options that can serve to achieve the aims of the MDNS pilot – that is, increasing access to specialist care. These include multidisciplinary team-based approaches, disease-specific nurses (as opposed to broader movement disorder specialists), and telehealth options. The evaluation also highlighted other potential interventions that could enhance patient and carer outcomes and experience – including exercise programs, occupational therapy, medication interventions and deep brain stimulation.

Given the findings of this evaluation, future policy discussions could consider the MDNS model as one of a suite of potential options – which can be used either as a standalone model, or in combination with other approaches.

Consideration 2 | Future approaches should be designed to meet regional or local community needs and context – it is appropriate that PHNs and / or LHNs lead this work (and consider appropriate integration with existing services / care)

The MDNS model is one of a number of approaches that regions and local communities can consider to enhance access to services for people living with neurological conditions including movement disorders. The exact approach (or approaches) chosen should be decided based on local needs and context and take into account other existing services and supports.

With regards to the MDNS pilot, each PHN involved in the pilot developed a unique model that met their community needs, expectations, and context. Whilst each model had the same overarching aim – to improve access to specialist services for people living in regional, rural, and remote communities – the PHNs each took different approaches to reach that aim.

Ultimately, the evaluation did not determine that any of the four models was the "best fit" model for meeting the overarching aim. Each model had individual benefits as well as challenges that needed to be overcome – there is no "one size fits all" model, and regional context should drive model design.

The WNSW PHN model had challenges retaining nurses to the full extent it intended and has not treated or supported a comparable number of patients with neurological conditions than the other models. However, the rationale for the design of the model was sound – growing the local workforce and not taking nurses out of positions just to create a new workforce gap. This model could work in other areas if the lessons from the WNSW PHN experience are heeded, including
support and effort for program oversight and coordination. The enablers for this model are discussed elsewhere in this report.

Specialist nursing supports like this pilot fall between primary and secondary health services, and thus fall between the responsibility of PHNs and LHNs. The NT PHN, WNSW PHN and WV PHN models each involved collaboration between PHNs and LHNs. This is a type of service that could benefit from further collaborative planning and integration or commissioning efforts between PHNs and LHNs.

The findings of this evaluation can be used in future to develop models to meet regional or local community needs and context. Given the PHN and LHN role in understanding community needs and designing or commissioning services to meet these needs, it is appropriate that PHNs and / or LHNs could lead future efforts by other regional, rural, and remote communities who require improved access to specialist services for people living with neurological conditions including movement disorders. This is preferable and more sustainable to State, Territory or Commonwealth Governments commissioning services directly.

Table 23presents an overview of some key elements of the models that were trialled, and when these elements may be most appropriate for other communities.

Options to develop new models and approaches include:

- Reviewing and adapting one of the models that was trialled through the MDNS pilot to local context and need.
- Creating a hybrid model that brings together key elements of a few models that were trialled through the MDNS pilot.
- Creating an entirely new model to meet unique community needs and context.

As part of creating a new model, PHNs should explore elements that were not core components of the models that were trialled – for example greater use of virtual care and telehealth.

Element	Community context considerations
Level of nurse	Communities may wish to consider this when:
specialisation: Generalist nurse with some additional specialist training	 The primary objective of the program is to identify people living with neurological conditions including movement disorders in order to support them to access specialist care and / or to support care coordination.
	• There is access to more specialist medical care through existing pathways such as hospitals and telehealth. A generalist nurse with some additional specialist training could collaborate with these services to facilitate access and referrals when required.
	 For a generalist nurse with some additional specialist training, communities should consider the appropriateness and intensity of training and upskilling provided. For example, if the intention

Table 23 | Key elements of the pilot models and community considerations

Element	Community context considerations
	of the nurse is to support disease identification and care coordination, less intense training would be required.
Level of nurse specialisation: Specialist nurse	 Communities may wish to consider this when: There are known challenges with accessing more specialist care through existing pathways – for example, specialist neurologists may be present in the community but have long waiting lists. There is a desire to support broad upskilling of the health workforce through nurse-led training – for example raising awareness of the signs of movement disorders.
Level of nurse specialisation: Expert specialist nurse	An expert movement disorder nurse specialist is defined by the Australasian Neuroscience Nurses' Association: Movement Disorder Chapter as a specialist nurse with a Masters degree or Doctorate in relation to movement disorder nursing. ¹¹⁰
	 Communities may wish to consider this when: There are no or few other options to access specialist care – for example, there may be no specialist neurologists available, specialist neurologists may not be accepting new patients, or telehealth may not be an option due to technological challenges or cultural considerations.
	 There is a desire to support more specific and specialised upskilling of the health workforce – for example training on new medications and treatment regimens.
Nurse placement location: Nurse based in a community health service	 Communities may wish to consider this when: There is an existing, active, and committed community presence – such as Parkinson's disease support groups – who are engaged in the service and can support service uptake and referral pathways. There is known buy-in and commitment from local hospitals and health services to support the model, support multidisciplinary team care and build referral pathways – the evaluation highlighted that community-based models face challenges if nurses are expected to independently generate referrals.
Nurse placement location: Nurse based in a hospital	 Communities may wish to consider this when: There will likely be a need for the nurse to regularly see patients on the ward or in hospital-run outpatient clinics.

¹¹⁰ Australasian Neuroscience Nurses' Association: Movement Disorder Chapter, Parkinson's Disease and Movement Disorder Nurse Specialists: Standards of Practice, First edition, 2017, p. 11

Element	Community context considerations
	• There is a desire to build strong multidisciplinary team links between the nurse and other hospital-based services such as allied health.
Nurse placement location: Nurse based in a private or non- governmental service provider organisation	 Communities may wish to consider this when: There is an existing, active and committed community presence – such as Parkinson's disease support groups – who are already connected to the service provider organisation and can support service uptake and referral pathways. There is known buy-in and commitment from local community health services and hospitals to support the model, support multidisciplinary team care and build referral pathways. The service provider organisation is well known and trusted in the community – by both community members and clinicians.
Nurse employment model: Full time nurse solely focused on providing specialist care	 Communities may wish to consider this when: There is a large population of people living with neurological conditions including movement disorders in the community, and it is likely that the nurse will be able to generate a full caseload. There is a desire to provide more highly specialised care and support, as the nurse can focus more time on upskilling and training and will have consistent patient numbers to maintain their currency of knowledge and practice.
Nurse employment model: Part time nurse providing some specialist care alongside their day- to-day substantive role	 Communities may wish to consider this when: It is a small community or there are only a few people living with neurological conditions including movement disorders, and it is unrealistic that the nurse will be able to generate a full caseload. There are other pressing health needs within the community, and the nurse can also provide this care and support. The nurse can easily and readily access specialist care (such as specialist nurse care) to support their clinical work. There is genuine commitment and buy-in from the employer of the nurse to support upskilling, placements, training, and delivery of specialist care – the evaluation highlighted that a part time nurse model faces challenges if nurses are not released from their day-to-day duties to complete training, or if nurses are not supported to protect clinical time for work related to neurological conditions including movement disorders.

Consideration 3 | Clear guidance and advice – drawn from the results of this evaluation – should be provided to PHNs (or other organisations) wishing to establish similar MDNS models

The evaluation highlighted several enablers and barriers to the successful development and delivery of the trialled models. The results of this evaluation should be used to develop clear guidance and advice for PHNs (or other organisations) who are wishing to establish similar models. This could include guidance and advice about:

- **Project initiation, set up, and ongoing governance approaches** including approaches to ensure that all key stakeholders are engaged when needed, and that stakeholders buy into the model.
- **Project management and delivery** including which organisations could manage the design and delivery of models, and how models can be supported in a sustainable manner.
- **Co-design processes** including approaches to successfully co-design a model to meet community needs and expectations.
- Education and training approaches including ensuring that the education and training that is provided (and required) meets nurse and model needs and expectations and is not overly burdensome.
- Establishing a model of care including tools and templates to support nurses establish, implement, and document a new model of care.
- Clinical governance and supervision including how nurses that are working outside of public health services can receive appropriate clinical supervision and support, and how new movement disorder nurse specialists can receive professional mentorship from more experienced specialist nurses.
- Funding considerations including considerations around co-commissioning of models, and guidance on funding elements that need to be considered to support project success (such as any funding to back-fill positions whilst nurses complete training). Specialist nursing supports like this pilot fall between Commonwealth and State funding responsibilities so it will be important to consider integration and joint commissioning approaches to make sure these supports do not fall through the gaps. Funding considerations must also take into account continuity of service delivery noting that PHN-funded programs tend to operate on defined funding cycles.

Guidance and advice could be circulated from the Department, through PHNs or through the ANNA Movement Disorders Chapter. Consideration should be given to establishing a community of practice (or similar) to enable PHNs to share challenges faced and lessons learned (noting the challenges faced throughout the evaluation with regards to data collection, and the subsequent strength of the evidence base).

Consideration 4 | Should MDNS model approaches be explored in the future, the model should be co-developed in partnership with service providers and communities

Two of the four PHNs involved in the MDNS pilot developed their models through in-depth codesign and collaborative design processes. The evaluation found that these processes were an important enabler and delivered benefits, including:

- Ensuring the pilot models supported and complemented, but did not overlap with, existing services and supports.
- Generating support and buy-in from key partners such as hospital and health services, private and not-for-profit service providers, local clinicians, and consumer representative bodies.
- Raising awareness of the service prior to the roll out of the model and generating initial interest and demand for the service.
- Supporting the creation of referral pathways.

Future models should be developed through a similar process, to ensure that models meet community needs and expectations, fit into the overarching service delivery context, and are best set up for success from initiation.

Note that the evaluation did not find that all regional, rural, and remote communities must develop a model to enhance access to specialist care for people living with neurological conditions including movement disorders. The decision to design and develop a model must be based on community needs and context.

PHNs are well placed to drive the co-design and collaborative design process given their existing role in understanding community context, mapping and identifying service needs and gaps, commissioning services to meet known gaps, and building links between key health stakeholders.

Consideration 5 | Future MDNS models may wish to continue to focus on broader movement disorder nurse specialist models, although disease-specific nurse models may be appropriate in certain local contexts

Throughout the evaluation, many stakeholders spoke of the highly specialist disease-specific nurses that are currently available in pockets across Australia – these include, for example, Parkinson's Nurse Specialists, Huntington's disease specialist nurses, and MND specialist nurses. This is in comparison to the broader movement disorder nurse specialists that were supported through the MDNS pilot.

The evaluation found that the nurses involved in the pilot successfully provided specialist care to patients living with a variety of different neurological conditions including movement disorders – although some conditions like Parkinson's disease were more prevalent than others.

Future models may wish to similarly consider the broader movement disorder nurse specialist role rather than disease-specific roles, as this broad role offers the opportunity for the nurse to provide care to a greater number of patients. This is particularly important in smaller regional, rural, and remote communities where it may be considered that there are too few patients with a specific disease to justify a disease-specific nurse – but this calculation may change should the nurse have a broader scope of practice. Nurses in regional, rural, and remote areas can also use telehealth and virtual care to access specialist services, including a specialist neurologist, in metropolitan areas.

The broader movement disorder nurse specialist role may also offer benefits in terms of sustainability and efficiency, as compared to disease-specific nurses. Nurses with a broader skill and knowledge base are able and encouraged to provide more coverage for a greater number of patients and carers than disease specific nurses.

However, disease-specific nurse models may be appropriate in certain local contexts – for example, in areas where there is a high prevalence on one specific neurological condition or movement disorder. Any decision regarding the focus area should be driven by knowledge of local needs, such as that captured through the PHN Needs Assessment process.

Consideration 6 | Future MDNS models should enable PHNs (or other organisations) to collect relevant data and information to enable evaluations and continuous quality improvement

Movement disorder nurse specialists are still in a nascent phase in Australia, and the MDNS pilot is one of the first major trials of this model. This evaluation provides key evidence that can support an understanding of the impact and effectiveness of this nursing role, to complement other work happening across Australia and overseas (including trials of disease-specific nurses).

Given the newness of this nursing role in Australia, it is vital that future models collect high-quality, appropriate, and accurate data to build the emerging evidence base.

This extends to improving prevalence data around neurological conditions including movement disorders. The data on the prevalence of movement disorders in Australia is poor. Similarly, there is limited information and research on the progression of certain movement disorders. Improved data collection from services provides an opportunity to improve knowledge about neurological conditions including movement disorders, and how to design the most appropriate models of care.

As noted throughout the report, the evaluation faced data collection challenges that impacted the robustness of the insights and, therefore, the strength of the evidence base. These include:

- **Recruitment of patients into the evaluation**. For practical reasons, and in line with ethics approval, the evaluation relied on the nurses engaged in the pilot to explain the evaluation to patients and carers and collect and document informed consent. Some nurses reported that they found this process time consuming and burdensome. As a result, there are fewer patients (and thus less patient-level data) in the evaluation cohort than planned for and expected.
- Collection of patient-level data. Detailed patient-level data was collected by the nurses in HNECC PHN, NT PHN and WV PHN at baseline and annually, and a subset of data collected at each patient interaction. As with consent processes, some nurses reported they found this process time consuming, burdensome, and challenging to integrate into the delivery of patient care and occasionally nurses forgot to collect evaluation data.

In addition, the evaluation intended to draw from patient-level data collected as part of the independent evaluation commissioned in WNSW PHN. Due to various factors, this data was not made available. Taken together, these challenges impacted the quality and completeness of the data that were available for the evaluation.

• Engagement with nurses in WNSW PHN. The evaluation found it difficult to engage with and get responses from nurses in WNSW PHN, especially as the evaluation progressed. It was, therefore, challenging to gain a full picture of the experience of nurses and outcomes achieved in WNSW PHN. Whilst the evaluation drew from data collected by the independent evaluation commissioned by WNSW PHN, the independent evaluator also reported challenges engaging nurses.

Engagement with nurse line managers and colleagues. The evaluation distributed surveys to
nurse line managers and colleagues at two points during the evaluation. These surveys had very
limited response rates and, ultimately, the results were not included in this evaluation report.
Qualitative insights were collected during site visits from the majority of line managers in
HNECC PHN, NT PHN and WV PHN and a small number of colleagues across all PHNs. These
insights should be considered illustrative rather than representative.

There is scope for the Department to consider how – in partnership with evaluation teams – it can address some of these challenges in future evaluations. In particular, the Department should consider whether there are mechanisms that could be built into grant agreements (or similar) that would ensure active participation (including supporting evaluation data collection) by those receiving funding, for instance PHNs and/or associated service providers.

Appendix A Detailed PHN Case Studies

This section presents detailed case studies on each of the PHN pilot models.

Hunter New England and Central Coast PHN

HNECC PHN's pilot model is made up of a single movement disorder nurse specialist who provides care and support to people living with movement disorders. This includes but is not limited to people with Parkinson's disease, dystonia, ataxia, and motor neurone conditions. The model involves providing clinical care and psychosocial support to patients, their families and carers, as well as education to other healthcare practitioners in primary and tertiary health services. The nurse is located at a central hub in Tamworth based at a community-based private health organisation – Rural Fit. The nurse also travels or uses telehealth to reach other parts of the region, collaborating with other services to provide care and support to patients. Targeted education and training to other health professionals in the PHN region includes both informal upskilling delivered by the nurse, and formal education and training symposiums organised by the PHN.



Key features of the pilot model and progress

The Hunter New England and Central Coast (HNECC) PHN model includes a range of education and training initiatives, a unique hub and spoke model of care, and comprehensive support from the PHN. The model initially included collaboration with local Aboriginal Medical Services, although this did not eventually continue. Progress against each key feature is outlined below.

Model of care

The pilot involved a central hub (in Tamworth) and spoke primary care outreach model to support patients and their families within the PHN region. The pilot provided a central point for the region's medical practitioners, practice staff, patients, families, and others to access specialist services. The delivery of care in the "spoke" areas aimed to provide access to specialist care for people living with Parkinson's disease in rural and remote areas, including through telehealth.

The pilot assisted the Local Health District (LHD) to develop specialised three-way telehealth consultations that involved the movement disorder nurse specialist, a neurologist and the patients' GP.

The pilot created a new nurse role based in a private allied health community organisation (Rural Fit). In addition, the pilot involved initial visits to introduce general practices to the pilot. The nurse sends a monthly newsletter to each practice within the region to provide updates on the program.

This was a new primary care model for the region, that aimed to bring together general practice, allied health, and medical specialists, including neurologists.

The pilot also included three other nurses that received scholarships to do additional education. One of these now works alongside a private neurologist, one works in a public hospital, and one works in an aged care service. There was no intention for the PHN to provide additional coordination of these nurses under the MDNS pilot.

Progress: The PHN conducted a significant co-design process across 2020 and 2021 to design and test a primary care pilot model. The pilot nurse commenced delivering services in 2021. Activities undertaken by the nurse included:

- Completing assessments for people living with neurological conditions including movement disorders and providing direct patient care.
- Providing care, support, information and education to patients and carers.
- Coordinating care for patients, their families and carers.
- Meeting regularly with and providing active support to Parkinson's disease support groups.
- Working with local GPs to ensure that all patients with Parkinson's disease have up-to-date Team Care Arrangement Plans, enabling patient access to a range of other community supports.
- Participating in a monthly specialist clinic with a fly in, fly out movement disorder neurologist.
- Providing informal education and training to other healthcare professionals.

Although based in Tamworth, the nurse provides care and support to surrounding communities due to high demand including in Armidale, Gunnedah, Guyra, Narrabri, Tenterfield, Glen Innes, Inverell, Moree and Warialda.

The HNECC model supports the person living with a movement disorder to flourish despite the presence of a chronic condition. There are four key service delivery elements provided by the nurse:

- 1. Evidence-based clinical interventions.
- 2. Empowerment of the person living with a movement disorder condition and their carer(s) through tailored counselling, information, education and referrals.
- 3. Movement and exercise prescriptions.
- 4. Social prescribing to address social determinants of health.

The HNECC model has nine support elements that drive program level success.

- 1. Outreach the nurse visits clients in their home and / or community rather than the client having to travel long distances to a clinic.
- 2. Identification and management of issues early and proactively rather than reactively, reducing the health burden for clients and their families and potentially avoiding hospital admissions.
- 3. Delivery of personalised / tailored care responding to diversity and difference including individual life goals, readiness for change, coping mechanisms and symptoms.
- 4. Organisation of care as close to home as possible.
- 5. Navigated access to specialised health and social care professionals.
- 6. Delivery of integrated care and continuity of care as clients see a range of health and social care practitioners across primary and secondary systems.
- 7. Use of technology-enabled health and social care.
- 8. A placed-based approach maximising the resources close to home, drawing on the strengths of local rural communities and addressing gaps where possible.
- 9. Education and empowerment of healthcare professionals through professional development opportunities and application of a continuous improvement framework.

The pilot initially intended to include an Aboriginal health worker role that would provide a level of cultural safety for First Nation's patients enrolled with the program. Rural Fit subcontracted the Aboriginal health worker role to a local Aboriginal Medical Service (AMS) who employed the person one day per week, working closely with the nurse. However, the AMS did not have any patients who had Parkinson's disease and no other First Nation's patients were being referred from other clinics. This is consistent with findings from other studies that have noted underdiagnosis of Parkinson's disease in First Nation's people.

To address this underdiagnosis, the nurse and Aboriginal health worker trialled the addition of Parkinson's disease-specific screening questions to annual health checks for First Nation's people (the 715 health check). The nurse worked with two AMS to incorporate the screening questions into the 715 health check. A booklet in Kamilaroi language was also developed by the nurse and Aboriginal health worker to provide awareness and information about Parkinson's disease.

Education and training | Information provision and education for others

The pilot model involved the specialist nurse building the capacity of local clinicians to care for people living with movement disorders. This included in-practice case conferencing with the pilot nurse, clinical practice staff and medical specialists. The pilot also involved the education of others within the community about the signs and symptoms of movement disorders, including Aboriginal communities and families.

Progress: The pilot has worked closely with Hunter New England Local Health District (LHD) to establish online education for nurses on Parkinson's disease.

The pilot worked with Walhallow Aboriginal Medical Service across 2022 and 2023 to establish a consulting service that works with Aboriginal communities and families on a needs basis to educate them about:

- Parkinson's disease.
- The signs and symptoms of Parkinson's disease.
- How to seek support if you see signs and symptoms.

The PHN designed and ran a Parkinson's Symposium in Tamworth in November 2022. The Symposium was themed Parkinson's Together and focused heavily on working with the disease using a multidisciplinary approach. The event drew 62 health professionals and 55 people with lived experience.

Education and training | Professional development

The pilot model included the provision of professional development activities for nurses within the community. This included capacity-building activities, the delivery of a series of formal education events, planned conferences, and targeted neurological nurse specialist scholarships.

Progress: The pilot nurse completed a combination of formal education (utilising ANNA resources), virtual placements and mentorship support. This upskilled her to deliver specialist care for people living with Parkinson's disease in the region.

The PHN also provided three other nurses with scholarships to undertake the Parkinson's Care unit through the Australian College of Nursing. One of these nurses worked at the local hospital, one in the office of a private neurologist and the other in an aged care service.

Four nurses completed formal accreditation, online training and on-the-job learning. One nurse (the full time specialist nurse) received formal mentorship from another movement disorder nurse specialist based in Newcastle, within the PHN region.

PHN management of the pilot

HNECC PHN worked together with Rural Fit, local members of the community living with movement disorders, general practice and medical specialists, Hunter New England LHD and Parkinson's NSW to co-design the pilot program between March and April 2021.

The PHN commissioned two participatory action research workshops to inform a plan, do, study, act (PDSA) continuous improvement process.

The PHN played a coordination and monitoring role for the ongoing implementation and evaluation across all stakeholders and service providers. The PHN representative met regularly with the nurse, managers at Rural Fit, and representatives from the Department.

Achievements against outcomes

The co-design process included consultations with clinical services, local subject matter experts, community organisations, clinicians and people living with Parkinson's disease and their carers. Two co-design workshops were held with stakeholders, which included meetings with local GPs and neurologists to test emerging pilot design themes.

Rural Fit recruited a Registered Nurse who provided services to patients using both centre-based clinics and home-visiting approaches, while running monthly clinics from the local neurologist clinic.

Patient-level outcomes

The specialist nurse is supporting approximately 140 patients. This includes patients who received an initial assessment from the nurse, patients who are receiving ongoing care and support, and patients who are participating in Parkinson's disease support groups that are facilitated by the nurse.

In addition to these 140 patients, the nurse also supports a number of carers including through providing education on Parkinson's disease and other movement disorders, enabling access to carer specific supports, and providing direct psychosocial care.

Patients and carers reported that the pilot contributed to improved outcomes for people living with Parkinson's disease, their families and carers. During visits to the PHN region, all patients and carers spoke positively of the nurse and the model of care and noted that the nurse was providing a highly valuable service that had not previously been available. Many patients and carers reported that they were unsure how they would receive care and support were the pilot to cease.

One patient being seen through the pilot reflected during the evaluation:

• "I don't know what we would do without [the nurse]. Maybe in the big cities there are lots of supports available, but out here in the country it's very little. We're so lucky to have this service...before this there was nothing."

The evaluation noted that quality of life scores increased for patients in HNECC PHN across the pilot (average baseline score 0.60, average follow-up score 0.61). HNECC PHN was the only pilot site that saw an increase in average quality of life score.

The PHN reported their impression that the pilot contributed to improved outcomes. The PHN highlighted instances in which the pilot nurse had been coordinating care for patients and advocating on behalf of patients to improve quality of life, such as through advocating for modifications to housing.

The pilot nurse developed a range of clinical tools to support the delivery of specialist care such as patient-centred plans, patient symptom diaries and patient booklets. These tools contributed to the delivery of higher quality care to patients living with Parkinson's disease. This includes a tool to incorporate Parkinson's disease questions into 715 health checks.

The new movement disorder nurse specialist role and the pilot more broadly likely contributed to increased access to specialist care for patients in the region. In the Tamworth and New England / Northwest region, there is very limited support for people living with movement disorders. Before the pilot, there were two outreach clinics in Tamworth conducted per year, delivered from Newcastle. Outreach to more rural and remote surrounding towns are very limited. The addition of the new nurse specialist role contributed to address this service and capability gap.

The scholarships provided to three other nurses in the PHN region likely also contributed to increasing access to specialist medical care. One of the nurses who received a scholarship had recently started a position with the local neurologist. This nurse reported they have independently seen and managed low acuity patients, which has reduced burden on the neurologist and freed up additional specialist neurologist appointments.

The PHN emphasised there is no shortage of patients presenting to the pilot nurse for service. As the pilot continued, the PHN, service delivery organisation and the nurse collaboratively focused on sustainably managing the number of pilot participants to ensure the maintenance of high-quality service delivery.

Nurse-level outcomes

The pilot contributed to growing the confidence and capability of nurses in the region to deliver specialist care. The provision of mentoring (from an established movement disorder nurse specialist in the Hunter New England LHD region), education and training to nurses within the region supported upskilling of the capability of the local workforce to deliver specialist care to patients living with movement disorders.

In addition, the pilot built the overall availability of specialised care in the region, by offering scholarships and training to three other nurses in the region.

The nurse reflecting on the pilot:

 "My skills and confidence have absolutely grown. I came into this knowing a little bit – I used to work in community aged care and General Practice – but it's amazing how much I've seen myself grow and develop."

Total nurses recruited into the pilot	1 full time nurse employed to care for people experiencing Parkinson's disease.
	4 nurses (including the full time nurse) have completed the Post Graduate Parkinson's Care subject through Australian College of Nursing

Table 24 | Overview of pilot nurse recruitment and training

Total nurses actively engaged in the pilot	1
Total nurses that have completed online training	4
Total nurses that have completed on- the-job training	4
Total nurses that have completed formal accreditation	4
Total nurses that have completed in- person training	4
Total nurses that have received formal mentorship	1

System-level outcomes

There may have been a strengthening of relationships across the system as a result of the pilot. This includes:

- Enhanced referral to other services and supports service interaction data collected by the nurse indicates that in approximately 40 per cent of appointments with patients, the nurse referred the patient to another service.
- Strengthened general practice relationships the pilot nurse was embedded in team care arrangements and regularly liased with GPs about patient care.
- Strengthened allied health relationships the pilot nurse was placed in a community-based private health organisation that was originally set up to provide allied health services. There were strengthened relationships between the nurse and allied health colleagues, including cross-referrals and collaborative team-based care.
- Established relationships between medical specialists and clinics in Tamworth the local neurology specialists and the neurology (movement disorder) specialist visited monthly and met with the pilot nurse. The pilot nurse was also co-located in the Tamworth Neurologist Specialist Clinic that is run once a month.
- Strong connections with acute care, including relationships with discharge teams the pilot
 nurse coordinated with hospital discharge teams to ensure all patients with Parkinson's disease
 were made aware of the pilot service and provided with a pilot Parkinson's pamphlet providing
 information about the pilot.

Enablers for success

The private allied health setting of the pilot model allowed for agility and flexibility in service delivery. The nurse had the flexibility to see patients and carers at the time and place that was most convenient for them – including at home, in the community, or in the service. During the peak of COVID-19, the pilot could continue servicing the patients that were seeking specialist care, whereas in other jurisdictions nurses were redeployed to COVID-related tasks such as testing and

vaccinations. The service delivery organisation reflected that the commercial nature of the organisation and small size allowed for more timely responses to implementation challenges.

The community-based location of the service was welcomed by patients and carers. The service delivery organisation is based in a broader sports precinct, which patients and carers reflected created a more welcoming environment – unlike a hospital or health clinic. Patients and carers reported feeling more comfortable attending consultations with the nurse in this environment, because they perceived that they were working on their fitness and movement rather than engaging in clinical activities.

One patient reflecting on the service location:

 "It really feels different here – it's a gym, I'm here to get healthy. It's not like the hospital where I feel like a sick person, and I'm reminded that I have this condition and that it's progressive."

The service delivery organisation had a long history of supporting people living with Parkinson's disease. The organisation had been supporting Parkinson's disease support groups for many years and had a significant patient base of people living with Parkinson's disease who were receiving care from exercise physiologists. The nurse reflected that this history meant there was a ready-made pool of patients to see – supporting rapid scale up of the pilot once service delivery commenced. Patients reflected that they had existing trust in the service delivery organisation, which gave them trust in the pilot and the nurse.

Co-location with exercise physiologists supported the provision of multidisciplinary care. Due to the nature of the service delivery organisation – as an allied health provider encompassing a number of different allied health professions – patients were able to attend appointments with the nurse and see other allied health professionals concurrently. The nurse and allied health professionals all reflected the importance of this multidisciplinary approach on maintaining quality of life.

Challenges faced and how they were overcome

The nurse and Rural Fit had to create new clinical governance systems to support the model. Whereas pilot models in other PHNs could leverage established clinical governance systems, the HNECC PHN model had to establish its own. The nurse used relationships with neurologists and the mentorship of the experienced movement disorder nurse specialist in HNE LHD for clinical guidance and advice. Formal clinical governance for the model is now in place and active.

COVID-19 impacted the initial phases of the pilot program, particularly in relation to the development of networks and partnerships. The formalisation of pilot relationships with other healthcare professionals was delayed due to COVID-19. Other staff were busy with COVID-19 preparedness and response, and engagement with general practitioners was delayed as they were engaged in the national vaccine rollout and treatment of COVID-19 patients. As Australia has moved into routine management of COVID-19 these delays and challenges have reduced.

There were delays and barriers to the original strategy of recruiting to the Aboriginal Health Worker role. The pilot was initially able to recruit to the Aboriginal Health Worker role, which was one day per week. The two Aboriginal Health Workers that were in the role both left the organisation and their incumbent roles during the peak of COVID-19. Due to no First Nation's patients with Parkinson's disease being enrolled in the pilot, it was decided not to continue to employ an Aboriginal Health Worker, as the original intent was to provide support to First Nation's patients. The focus was then placed on promoting the Parkinson's disease risk calculator to improve screening and early identification in the First Nation's community.

Northern Territory PHN

Northern Territory PHN recruited a single, full-time nurse who provided specialist nursing care and care coordination to patients with movement disorders living in the Northern Territory. The nurse has extensive experience in neurology and also in specialised research in movement disorders. The nurse participated in multidisciplinary team care including coordination across primary care providers, specialist and support services, and was embedded within the Community Allied Health Team in NT Health.¹¹¹



*Figures do not add to 100 per cent due to other expenses and some program underspend.

¹¹¹ NT PHN agrees that this case study is a factually accurate summary of the NT PHN model. As part of best practice community collaboration, NT PHN is sharing the case study with members of the model's co-design team. Any feedback received after the finalisation of this report will be provided to the Commonwealth for its consideration.

Key features of the pilot model and progress

- There is one movement disorder nurse specialist based in Darwin working as part of the community allied health team at NT Health.
- The nurse sees patients in Darwin as well as people in regional, rural and remote areas of the Northern Territory.
- The nurse does a significant amount of travel to see patients in remote communities, undertaking assessments, providing information and support and care coordination.
- The nurse has undertaken extensive community engagement to promote a broader understanding of movement disorders within the community.

Given the vastness of the Northern Territory, the dispersed nature of many of the patients, and the lack of data available on the prevalence of many neurological conditions, it was determined the pilot would focus on movement disorders. The pilot nurse has provided holistic assessment and support to a broad range of movement disorders including:

Huntington's disease	Tremor	Restless legs syndrome
Chorea	Essential tremor	Stiff person syndrome
Parkinson's disease	Myoclonus	Wilson's disease
Atypical Parkinsonism	Startle	Tardive dyskinesia
Dystonia	Tics	Functional movement disorder
Ataxia	Tourette syndrome	Lewy body dementia

While the pilot targeted these movement disorders, services were provided to patients living with other movement disorders if they presented. A large majority of patients the nurse saw had Parkinson's disease.

The model also involves:

- Provision of a consultancy service to health professionals and other relevant staff primarily caring for the patient (in remote communities particularly).
- Control of the case management function through education that builds the capacity of alternative services and through client referrals to those services.

Model of care

The pilot nurse provided individual support, care and care coordination to patients. The pilot nurse provided holistic assessment and support through all stages of movement disorders from diagnosis through maintenance, complications and palliation. The nurse applied specialist knowledge and skills to address symptom management, side effects, complications, disease progression, counselling, referral, medication management, lifestyle factors, mobility, maintaining independence, mental health, and cognition for patients, their families and carers.

The pilot nurse provided care and support across all areas of the NT. In line with the objectives of the MDNS pilot, the NT PHN model initially focused care and support on patients outside of metropolitan Darwin. During the pilot period, a decision was made to extend the pilot to those living in metropolitan areas. This is because people living in Darwin did not have access to movement disorder nurse specialist and there was evidence to suggest there was a higher prevalence of people living with movement disorders in Darwin due to people moving closer to services. To deliver care and support across the NT, the nurse frequently travelled to remote communities across the Top End including Borroloola, Katherine, Maningrida and Wadeye, and to communities in Central Australia.

The pilot nurse played an important care coordination role for patients. The pilot nurse participated in multidisciplinary team care, including coordination across primary care providers, specialist and support services. Consultations with the PHN and nurse highlighted that a large part of the nurse role was to connect patients to the appropriate healthcare teams and other parts of the system. The care coordination role addressed key challenges faced by patients in the region, including:

- Lack of access to therapy services, like speech therapists.
- Limited understanding about ways to access NDIS and aged care services.
- Limited access to advanced treatment options for Parkinson's disease patients when compared to other states and territories e.g. deep brain stimulation and apomorphine injection / infusion.

In 2023, the PHN identified that it had underspent funds due to delays with pilot implementation. The PHN worked with the nurse and the Department to reallocate some funding for a speech pathologist, who will work alongside the nurse and provide multidisciplinary care.

Progress: The PHN facilitated a comprehensive co-design process with local stakeholders to design the model of care to meet the needs of patients living in the Northern Territory. The PHN also commissioned NT Health, who recruited the movement disorder nurse specialist for the pilot. The nurse was placed within the Community Allied Health Team in NT Health.

To support service delivery, referral forms, brochures and other materials were developed to promote the service across the Northern Territory with specialists, private and public hospitals, aged care, NDIS, palliative care, community health services and peak bodies. The role was also promoted on Parkinson's Day, and the celebration of Parkinson's disease morning tea with Territorians affected by movement disorders.

Across the pilot, the nurse received referrals from neurologists, geriatricians, rehabilitation teams, allied health teams and self-referrals. The source of the referral differed for the different types of movement disorders.

Activities undertaken by the nurse included:

- Providing direct care and support to patients living with movement disorders and some neurological conditions, their families and carers.
- Working with the Royal Darwin Hospital and Palmerston Hospital to ensure the provision of appropriate support to patients (with movement disorders) who are admitted to the hospitals.

• Providing case management to support timely neurologist review for patients. The pilot nurse worked closely with the Neurology Outpatient Department to ensure all patients requiring movement disorder review were seen within clinically recommended timeframes.

Education and training | Professional development and supervision

The pilot included the provision of telephone advice and information, face-to-face upskilling, education events and other resources and tools to support nurse training and professional development. On-the-job learning was provided through participation in multidisciplinary team care planning.

Progress: In early stages of the pilot, the nurse attended virtual clinical placements with Movement Disorder Nurse Specialists based in NSW.

While the nurse came to the pilot with substantial experience in movement disorders, the pilot nurse also completed a range of education and training. The nurse completed the Parkinson's Care postgraduate unit of Study from Australian College of Nursing, and attended the 2022 ANNA conference in Melbourne to meet movement disorder specialist nurses from other states and territories. The nurse is also a member of ANNA and became a member of the International Parkinson's and Movement Disorders Society.

The nurse reflected that they worked closely with neurological specialists and geriatricians in Darwin and received extensive clinical mentorship and on-the-job learning from these health care professionals.

Education and training | Information provision and education for others

The pilot nurse provided comprehensive information on living with movement disorders to patients, their families, and carers, including treatment options, symptom management and disease progression information. In addition, the pilot nurse leveraged their specialist training to educate and train other staff in different care settings, particularly in relation to medication management during acute hospital admissions.

Progress: The nurse provided informal training and upskilling to other staff involved in the care of patients with movement disorders including nursing homes, hospitals and allied health teams to support diagnoses, treatment and support for people living with movement disorders. Health care providers reflected the value that the nurse brought in this space, noting that she had extensive prior experience working in neurological settings (including formal qualifications) and had prioritised raising awareness and building the skills of colleagues.

The nurse has also undertaken extensive community engagement to promote a broader understanding of movement disorders within the NT. The nurse led a range of activities during Parkinson's month in April 2022 to increase awareness of Parkinson's disease, including interviews with the NT News, radio interviews with Mix FM and ABC radio, and a TV interview on 9 News.

A health care professional reflected on the nurse:

• "She [the nurse] is wonderful, we are so lucky that we were able to recruit her – she was the right person, at the right time, to do this job. She's passionate and she's skilled, and she's spent so much time educating others."

PHN management of the pilot

NT PHN facilitated and conducted the comprehensive co-design process for the pilot model and managed the ongoing monitoring of the pilot.

The commissioned provider, NT Health, recruited the pilot nurse and provided day-to-day management and supervision.

The PHN supported and facilitated the national evaluation team to secure NT-specific ethics approval addendum for Aboriginal and Torres Strait Islanders through the appropriate channels and organisations. The local relationships through the PHN were critical to progression.

The PHN was integral to coordinating the input of various stakeholders from within and outside the Northern Territory to develop a pilot model tailored to the unique local need, demographics and geography.

Achievements against outcomes

The PHN undertook an extensive co-design process to design the pilot model. This involved input from various local stakeholders at different times throughout the needs assessment and design phases, including:

- Clinicians Palmerston Hospital Geriatrician / General Physician, Royal Darwin Hospital Neurology Nurse, Central Australia Health Service (CAHS) allied health professionals.
- Aged care representatives Hetti Perkins Aged Care Alice Springs, Rocky Ridge Aged Care Katherine, Australian Regional and Remote Community Services (ARRCS).
- PHN representatives Brisbane South PHN, Country SA PHN.
- Peak bodies Parkinson's SA and NT, MND NSW and NT, Disability Advocacy Service, Huntington's SA and NT, Aboriginal Medical Services Alliance Northern Territory (AMSANT).

The PHN established a co-design group with representatives from neurology and geriatrician services, community allied health professionals, NDIS, general practice, aged care, people with lived experience, their carers, peak bodies and people involved in the lived experience support group in the Northern Territory. The co-design process lasted six months.

The PHN recruited a full-time movement disorder nurse specialist for the pilot during a period of significant health workforce pressure and thin markets. The nurse commenced delivering care and support for patients living with movement disorders across the Northern Territory in early 2022.

Patient-level outcomes

Up to September 2023, the movement disorder nurse specialist was supporting approximately 170 patients. The nurse had identified additional patients with movement disorders that are not currently receiving care or support. Unlike some other PHN models, the NT PHN model was explicitly designed to provide support to patients with a range of neurological conditions including movement disorders. Quality of life scores for patients under the NT PHN model were maintained across the pilot (average baseline score 0.60, average follow-up score 0.59).

Patients, carers and health system stakeholders reported that the pilot contributed to improved patient outcomes for people living with movement disorders in the Northern Territory. During visits to the PHN region, patients and carers highlighted the value of the nurse in providing advice on medication management, coordinating care, and reducing loss to follow-up by specialist services. Many health system stakeholders noted that, due to ongoing workforce challenges across the NT, prior to the pilot it had been exceedingly difficult if not impossible for patients living with neurological conditions including movement disorders to access specialist care in a timely manner.

The pilot expanded access to care to patients and carers living in remote communities. The nurse was placed in the Community Allied Health Team (CAHT) within NT Health. As part of CAHT, the nurse completed fly-in fly-out visits to a number of communities across the Top End region. Health system stakeholders noted that many patients in these communities had very limited if no access to care prior to the pilot.

There are indications that the pilot contributed to more effective patient care coordination, in response to system fragmentation that patients often must navigate themselves. The pilot nurse helped to connect patients to specialist, generalist and allied health services, as well as helping patients navigate the interface between health, disability and aged care systems. The nurse highlighted that a key part of her role was supporting some patients with Parkinson's disease who were eligible to access the NDIS, but are unaware or unsure of how to do so.

Reflecting on access to care, one health system stakeholder mentioned:

 "Some of those patients in remote communities – out in Maningrida, out in Borroloola – they wouldn't have seen anyone with these skills in years. Maybe never. Having [the nurse] has really enhanced access to care for these patients."

Nurse-level outcomes

The pilot likely contributed to increased confidence of clinicians to deliver appropriate care to people living with movement disorders in the Northern Territory. The pilot nurse drew on her own specialist knowledge and training – gained prior to joining the pilot – to deliver education to staff within allied health teams, hospitals and residential aged care facilities among others. This enhanced the capability of providers in the region to support people living with movement disorders.

Total nurses recruited into the pilot	1 full-time nurse with existing experience and knowledge in neurological conditions.
Total nurses actively engaged in the pilot	1
Total nurses that have completed online training	1
Total nurses that have completed formal accreditation	1
Total nurses that have completed on-the- job training Total nurses that have completed in- person training Total nurses that have received formal mentorship	Not applicable for this model: The nurse has existing specialisation in neurological conditions and has not required on-the-job training, in-person training or formal mentorship. Instead, the pilot nurse has been educating and training other staff in different
	care settings.

Table 25 | Overview of pilot nurse recruitment and training

System-level outcomes

The pilot may have reduced burden on specialists in the NT. Health system stakeholders, including neurologists and gerontologists, spoke very highly of the nurse and her specialist skills. These stakeholders noted their perception that the pilot had reduced overall health system burden as the nurse had the specialist skills and capabilities, and the confidence to act as an independent practitioner and provide care and support to patients who would otherwise need to see a medical specialist.

The pilot may have contributed to greater collaboration across the system. The PHN's extensive co-design process involved collaboration between various stakeholders across aged care, disability services, acute care, peak bodies, PHNs and others. The PHN highlighted the value of this process in building and strengthening connections and relationships with key system stakeholders within the Northern Territory. The nurse echoed these reflections, and noted that her position within CAHT enabled her to build connections between neurology, gerontology and allied health that previously did not exist.

Reflecting on the impact of the pilot on access to specialised care at the system level, a health professional noted:

• "Definitely it's making a difference. There are some patients that I used to see every 3months that now come every 6-months, because I know [the nurse] can see them inbetween times. In effect, it's doubled the number of appointments I have available."

Enablers for success

Recruiting an existing nurse with specialisation in movement disorders enabled the rapid commencement of service delivery within the region. The longer process of co-design meant that it was particularly important to ensure service delivery commenced quickly. The PHN also highlighted a key requirement of the pilot nurse role was expertise in movement disorders because of the very limited access to neurologists within the Northern Territory.

The pilot nurse developed effective connections into acute care. The pilot nurse developed effective relationships and collaboration with hospital staff, particularly to ensure the provision of appropriate support to patients (with movement disorders) who are admitted to hospital and to support care coordination across providers and settings.

The structural supports, including an allied health assistant, prioritised through the co-design process were critical in supporting the nurse's activities and maximising the time devoted to clinical care. An allied health assistant within NT Health supported the pilot nurse, including by coordinating trips for the nurse to travel to different parts of the Northern Territory to deliver care. The PHN and nurse highlighted the importance of this role, given the large expanse of the Northern Territory region covered by the pilot and identified these structural supports maximised the time allowed for clinical care provision to patients.

Challenges faced and how they were overcome

There was a limited understanding of local need for movement disorder specialist nurse care in the Northern Territory. Prevalence estimations for movement disorders in the Northern Territory are based on national prevalence rates and are unlikely to be accurate given differences in the demographic profile of the Northern Territory population.¹¹² Subsequently, there was limited data to inform the design of the pilot model. Through this pilot, the nurse has been working to establish a baseline prevalence rate for people living with Parkinson's disease in the NT.

The PHN undertook an in-depth co-design period, which pushed pilot patient recruitment to 2022. The PHN highlighted the value of the co-design process in ensuring the pilot model was fit-for-purpose and reflective of local needs, and also in strengthening connections and relationships across the system. The process took 6 months, which delayed the start of service delivery.

There was a challenge in ensuring the target group of movement disorders in the pilot was broad enough to effectively deliver care to those who need it, while narrow enough to still be viable and sustainable for the single pilot nurse to service. The PHN highlighted that having a broader target group of movement disorders could dilute the capacity and ability of the pilot nurse to deliver appropriate specialist support to patients, their families and carers. The co-design Advisory Committee balanced these considerations during the co-design process and delineated the scope of pilot services by geographical reach, range of conditions, level of service pre- and

¹¹² Note that it is possible that prevalence rates are lower in the NT than in other parts of Australia, given the lower life expectancy in the NT – particularly for First Nations Territorians – and that neurological conditions including movement disorders tend to present later in life.

post-diagnosis and balance of service that is directly delivered to clients (rather than other health professionals).

COVID-19 impacted the ability of the pilot nurse to build and strengthen relationships across the system, including within health and aged care settings. The PHN shared that during early service implementation many stakeholders with whom the pilot nurse wanted to engage were busy providing COVID-19 responses in their communities, making it challenging to effectively promote the pilot service. COVID-19 also had direct patient impacts, creating barriers for some clients to access community-based services during the pandemic.

Western NSW PHN

Western NSW PHN delivered a pilot model that focused on building the skills and confidence of 12 Registered Nurses who were already working within the PHN region. The model targeted patients living with Parkinson's disease in rural and remote NSW and was implemented in Local Health District (LHD), community settings and general practice. The recruited nurses were not movement disorder specialists at the start of the pilot, and were provided education, training and mentorship to increase their capabilities. The nurses each designed a model of care to be responsive to the unique needs of each local community.



Key features of the pilot model and progress

The Western NSW model involved providing nurses already working in communities in the region with additional skills and knowledge to support people living with neurological conditions including movement disorders. The nurses were not full-time movement disorder nurse specialists but were expected to incorporate their care for people living with movement disorders alongside their substantive day-to-day roles.

- Model focuses on building movement disorder specialist knowledge and skills for nurses already working in the PHN region.
- Nine of the nurses were based in the Local Health District, one in a regional clinic run by the Royal Flying Doctor's Service, one in general practice and one was coordinating the program at the Primary Health Network.
- The nurses that are still actively engaged in the program are undertaking a range of activities including running a multidisciplinary clinic, facilitating exercise groups, and seeing patients as part of a broader primary healthcare team.

Model of care delivery

The pilot involved nurses working within their existing health services or employers to develop and run nurse-led clinics and utilise telehealth to connect with other movement disorder specialist services. Nurses drew on their training and education to incorporate the provision of specialist care for those living with Parkinson's disease into their existing community nursing duties.

The model focused on delivering specialist care to people with Parkinson's disease because there was a higher prevalence of Parkinson's disease in the region compared to other movement disorders. Despite this focus, some of the pilot nurses also supported patients with other movement disorders.

Progress: At the beginning of the pilot, each of the nurses worked to design a model of care appropriate for their communities. Associate Professor Rachel Rossiter, Charles Sturt University, developed a workbook, "Preparing to improve care for people living with Parkinson's disease in your community", to assist the nurses to plan their models of care. Individual follow up meetings were held with all but one nurse due to their availability.

Each nurse designed a different model of care, aligned with their local community context and integrated, to the extent possible, with other services provided by the organisation in which they were working. Some nurses designed a model of care that did not change their substantive role significantly, whilst others added new clinics or services to their existing workload. Examples of different approaches include:

- One nurse designed and delivered a multidisciplinary movement disorder clinic once a fortnight with an occupational therapist and a physiotherapist.
- One nurse facilitated Parkinson's disease exercise groups and support groups with the assistance of Parkinson's NSW in their local community.
- One nurse was part of a broader primary health clinic. This nurse operated as a practice nurse and was able to identify Parkinson's disease and other movement disorders when

patients present to the clinic. The nurse could refer patients to other services and specialist services as appropriate.

Of the original 12 nurses recruited to the pilot, four remain actively involved at the time of the final evaluation report. A further four nurses continue to utilise the knowledge they learned as part of their training through the pilot in other roles. It is understood the models of care developed by the eight nurses no longer actively engaged with the pilot were not implemented.

The pilot nurses were employed by different health services and worked in a range of settings. This includes:

- Specialist Medical Centre Neurology Dubbo Hospital, WNSW LHD.
- General Practice in Warren, now run by Royal Flying Doctor Service and previously run by Rural and Remote Medical Services.
- Community Health Centre in Parkes, WNSW LHD.
- Community Health Centre in Grenfell, WNSW LHD.
- Royal Flying Doctor Service Community Wellbeing Building in Lightning Ridge (and not working as an ACAT Assessor).
- Stroke Ward at Orange Health Service, WNSW LHD.
- Community Health Service in Coonamble, WNSW LHD.
- Community Health Service in Molong, WNSW LHD.
- Community Health Service in Mudgee WNSW LHD.
- Far West LHD.
- WNSW PHN Employee (now working in General Practice, Patient Transport).
- Bathurst Hospital Medical Ward, WNSW LHD.

Education and training | Post graduate study

Nurses were supported to complete post-graduate study to improve their knowledge and skills in movement disorders. Nurses recruited to the pilot were provided scholarships to complete postgraduate study. Scholarship recruitment targeted LHD nurses, general practice nurses and Aboriginal Medical Service nurses to undertake post-graduate study to become qualified movement disorder nurse specialists. Nurses were also provided funding and support to complete a postgraduate unit of study in Parkinson's Care at the Australian College of Nursing.

Progress:

All 12 pilot nurses completed online training and on-the-job training between January and December 2021. This included:

• All 12 nurses completed the Parkinson's Care postgraduate unit of study at the Australian College of Nursing.

- All 12 nurses completed the Health Education and Training Institute (HETI), NSW Health Caring for People with Parkinson's Disease short course.
- All 12 nurses participated virtually in the Australasian Neuroscience Nurses Association (ANNA) Movement Disorder Chapter Parkinson's Disease Education Day for Nurses.
- Some nurses commenced the Charles Sturt University Three Rivers Department of Rural Health Open Learning Telehealth, Embracing Technology in Health Care online course.

Some nurses reported the training and upskilling expectations were greater than they anticipated. Some nurses said they found it challenging to complete the education and training required as well as continuing to provide day-to-day patient care.

Education and training | Clinical placements

It was intended the nurses would apply their knowledge and receive further knowledge and skills through clinical placements. Upon completion of post-graduate studies, the nurses were to complete a one week clinical placement facilitated by Parkinson's NSW.

Progress: Clinical placements were delayed during 2021 and 2022 due to the impacts of COVID-19 across the health system, including staff shortages in hospitals. Pilot nurses were part of the COVID-19 response, which took priority over the work required for this program.

In response to the delay in clinical placements, the pilot nurses had the opportunity to shadow virtual assessments undertaken by three Parkinson's clinical nurse consultants (CNC) in other LHDs and debriefed and discussed the assessments with the CNC after the sessions.

Nine nurses attended more than one virtual assessment session with Parkinson's CNC from Westmead Hospital, Royal North Shore Hospital and Coffs Harbour Hospital.

All nurses have completed their clinical placement.

Other education and training

Nurses were provided other opportunities for education and training in movement disorder healthcare, including membership of peak bodies, access to a regional professional network, or community of practice, and a series of webinars. The pilot offered nurses memberships to the:

- International Parkinson and Movement Disorder Society (MDS), which includes access to and use of the MDS Unified Parkinson's Disease Rating Scale tool.
- ANNA Movement Disorder Chapter.

The nurses participated in a regional professional network, which enabled ongoing peer-to-peer support and learning via regular teleconferences.

Progress: Twelve memberships were purchased to the ANNA Movement Disorder Chapter and all nurses attended a virtual conference in November 2021. Nurses had access to all webinars on the ANNA website and access to the Parkinson's Disease Education Day on 6 May 2022. Pilot nurses participated in monthly community of practice meetings during the early stages of pilot implementation. PHN representatives reflected that participation in these meetings slowed over time and eventually ceased entirely.

PHN management of the pilot

At the commencement of the pilot, Western NSW PHN had a dedicated pilot coordinator that was integral to designing the pilot, managing pilot activities, providing clinical and administrative oversight, and mentoring and supporting the pilot nurses. The PHN also established a pilot Steering Committee. The original pilot coordinator role was discontinued in March 2022, and the pilot moved into the PHN Primary Healthcare and Integration team.

The PHN Primary Healthcare and Integration team continued to manage the pilot, including holding regular meetings for nurses to connect and provide peer support and mentorship. The PHN representative reported that these meetings were often poorly attended. It was not possible to hold these meetings during the day because the nurses were working. Nurses were also not always available to attend meetings outside of hours.

In addition to participating in the national evaluation, Western NSW PHN commissioned an independent academic to conduct an in-depth evaluation of their pilot model. The national evaluation team and Western NSW PHN worked closely to agree on an approach that would leverage, to the best extent possible, data that was already being collected by the PHN-specific evaluation for the national evaluation to prevent duplication, streamline data collection for the nurses and complement efforts.

A realist evaluation report was provided to the Western NSW PHN in August 2023. The final evaluation report was unable to collect patient data as was originally planned. However, the evaluation does have information from interviews with most of the nurses including some that are no longer actively engaged with the pilot.

Achievements against outcomes

Western NSW PHN undertook an extensive design process informed by local knowledge of the PHN pilot coordinator to develop the model of care and recruited twelve nurses for the pilot. In 2021 the nurses started delivering care and support for patients living with Parkinson's disease in rural and remote NSW.

Patient-level outcomes

There are anecdotal indications the pilot contributed to enhanced access to specialist care for people living with Parkinson's disease in Western NSW. There were anecdotal reports via the PHN's monitoring and oversight that patients were being seen by nurses in the pilot, who may not have otherwise received or sought care.

The nurses still actively involved in the pilot are regularly seeing patients with movement disorders. Table 26 provides more information about the number of patients regularly seen by three of the pilot nurses.

One patient living with Parkinson's disease presented to a hospital emergency department where their Parkinson's medications were ceased. The patient was subsequently placed on the

stroke ward for palliative care, without consideration of appropriate medication to treat the patient's movement disorder.

The patient then experienced freezing and was unable to move in bed. Only after the pilot nurse arrived on shift, made an assessment with her specialist skills, and consulted the staff neurologist was the patient able to access the right medication. This patient was able to leave a misdiagnosis of palliative care for home.

Table 26 Number of patients with movement disorders being seen by the Western NSW pilo	t
nurses	

Community nurse is located in	Number of patients being seen
Dubbo	 Two patients for two hours per fortnight in the clinic. 25 patients and 25 carers seen as part of a regular support group.
Warren	 Has around six patients with Parkinson's disease and one with Huntington's disease.
Grenfell	• Runs two weekly exercise group with approximately five people in each.

Nurse-level outcomes

Nurses started to build their confidence in delivering specialist movement disorder care and identified patients to be screened for movement disorders who otherwise may not have been screened. This increase was likely linked to their participation in the various education and training activities, including completing post-graduate studies, attending virtual learning conferences, shadowing a Parkinson's Clinical Nurse Consultant (CNC) and accessing online learning materials.

Nurses started to strengthen connections with other clinicians and medical specialists. The pilot contributed to the ongoing development of peer networks and connected nurses with support groups they could draw on to improve the delivery of health services for people with movement disorders. For example, in early stages of the pilot the nurses drew on support and guidance from Parkinson's NSW and ANNA and connected with clinicians with more advanced skills in movement disorders through these channels.

Total nurses recruited into the pilot	12
Total nurses using their specialist movement disorder knowledge in the region	8
Total nurses still actively involved in the pilot	4
Total nurses that completed online training	12
Total nurses that completed on-the-job training	3 – The final nurse still actively involved in the pilot will complete their on-the-job training in October 2023.
Total nurses that completed formal accreditation	Whilst there is no formal accreditation, the pilot is following the ANNA recommended pathway for movement disorder nurse specialists.
Total nurses that completed in-person training	Three of the four nurses have completed their clinical placements. The remaining nurse actively involved in the pilot is due to complete their clinical placement in October 2023.
Total nurses that received formal mentorship	One of the nurses is participating in ANNA's mentoring program.

Table 27 | Overview of pilot nurse recruitment and training

System-level outcomes

In early stages, the pilot may have contributed to greater collaboration and communication across the system, including between ANNA, Parkinson's NSW, Western NSW PHN and LHDs in the region. The PHN originally reported strong engagement between these stakeholders, despite the challenging COVID-19 context. This engagement tended to drop away during the delivery of the pilot.

Some of the nurses are using their knowledge and skills to identify the signs and symptoms of movement disorders. Regardless of the role they are in, the nurses that remain actively engaged with the pilot are using their knowledge to identify the early signs of Parkinson's disease and other movement disorders. The nurses are encouraging their patients to seek additional help for their symptoms and connecting them with relevant services and supports.

A nurse who remains actively engaged in the pilot said:

 "Identifying symptoms. They jump out at you. I've been a community health nurse for years but being able to see that and encouraging them with medications to go back and see their GP, that's been one of the key points that I see. Everyone I see, I seem to say, go back to your GP, and sometimes I have actually said, well, we need to see a geriatrician, to get this sorted so that somebody can make a formal diagnosis. And so that's through my work, I refer them on."

Enablers for success

The PHN's strong relationship with the nurses and other system stakeholders was key to the pilot's initial success. The PHN played an important role in supporting the nurses upskill to deliver specialist movement disorder care, including through:

- Ongoing communication with nurses and encouragement to build their confidence
- Provision of clinical oversight
- Provision of administrative support to enable learning and development.

Strong networks within the community were critical to the initial success of the pilot, especially in rural and remote areas. The nurses were embedded in their communities and had strong relationships with members of the local community – both patients and professionals. This allowed the nurses to initially raise awareness of their role and highlight opportunities to access specialist care for Parkinson's disease.

Support from the nurse's employer and clarity about how the nurse will see patients with movement disorders has been key for the success of the nurses that remain actively engaged with the pilot. The nurses still actively engaged with the pilot have had strong support from their employer and managers to participate in the pilot including completing all the required education and training. They have also had clarity about how they would see and treat patients with movement disorders as part of their role.

Challenges faced and how they were overcome

Challenges with practical support from operational managers and employers of nurses was a significant challenge for the WNSW PHN model. Around twenty Registered Nurses responded to the initial expression of interest for the pilot, but some were not able to progress an application due to hesitation from their operational managers.

The PHN shared that many managers were supportive of nurses upskilling for movement disorders but were of the view that nurses did not have time to participate in training or education in addition to their existing duties or did not have the back-fill capacity to support their involvement.

As a result of these challenges, many of the nurses were unable to complete required training and clinical placements and some are no longer actively engaged with the pilot.

A nurse who remains in the pilot reflected:

• "It's often hard to see how I can use my new skills in this role. I've already got so much to do, and there's never a spare moment. How am I supposed to find the time?"

The COVID-19 pandemic and natural disasters in the region impacted the workload and priorities of the participating nurses. Many of the nurses were re-directed to COVID-19 response roles in their health service such as supporting the vaccination roll-out and testing for COVID-19. The impact of COVID-19 on staff shortages within LHDs saw some nurses redeployed to other positions.

Many of the nurses also experienced significant disruption to their personal and professional lives from droughts, mouse plagues and floods that affected the region.

These disruptions impacted the implementation of the pilot and delayed the delivery of planned activities including clinical placements. The PHN reflected these disruptions may also have contributed to nurses feeling burnt out and ceasing to engage in the pilot.

Many nurses found it difficult to incorporate the additional demands of movement disorder care into their existing role. All nurses under the WNSW PHN pilot model were employed in an existing nursing role that had ongoing demands and requirements. The nurses that remained in the pilot in September 2023 have worked with their employer and manager to carve out time to provide specialised care to people with movement disorders. PHN stakeholders reflected that nurses who exited the pilot tended to report they had a lack of clarity around how they would fit their new responsibilities on top of their existing role. Many of these nurses did not feel they had the capacity or organisational support to provide additional, specialised care to people with movement disorders.

Western Victoria PHN

Western Victoria PHN's pilot model focuses on building local specialist knowledge and providing care coordination to people living with movement disorders. The pilot model supports four movement disorder nurse specialists embedded within the three tertiary health services and one community health service located in Horsham, Warracknabeal, Stawell and Warrnambool. Each site developed its own model of care, specific to the needs of the local community, and were integrated into existing referral pathways at each of the sites. The nurses had no previous movement disorder expertise and were provided with access to professional development opportunities and mentoring support. The pilot initially focused on support for people living with Parkinson's disease. The nurses now see people with a range of movement disorders although Parkinson's disease remains the most prevalent.


Key features of the pilot model and progress

The WV PHN model included education and training initiatives, four unique models of care in local communities, and coordination support from the PHN. Progress to date against each key feature is outlined below.

- A movement disorder nurse specialist is working at four different services across the region.
- Nurses are based in an outpatient setting and undertaking a range of activities including completing assessments, providing care, support and information to patients and their carers and providing education to other healthcare professionals.
- The nurses are completing a range of education and training activities and meet monthly with Fight Parkinson's (formerly Parkinson's Victoria) for professional clinical support.

Model of care

Each site focused on a nurse-led interdisciplinary model of care. The model embedded a movement disorder nurse specialist in each health service, with access to a multidisciplinary team to provide outreach to patients in primary, acute and aged care settings. The model of care was unique to each of the four health services engaged in the pilot.

All the nurses were employed by a state-funded health service:

- Wimmera Health Care Group (Horsham) (part of Grampians Health) working across the community health service, hospital service and aged care service.
- Grampians Community Health (Stawell) as part of the community health nursing team.
- South West Health Care (Warrnambool) working as part of the community health team.
- Rural Northwest Health Care (Warracknabeal) as part of the community health team that includes allied health, district nursing and health promotion. The nurse also sees patients across the care continuum from community through to urgent care, acute, and residential aged care.

The nurses were all based in an outpatient setting and spend the majority of their time in the community providing direct care to patients and carers. Each of the models are slightly different as they have been designed to meet the needs of their communities and build on the existing services available.

- Across all models, the nurses undertake the following activities:
- Completing assessments for movement disorders.
- Providing care, support and information to patients and their carers.
- Working with medical specialists, including neurologists, in the area.
- Attending Parkinson's disease support groups.
- Providing education and training to other healthcare professionals.

Progress: The four pilot nurses each designed tailored models of care for their communities, established their own nurse clinics, and saw patients. Nurses are supported by the PHN, Fight Parkinson's and the existing movement disorder nurse in Goulburn Valley Health.

Details of the four nurses were included on HealthPathways (an online clinical and referral information portal for primary care clinicians) to assist care providers in the region to refer patients to the nurses.

Some nurses reflected they would have appreciated greater initial guidance and support from the PHN and other stakeholders to help design their model of care. Nurses noted designing and establishing a new service model required specialised skills they did not necessarily have.

Education and training | Professional development and supervision

Nurses were provided opportunities for professional development and supervision. A multidisciplinary team from Fight Parkinson's (formerly Parkinson's Victoria) provided ongoing support, clinical supervision, access to peer networks, education and information products about Parkinson's disease and other movement disorders to the nurses across the pilot. The nurses were also provided other professional development opportunities to expand their knowledge and skills.

Progress: Fight Parkinson's delivered a mentoring program to the pilot nurses throughout the entire duration of the pilot, offering regular clinical guidance and support. This included fortnightly education and support sessions.

All four of the recruited nurses completed the Parkinson's Care unit delivered by the Australian College of Nursing.

Almost all nurses have completed their formal education and training activities, including inperson and online components and clinical placements. One nurse has not yet completed onthe-job training.

Education and training | Collaboration and engagement with other nurses and practitioners

Nurses were able to participate in an online community of practice. An online community of practice involving the pilot nurses and Fight Parkinson's practitioners was established and is intended to support the nurses and improve their skills and knowledge. The purpose of the forum was to provide the most up-to-date information and support the nurses through a collegiate network.

Progress: The community of practice was established on Basecamp, a cloud based discussion communication tool. The PHN noted there was limited use of the platform with nurses communicating organically via telephone or email instead.

Practitioners including the pilot nurses collaborated and learnt via online symposiums known as Enhanced Community Health Outcomes (ECHO). ECHO collaboration enabled practitioners to join online symposiums to hear education materials and present case studies. This ensured nurses living and working in rural and remote areas, including the pilot nurses, had access to real-time and upto-date practical information for supporting patients living with movement disorders. **Progress:** ECHO sessions continued over the course of the pilot, with participation from all WV PHN nurses. Invitations were also extended to other PHN pilot nurses and staff, and local practitioners in the PHN region.

The ECHO methodology focuses on engaging participants with peers to provide the opportunity to share, guide and give feedback. It is a relaxed and interactive format that was well received by participants.

PHN management of the pilot

WV PHN managed the contracts for each of the four health services involved in the pilot, as well as the contract with Fight Parkinson's to deliver professional development activities and support. The PHN provided coordination to all parties, input to health services regarding the implementation of models of care and strengthened relationships with the health services in the process.

The management of the PHN model transferred in late 2022 when the original PHN contact person, who had been with the pilot since inception, left the PHN and moved to a new role. The transfer was smooth and managed effectively by the PHN.

During the pilot, two nurses left their movement disorder nurse specialist roles. The PHN worked with the nurses and the service delivery organisations to understand the reasons for departure, and to support these nurses to return. Eventually the two nurses switched locations and employers – the nurses, PHN and service delivery organisations all noted this delivered a positive outcome, maintaining service delivery across the two sites and ensuring the nurses continued to build their knowledge and skills.

Achievements against outcomes

The four nurses delivered care and support for patients living with movement disorders in rural and remote Western Victoria.

Patient-level outcomes

The pilot is providing support to 145 patients across the four sites. Not all nurses have the same caseload – one nurse had challenges raising awareness about the service and generating referrals. This nurse still has a lower caseload than the other nurses but has invested time and effort into building referral pathways and now supports a number of patients with movement disorders in the region.

There are indications that the pilot contributed to improved patient outcomes for some people living with movement disorders. During engagement with people from the PHN region, patients and carers said they had benefited from the support and care delivered by the four nurses, including through building knowledge about Parkinson's disease, providing advice on effective management of symptoms, coordinating care, and supporting patients and carers to access services they needed. Quality of life for patients in WV PHN was maintained during the pilot (average score at baseline 0.57, average score at follow-up 0.56).

There were more skilled movement disorder nurse specialists in the region, contributing to increased access to specialised care. Prior to the pilot, there were no movement disorder nurse specialists in Western Victoria. The implementation of the pilot helped to address a critical service gap in the region and contributed to increased patient access to this specialised care. All local Parkinson's disease support groups were advised of the new services at each of the four sites.

Nurse-level outcomes

Nurses built their confidence in delivering specialist care to people with movement disorders. PHN representatives reported they observed increased confidence amongst the pilot nurses, including confidence to coordinate patient care and connect patients to the appropriate services they needed. During visits to the PHN regions the nurses also said they grew in confidence with many noting they felt they had improved their skills and knowledge over the course of the pilot.

There were indications the pilot nurses began to see more complex cases and leveraged their learning, including from the Parkinson's Care post-graduate unit and the mentoring program delivered by Fight Parkinson's, to support these patients. Nurses particularly valued the clinical leadership, guidance and mentorship from Fight Parkinson's, saying they felt they could turn to Fight Parkinson's at any time for advice and to troubleshoot issues.

Reflecting on the education and training that was provided, one of the nurses said: "Have I seen my skills grow? Of course – when I think back to where I was then and where I am now...it's just night and day. I'm a different practitioner. I'm moving into advanced practice nursing."

Total nurses recruited into the pilot	4
Total nurses actively engaged in the pilot	3
Total nurses that have completed online training	4
Total nurses that have completed on-the-job training	3
Total nurses that have completed formal accreditation	4
Total nurses that have completed in-person training	4
Total nurses that have received formal mentorship	4

Table 28 | Overview of pilot nurse recruitment and training

System-level outcomes

The pilot likely contributed to greater collaboration and communication across the system, including between the nurses participating in the pilot, general practice, and with neurologists within the region. In addition, the three nurses based in hospital settings reported enhanced collaboration with allied health professionals, and increased engagement in multidisciplinary team care. This collaboration increased over the course of the pilot as the expertise and confidence of each nurse grew.

Enablers for success

Nurses leveraged existing processes, clinical governance and referral pathways of their health services in which they were based. The pilot models of care were integrated into existing health service models. As a result of working in existing, larger, multidisciplinary health services, the nurses were able to take advantage of existing clinical governance mechanisms. This option was not available to nurses in some other PHNs who instead were required to develop new clinical governance structures.

The nurses' placement in existing health services also benefited from connection to existing referral pathways such as through hospital-based allied health. This likely contributed to greater efficiencies in the set-up and implementation of the pilot models. Note that not all nurses in the WV PHN model were able to benefit from existing referral pathways. The nurse working in a community health service reported they found it challenging to develop referral pathways with tertiary health services as they did not have these existing, collegiate relationships.

Embedding nurses within tertiary health services provided three of the four pilot nurses with the authority to deliver pilot services in acute care settings. These nurses were able to occasionally see patients in inpatient units and provide support and education to hospital staff on appropriate care for people living with Parkinson's disease.

The PHN highlighted the pilot nurse working in a community health service did not have the same authority. The nurse could not easily enter the local hospital to see patients when needed but was developing increased connections with local health services.

Collaboration with Fight Parkinson's was a key enabler to the pilot's ongoing success. The involvement of the State-wide Health Information and Education team at Fight Parkinson's in the pilot contributed significantly to:

- Building the confidence of pilot nurses.
- Improving the clinical knowledge and skills of the pilot nurses (through clinical mentorship).
- Iterating and improving the implementation of the pilot models of care in each service.

Fight Parkinson's provided nurses with clinical leadership, mentoring and ongoing support, and also supported content for the ECHO series of seminars.

Challenges faced and how they were overcome

There were initial challenges with recruitment of the nurses. There was a limited response to initial advertisements to recruit nurses into the pilot. Many of the nurses that were eventually recruited into the role were specifically targeted, given their previous experience at the health services.

The pilot nurses faced challenges attempting to engage with some healthcare professionals. All four nurses reported they struggled to connect with general practice, limiting referral pathways and potential shared care arrangements. Some of the pilot nurses also reported facing challenges in engaging others within the health services in which they operated.

COVID-19 impacted service delivery to varying extents at the four health services. The most significant challenge faced by nurses as a result of COVID-19 was the inability to undertake face-to-face assessments and home visits during COVID-19 outbreaks and lockdowns. In addition, at South West Healthcare (Warrnambool), the impact of COVID-19 in the local community required the health service to redirect the pilot nurse to the role of managing their COVID-19 remote patient monitoring service. This significantly impacted initial pilot service delivery in this community, with no services being delivered between January and April 2022, reducing the cost by 30 per cent in 2021-22.

Nurses faced challenges when establishing their tailored models of care in each service. Without a prescribed model of care to work towards and with flexibility to develop tailored models of care for their regions, the nurses needed greater guidance at the beginning of the pilot. Representatives from the PHN noted a more focussed approach to professional development and support in the early stages of the pilot may have assisted nurses to establish their care models more rapidly. The PHN also suggested more consideration of clinical placements in established services may have assisted the nurses in the initial phases of the pilot.

The nurse at South West Health Care (Warrnambool) has recently moved on to another position. Due to the anticipated difficulty recruiting to the role for the remainder of the pilot, the role has not been filled. There are ongoing discussions with the service to identify options for how the role could continue.

When the pilot nurses initially established their models of care, some felt unsure of how to best set up their clinics. They subsequently were able to draw on support from the State-wide Health Information and Education team at Fight Parkinson's for guidance and mentorship.

Appendix B Detailed key evaluation questions

This section presents detailed key evaluation questions that guided the evaluation.

Table 29 presents detailed evaluation questions that guided data collection and analysis across the evaluation, including sub-questions and research questions.

Overall evaluation question: What are the most appropriate and evidence-based models for improving access to specialist care and quality of life for people living with neurological conditions including movement disorders in regional, rural and remote locations?

Table 29	Detailed	key ev	aluation	questions
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Key evaluation questions	Sub-questions	Research questions
KEQ 1 What are the movement disorder nurse specialist pilot models and how well have they been designed and delivered across PHNs?	1.1 What are the key features of each PHN pilot models?	 1.1.1 What is the scope, targets / goals, implementation plan, monitoring and measurement incorporated into the design of the pilot models? 1.1.2 How do each of the pilot models align with existing evidence and best practice?
KEQ 1 What are the movement disorder nurse specialist pilot models and how well have they been designed and delivered across PHNs?	1.2 How well have the pilot models been designed by PHNs to address regional needs and build on / integrate with existing services and programs?	 1.2.1 What was / is the plan for implementation? How were the pilots implemented in practice? 1.2.2 What is the expected geographical spread of services? Are there gaps in the availability of services?
KEQ 1 What are the movement disorder nurse specialist pilot models and	1.3 How well have the pilot models been delivered by PHNs to address regional needs?	 1.3.1 How effectively have the pilot models been implemented relative to their design? 1.3.2 What are the strengths, weaknesses, barriers and enablers required for implementation from the perspective of PHNs?

Key evaluation questions	Sub-questions	Research questions
how well have they been designed and delivered across PHNs?		 1.3.3 Are PHNs and commissioned service providers (where appropriate) adequately equipped in terms of capability for implementation?
KEQ 2 How do the pilot models impact on access to specialised nursing care and quality of life for people living with neurological conditions including movement disorders?	2.1 Do those living with neurological conditions, including movement disorders, report improved experience of care quality and access?	 2.1.1 How many people accessed the service? How does this vary across regional and rural settings? 2.1.2 Are patients satisfied with the quality of services they receive? 2.1.3 What is the impact of service delivery on clinical outcomes? 2.1.4 What is the impact of service delivery on quality of life? 2.1.5 Are patients accessing services better able to manage other complex chronic needs?
KEQ 2 How do the pilot models impact on access to specialised nursing care and quality of life for people living with neurological conditions including movement disorders?	2.2 What is the experience of families and carers?	• 2.2.1 How are carers supported and what is their experience?
KEQ 2 How do the pilot models impact on access to specialised nursing care and quality of life for people living with neurological conditions including movement disorders?	2.3 What are the key barriers and enablers of quality specialist care?	• 2.3.1 What are the strengths, weaknesses, barriers and enablers required for effective implementation from the perspective of patients?

Key evaluation questions	Sub-questions	Research questions
KEQ 3 How do the pilot models impact the upskilling and experience of the nurse workforce to provide specialised care?	3.1 Do nurses participating in the pilot report upskilling, learning and enhanced professional development opportunities?	 3.1.1 What training and development opportunities have been made available? What were the target skills, knowledge, behaviours and outcomes? 3.1.2 What was the learning experience of participants? 3.1.3 Were key skills or knowledge gained / learned? 3.1.4 Were key skills, knowledge and behaviours applied to care, and how effectively? 3.1.6 Are nurses within the pilot models equipped to provide high quality specialised care? 3.1.7 What mentoring or support for career progression was provided?
KEQ 3 How do the pilot models impact the upskilling and experience of the nurse workforce to provide specialised care?	3.2 What are the key barriers and enablers for trends observed?	 3.2.1 How were the pilot models implemented in practice by nurses and / or commissioned service providers? 3.2.2 What are the strengths, weaknesses, barriers and enablers required for effective implementation from the perspective of nurses and / or commissioned service providers?
KEQ 4 How do the pilot models impact delivery of specialised care at the system level?	4.1 Do the pilot models contribute to enhancing the overall capacity and sustainability of the health system?	 4.1.1 How many nurses are available within each PHN region to provide specialised care? Is the supply of nurse capability appropriate relative to demand? 4.1.2 What do the pilot models indicate would be successful or effective for future workforce planning? 4.1.3 How effectively do the pilot models integrate with other health services and health professionals (e.g. General Practitioners, Aboriginal Health Workers, allied health professionals)?

Key evaluation questions	Sub-questions	Research questions
		 4.1.4 How (if at all) do the pilot models build the capability and capacity of other health services and health professionals to deliver specialised care? How effective is this capability and capacity building?¹¹³ 4.1.5 What is the impact on patient usage of other services (e.g. ED presentations, hospital admissions)?
KEQ 5	5.1 How have resources been used?	• 5.1.1 How are costs allocated within the pilot models?
How cost effective are the different		• 5.1.2 What is the comparative cost of different pilot design elements?
pilot models for Government,		 5.1.3 Is funding used appropriately and effectively by PHNs?
providers and patients?		
KEQ 5	5.2 How cost effective are the pilot	• 5.2.1 What are the costs to government, providers and patients?
How cost effective are the different	models?	 5.2.2 What is the average cost per service provided?
pilot models for Government, providers and patients?		 5.2.3 What outcomes are achieved relative to costs, as measured by Quality Adjusted Life Years (QALYs)?
		• 5.2.4 What is the likely cost or impact of discontinuing any of the pilot models?
KEQ 6	6.1 What lessons have been learned	6.1.1 What lessons have been learned by PHNs?
What lessons have been learned	and shared by PHNs?	6.1.2 What mechanisms are in place to facilitate sharing of
through the pilot that could		information? How effective have these been, and can they be
support scalability and further roll		enhanced?
out?		

¹¹³ Note that this question may be more appropriate and applicable for some PHN models than others.

Key evaluation questions	Sub-questions	Research questions
KEQ 6 What lessons have been learned through the pilot that could support scalability and further roll out?	6.2 Are any of the pilot models suitable for further rollout?	 6.2.3 What features of the pilot models are effective for whom and under what circumstances? 6.2.4 Are any of the pilot models scalable? 6.2.5 How appropriate are the pilot models, or features of the pilot models, for other PHNs? (What works for whom and under what circumstances?) 6.2.6 What is the appropriate funding model for broader roll-out?
KEQ 7 What evidence-based models of care to support those living with neurological conditions including movement disorders could be considered in future in regional, rural and remote areas?	7.1 What is the future demand for specialist care in regional, rural and remote areas?	 7.1.1 What is the critical demand, prevalence or contextual threshold for dedicated specialist care?
KEQ 7 What evidence-based models of care to support those living with neurological conditions including movement disorders could be considered in future in regional, rural and remote areas?	7.2 What evidence of appropriateness and effectiveness is available on each of the pilot models?	 7.2.1 Has overall system capacity for providing specialist care for people with neurological disorders including movement disorders increased? 7.2.2 Has overall patient experience increased? 7.2.3 Is there evidence to support an ongoing PHN-led response?
KEQ 7 What evidence-based models of care to support those living with	7.3. What other evidence-based models are available to support those living with neurological	 7.3.1 What are the features of other effective models of care in Australia and comparable international health systems?

Key evaluation questions	Sub-questions	Research questions
neurological conditions including	conditions including movement	
movement disorders could be	disorders?	
considered in future in regional,		
rural and remote areas?		

Appendix C Detailed description of data collection and analysis

This section presents further detailed information on data collection and analysis.

C.1 Data collected through the evaluation

Table 30 presents additional information on data sources and data collected through the evaluation.

Data source	Detail
Nurse survey	The nurse survey sought the following information:
	Demographic information including about nursing experience.
	 Information about the activities and training completed.
	 Information about nurse skills and capabilities.
	 Assessment of advanced nursing practice using the Australian Advanced Practice Nursing Self-Appraisal Tool.
	Satisfaction and support for the program.
	The survey was sent to all participating nurses. In 2022, nine nurses completed the survey. One other nurse partially completed the survey. In 2023, five nurses completed the survey. One of the nurses only completed the survey in 2023, and the other four nurses completed the survey in 2022 and 2023.
Nurse colleague	The nurse colleague survey sought the following information.
survey	Demographic information.
	 Assessment of the nurse's capabilities including against the Australian Advanced Practice Nursing Self-Appraisal Tool.
	Barriers and enablers to success in the program.
	The survey was sent to the Primary Health Networks to distribute to nurse colleagues and line managers. In 2022, only one person completed the survey. In 2023, no one completed the survey.
Patient survey	The patient survey sought the following information.
	Information about patient condition.
	 Information about patients' ability to manage with their condition.
	Satisfaction and experience with the service.
	The survey was sent to all patients that had consented to participate in the pilot and had provided an email address. A number of other patients that

Table 30 | Further detailed information on data sources

Data source	Detail
	had consented to participate were called by the evaluation team and completed the survey over the phone. In 2022, 16 patients completed the survey. In 2023, seven patients completed the survey. Two patients completed the survey in 2023 only, the other five completed the survey in both 2022 and 2023.
Carer survey	The carer survey sought the following information
	Level of carer burden.
	Satisfaction with the service.
	The survey was sent to all carers that had consented to participate in the pilot and had provided email addresses. A number of other carers also completed the survey over the phone. In 2022, only five carers completed the survey. In 2023, only three carers completed the survey.
Patient outcomes data	Pilot nurses recruited patients to participate in the evaluation by seeking consent. For patients that provided consent, outcomes data was collected and provided to the evaluation team.
	The nurse collected outcomes data from patients and provided this data assigned to a unique patient ID, ensuring data was de-identified.
	The nurses collected outcomes at two time points.
	 The first occurred at or close to the initial interaction with the patient. the beginning of the nurse working with the patient.
	 The second was intended to occur annually (i.e. 12-months post initial assessment).
	 In reality, follow-up data was collected at different intervals. Some patients provided follow-up data earlier than 12-months due to the shortening of the evaluation. Other patients provided follow-up data much later due to the timing of appointments with the nurse.
	The patient outcomes dataset contained four key sets of questions:
	Patient characteristics.
	• Quality of life using the 36-item Short Form Survey (SF-36).
	Charlson Comorbidity Index.
	• Service use.
	102 patients responded to the outcomes dataset at both baseline and follow-up.
Service interaction data	The nurses collected unit record level data for every interaction they had with a patient that had provided consent to participate in the evaluation.
	The nurses recorded the time and place of the interaction, as well as the type of service provided.

Data source	Detail
	The service could be recorded as one of the following types of
	interactions.
	Assessment.
	• Treatment.
	Education.
	• Referral.
	• Other.
	The location of where the service interactions occurred could be recorded as:
	Patient's home.
	Disability supported accommodation.
	Via telehealth.
	In-person at a health service or clinic.
	There were 1,896 service interactions recorded from a total of 142 unique patients of a total of 541 patients that received care from the nurses. This included 105 service interactions and 31 patients from HNECC PHN, 171 service interactions and 25 patients from NT PHN, and 1,206 service interactions and 86 patients in WV PHN.
Administrative data from PHNs	Each PHN provided administrative data across three categories in calendar years 2022 and 2023.
	Category 1 Patient numbers. PHNs provided an estimate of the total number of patients who had received care and support from the nurse (across the entire pilot to date). Estimates were provided in April 2023 and September 2023.
	Category 2 Budget. PHNs provided an overview of total budget per calendar year, and breakdown of budget spending under four categories:
	Spending on workforce development.
	 Spending on developing the operating model.
	Spending on administrative cost.
	Spending on service delivery.
	Category 3 Nurse training . PHNs provided information on training provided to the nurses. The education and training activities were broken down into the following categories:
	Formal accreditation.
	Online learning.
	In-person learning.
	On-job learning.

Data source	Detail
	Mentoring.

C.2 Further detail on data analysis

Before the data was analysed, it was collated and cleaned. The following data cleaning activities were completed.

- Removed all records with missing patient IDs.
- Removed duplicate records if entries were identical.
- Removed patients where nurses had mistakenly recorded data but formal consent was not recorded.
- Removed participants who only had a follow-up survey response recorded.

With the desire to preserve as much information as possible, rows with a small number of missing values or errors were kept. These records were only omitted in calculations if the relevant variable had missing data.

For most of the analysis, only participants who completed both surveys were included in the analysis, where the analysis was considering changes over time.

Table 31 presents further detail on the data analysis process, including summary statistics of patient survey responses and service interactions.

Data source	Further detail and analysis process
Quality of life scores (SF-36)	The evaluation used the standard SF-6D to translate responses to the SF- 36 survey to scores for six quality of life domain and a single health- related quality of life score.
	These are the six domains that help to understand a patient's physical and mental health status:
	• Physical functioning . This domain assesses the degree to which health impacts physical activities like bathing, dressing, walking, carrying groceries, etc.
	• Role limitations. This domain measures the impact of both physical and emotional health on roles such as work, daily activities, and other usual roles.
	• Social functioning. This domain records the extent to which the health problems impact the ability to participate in social activities with others.

Table 31 | Further detail on the data analysis process

Data source	Further detail and analysis process					
	 Pain. This domain assesses the level of bodily pain and how much it interferes with normal work including both outside the home and housework. 					
	• Mental health. This domain assesses the overall mental health and emotional wellbeing of an individual that encompasses aspects such as nervousness, depression, calmness and happiness.					
	 Vitality. This domain measures energy and fatigue levels of an individual. 					
	This translation uses a validated algorithm to calculate health states based on the US population. There was no equivalent validated algorithm for the Australian population available to the evaluation team. However, studies ¹¹⁴ suggest the Australian population's health preferences are closely aligned with the US.					
	The quality-of-life score produced from each patient's survey is scaled from 0, indicating death, and 1, indicating full health. A higher score indicates a better health-related quality of life. The interpretation of a clinically significant improvement is subject on the context and the specific population being studied.					
Charlson Comorbidity Index	The Charlson Comorbidity Index (CCI) is a tool used to assess the burden of comorbidities on a patient. CCI is generally used to predict the 10-year mortality risk for a patient with chronic disease or diseases.					
	The CCI assigns a score to each comorbid condition based on its potential impact on mortality. The comorbidities included in the index are weighted according to their association with ten-year mortality risk. A higher weight of a specific comorbidity indicates a higher survival risk (e.g. metastatic solid tumour has a weight of 6, whereas dementia has a weight of 1). The total score is then calculated by summing the individual scores for each comorbidity present in a patient.					
	The conventional CCI contains 19 categories of comorbidity in convention. ¹¹⁵ The evaluation survey omitted three categories to reduce the burden on patients: chronic obstructive pulmonary disease, Leukemia and Lymphoma.					
	Overall, the survey asks the patients 13 questions across 16 categories:					
	Myocardial infraction.					
	Congestive heart failure.					

¹¹⁴ Butterworth, P., & Crosier, T. (2004). The validity of the SF-36 in an Australian National Household Survey: demonstrating the applicability of the Household Income and Labour Dynamics in Australia (HILDA) Survey to examination of health inequalities. BMC public health, 4, 1-11.

¹¹⁵ <u>https://www.mdcalc.com/calc/3917/charlson-comorbidity-index-cci#evidence</u>

Data source	Further detail and analysis process
	Peripheral vascular disease.
	Cerebrovascular diseases.
	• Dementia.
	Connective tissue disease (incl. rheumatologic disease).
	Peptic ulcer disease.
	Liver disease (3 categories).
	Diabetes (3 categories).
	Hemiplegia or paraplegia.
	Moderate to severe chronic kidney disease (i.e., renal disease).
	Solid tumour and cancer / malignancy (3 levels).
	• AIDS.
	The summed weighted score provides a raw singular comorbidity score for each patient, and it can transform into the 10-year survival probability with combination of calibrated parameter estimates. Due to the omitted categories, the raw overall score cannot be interpreted as a 10-year survival probability. However, it can be used as an indication of the level of comorbidities each patient is experiencing.

The total economic cost included in the evaluation is broken down into service use costs and the cost of providing services to each patient. Table 32 presents further detail on the cost-effective analysis.

Table 32 | Further detail on cost-effectiveness analysis

Category	Further detail
Service use costs	The service use costs are calculated by using the service use data provided by patients and units costs from a variety of sources. The costs are in 2020-21 dollars. As the same unit costs are used, the follow-up service use costs do not need to be deflated to 2020-21 dollars.
	The average cost per presentation at emergency department (non- admitted) is \$611 ¹¹⁶ . Generally, the average cost per patient admitted episode should be calculated using the price per admission and associated Diagnosis Related Group weights from the Independent Health and Aged Care Pricing Authority. However, the reason for patients being admitted to hospital was not available so this method could not be used. Instead, the average cost per patient day in hospital was calculated. The
	average cost per admitted patient day is based on the average cost per

¹¹⁶ Report on Government Services 2023, Part E Health, Chapter 12 Public Hospitals. Table 12A.53.

Category	Further detail
	admitted acute separation ¹¹⁷ , total patient days ¹¹⁸ and total separations ¹¹⁹ . The average length of stay for each patient in any hospital across Australia is three days based on dividing the total patient days by the total separations. Hence, knowing the implicit length of stays of each admitted acute separation cost, the average cost per admitted patient day is simply the cost divided by the length of stay, which is \$1,720.
Costs of providing services to patients	The average cost of providing services to each patient is based on both the total budget spending and the total patients that received services. The total budget spent is the sum of the budget amount in 2022 and the portion of 2023 budget spent to date in the pilot. The average cost of providing services to each patient is the total budget spending divided by the total number of patients receiving care.
Calculating incremental cost- effectiveness ratios	Incremental cost-effectiveness ratios (ICER) are calculated by dividing the incremental costs of the pilot by the incremental benefits. The incremental benefits are calculated by subtracting the average change in quality of life scores between baseline and follow-up for patients in the pilot (-0.01), to the weighted average change in quality of life scores from control groups from available published studies (0.024). This figure represents quality-adjusted life years gained. The incremental costs are calculated by subtracting the average cost per patient in the pilot by the average avoided cost per patient in the pilot. Usually, to calculate an ICER, the costs of providing a control would be subtracted. As there is no substitute for the MDNS pilot, the patients were receiving no service beforehand, no additional amount is subtracted.
Bootstrapping analysis to estimate uncertainty	Bootstrapping is used to estimate the uncertainty of these estimates. Bootstrapping involves modelling a new, large distribution of observations based on the sample data available. Bootstrapping was performed using R for 1,000 observations. Confidence intervals for the mean are based on these observations.

¹¹⁷ Report on Government Services 2023, Part E Health, Chapter 12 Public Hospitals. Table 12A.51.

¹¹⁸ AIHW, Admitted patient care 2020-21, Costs and funding tables. Table S7.2.

¹¹⁹ AIHW, Admitted patient care 2020-21, Costs and funding tables. Table 7.5.

Appendix D Comparison with results from other studies

This section provides more detail about the studies used in this evaluation as comparison.

Table 33 presents the full results from the studies used in the cost effectiveness analysis in Section 3.3.1 and Figure 24.

Study	Study description	Year of study	Country	Incremental cost (2020- 21 AUD) ¹²⁰	Incremental QALYs	ICER (cost per QALY gained)	Type of intervention
Study in Australia 2012 Economic evaluation of a fall's prevention exercise program among people with Parkinson's disease. ¹²¹	 The study aimed to evaluate the cost effectiveness of a 6-month minimally supervised exercise program for individuals aged 40 and over with Parkinson's disease. Economic analysis was performed using data from a randomised, controlled trial of 231 participants. The average cost for the exercise intervention was \$1,010 per participant. 	2012	Australia	\$1,947	0.005	\$389,412	Exercise therapy
Study in the UK 2016 Cost-utility analysis of deep brain stimulation	The study reports an economic evaluation of deep brain	2016	UK	\$18,737	0.020	\$913,983	Deep Brain Stimulation

Table 33 | Incremental costs, incremental QALYs and ICERS of studies of other interventions for people with Parkinson's disease

¹²⁰ The incremental costs have been translated from foreign currencies to Australian dollars using the average exchange rate for the relevant financial year of the study. The exchange rates have been taken from the Australian Tax Office's website. Accessed here: https://www.ato.gov.au/Rates/Foreign-exchange-rates/#Endoffinancialyearrates. The costs are then inflated to 2020-21 values using the Reserve Bank of Australia's inflation calculator, accessed here: https://www.rba.gov.au/calculator/

¹²¹ Farag, I., Sherrington, C., Hayes, A., Canning, C. G., Lord, S. R., Close, J. C., ... & Howard, K. (2016). Economic evaluation of a falls prevention exercise program among people with Parkinson's disease. Movement disorders, 31(1), 53-61.

Study	Study description	Year of study	Country	Incremental cost (2020- 21 AUD) ¹²⁰	Incremental QALYs	ICER (cost per QALY gained)	Type of intervention
surgery plus best medical therapy versus best medical therapy in patients with Parkinson's: Economic evaluation alongside the PD SURG trial. ¹²²	 stimulation for people with Parkinson's disease. The average cost for surgery at £19,069 was significantly higher than best medical therapy at £9,813 in the first year. 						
Study in the UK 2008 Economic evaluation of a Tai Ji Quan intervention to reduce falls in people with Parkinson disease. ¹²³	 The study conducted a cost effectiveness analysis of Tai Ji Quan as an intervention for reducing falls in patients with mild-to-moderate Parkinson's disease, using data from a 9- month trial to compare it with resistance training and stretching. Tai Ji Quan emerged as the most cost-effective intervention, costing an average of \$175 less 	2008	UK	\$234	0.11	\$2,130	Exercise therapy

¹²² McIntosh, E., Gray, A., Daniels, J., Gill, S., Ives, N., Jenkinson, C., ... & PD SURG Collaborators Group. (2016). Cost-utility analysis of deep brain stimulation surgery plus best medical therapy versus best medical therapy in patients with Parkinson's: Economic evaluation alongside the PD SURG trial. Movement Disorders, 31(8), 1173-1182.

¹²³ Li, F., & Harmer, P. (2015). Economic Evaluation of a Tai Ji Quan Intervention to Reduce Falls in People With Parkinson Disease, Oregon, 2008-2011. Preventing chronic disease, 12, E120. https://doi.org/10.5888/pcd12.140413

Study	Study description	Year of study	Country	Incremental cost (2020- 21 AUD) ¹²⁰	Incremental QALYs	ICER (cost per QALY gained)	Type of intervention
	per fall prevented compared to Stretching, and also led to a significant increase in QALY gained at a lower cost.						
Study in Norway 2008 Real life cost and quality of life associated with continuous intraduodenal levodopa infusion compared with oral treatment in Parkinson patients. ¹²⁴	 The study evaluated the costs and quality-of-life benefits of intraduodenal levodopa (IDL) for treating advanced-stage Parkinson's disease comparing it with conventional oral medication over a one-year period. Although IDL showed significant improvement in functional scores and was safe to use, it was substantially more expensive, costing NOK890,920 compared to NOK419,160 for conventional treatment, and only resulted in a 	2008	Norway	\$77,192	0.02	\$3,859,598	Medication

¹²⁴ Lundqvist, C., Beiske, A. G., Reiertsen, O., & Kristiansen, I. S. (2014). Real life cost and quality of life associated with continuous intraduodenal levodopa infusion compared with oral treatment in Parkinson patients. Journal of neurology, 261(12), 2438–2445. https://doi.org/10.1007/s00415-014-7515-4

Study	Study description	Year of study	Country	Incremental cost (2020- 21 AUD) ¹²⁰	Incremental QALYs	ICER (cost per QALY gained)	Type of intervention
	marginal QALY gain of 0.68 vs 0.63.						
Study in the UK 2015 Cost-effectiveness of the PDSAFE personalised physiotherapy intervention for fall prevention in Parkinson's: an economic evaluation alongside a randomised controlled trial. ¹²⁵	 PDSAFE is a training program aimed at preventing falls among people with Parkinson's disease. The PDSAFE intervention was associated with an incremental cost of £925 with QALY gain of 0.008 over a 6-month time horizon. 	2015	UK	\$2,067	0.03	\$68,907	Exercise therapy
Study in the Netherlands 2015 Economic evaluation of occupational therapy in Parkinson's	• The study aimed to assess the cost effectiveness of home-based occupational therapy that involved 191 patients and 180	2015	The Netherlands	-\$178	0.02	-\$8,922	Occupational therapy

¹²⁵ Xin, Y., Ashburn, A., Pickering, R.M. et al. Cost-effectiveness of the PDSAFE personalised physiotherapy intervention for fall prevention in Parkinson's: an economic evaluation alongside a randomised controlled trial. BMC Neurol 20, 295 (2020). https://doi.org/10.1186/s12883-020-01852-8

Study	Study description	Year of study	Country	Incremental cost (2020- 21 AUD) ¹²⁰	Incremental QALYs	ICER (cost per QALY gained)	Type of intervention
disease: a randomised controlled trial. ¹²⁶	 caregivers over a 6-month period. The costs were lower for the intervention group compared to the control group by €125 for patients and €29 for caregivers but were €122 higher for patient-caregiver pairs; these differences were not statistically significant. The intervention did not significantly affect total costs when compared to usual care. However, its cost-effectiveness was only found to be significant for caregivers, with a net monetary benefit of €866 at a €40,000 per QALY threshold. The analysis presents costs for both the patient and the caregiver. Only the patient costs 						

¹²⁶ Sturkenboom, I. H., Hendriks, J. C., Graff, M. J., Adang, E. M., Munneke, M., Nijhuis-van der Sanden, M. W., & Bloem, B. R. (2015). Economic evaluation of occupational therapy in Parkinson's disease: A randomized controlled trial. Movement disorders : official journal of the Movement Disorder Society, 30(8), 1059–1067. https://doi.org/10.1002/mds.26217

Study	Study description	Year of study	Country	Incremental cost (2020- 21 AUD) ¹²⁰	Incremental QALYs	ICER (cost per QALY gained)	Type of intervention
	are presented here to be consistent with the MDNS pilot.						
Study in the UK 2021 An exercise intervention to prevent falls in Parkinson.	 The study aimed to understand the impact of an exercise intervention for people with Parkinson's disease. When analysing the costs compared to regular care, the exercise therapy group had lower costs driven by reduced hospitalisations. 	2012	UK	-\$1,126	0.08	-\$14,069	Exercise therapy

Table 34 | Comparison between patients that remained in the MDNS pilot and in the 2016 study in Australia

Demographic	2016 comparative study in Australia ¹²⁷ : Intervention	2016 comparative study in Australia: Control	MDNS pilot
Age (years)	71.4	69.9	72.1
Female	31 per cent	34 per cent	43 per cent
Disease duration (years)	7.5	8.3	8.9

This study was of a falls prevention program for people with Parkinson's disease.

Table 35 | Comparison between patients that remained in the MDNS pilot and the 2015 study in the US

Demographic	2015 comparative study in the US ¹²⁸ : Intervention	2015 comparative study in the US: Control	MDNS pilot
Age (years)	76.9	77.99	72.1
Female	87 per cent	92 per cent	43 per cent
Disease duration (years)	NA (mild to moderate PD)	NA (mild to moderate PD)	8.9

This study was of Tai Ji Quan for people with Parkinson's disease.

Table 36	Comparison betw	ween patients that	remained in th	e MDNS pil	ot and in the	2016 study
in the UK						

Demographic	2016 comparative study in the UK ¹²⁹ : Intervention	MDNS pilot
Age (years)	N/A – this study did not provide demographic information	72.1

¹²⁷ Farag, I., Sherrington, C., Hayes, A., Canning, C. G., Lord, S. R., Close, J. C., Fung, V. S., & Howard, K. (2016). Economic evaluation of a falls prevention exercise program among people With Parkinson's disease. Movement disorders : official journal of the Movement Disorder Society, 31(1), 53–61. https://doi.org/10.1002/mds.26420

¹²⁸ Li, F., & Harmer, P. (2015). Economic Evaluation of a Tai Ji Quan Intervention to Reduce Falls in People With Parkinson Disease, Oregon, 2008-2011. Preventing chronic disease, 12, E120. https://doi.org/10.5888/pcd12.140413

¹²⁹ McIntosh, E., Gray, A., Daniels, J., Gill, S., Ives, N., Jenkinson, C., Mitchell, R., Pall, H., Patel, S., Quinn, N., Rick, C., Wheatley, K., Williams, A., & PD SURG Collaborators Group (2016). Cost-utility analysis of deep brain stimulation surgery plus best medical therapy versus best

Demographic	2016 comparative study in the UK ¹²⁹ : Intervention	MDNS pilot
Female	N/A – this study did not provide demographic information	43 per cent
Disease duration (years)	N/A – this study did not provide demographic information	8.9

This study was of deep brain stimulation for people with Parkinson's disease.

Table 37 Comparison between patients that remained in the MDNS pilot and in th	e 2014 study
in Norway	

Demographic	2014 Comparative Study in Norway ¹³⁰ (demographic details for both intervention and control group)	MDNS pilot
Age (years)	64	72.1
Female	50 per cent	43 per cent
Disease duration (years)	10	8.9

This study was of the continuous intraduodenal administration of levodopa, an advanced medical therapy, for people with Parkinson's disease.

Table 38	Comparison between patients that remained i	n the MDNS	pilot and in the	2020 study
in the UK				

Demographic	2020 Comparative Study in the UK ¹³¹ : Intervention	2020 Comparative Study in the UK: Control	MDNS pilot
Age (years)	71	73	72.1
Female	NA	NA	43 per cent

medical therapy in patients with Parkinson's: Economic evaluation alongside the PD SURG trial. Movement disorders : official journal of the Movement Disorder Society, 31(8), 1173–1182. https://doi.org/10.1002/mds.26423

¹³⁰ Lundqvist, C., Beiske, A. G., Reiertsen, O., & Kristiansen, I. S. (2014). Real life cost and quality of life associated with continuous intraduodenal levodopa infusion compared with oral treatment in Parkinson patients. Journal of neurology, 261(12), 2438–2445. https://doi.org/10.1007/s00415-014-7515-4

¹³¹

Demographic	2020 Comparative Study in the UK ¹³¹ : Intervention	2020 Comparative Study in the UK: Control	MDNS pilot
Disease duration (years)	8	8	8.9

This study was of a physiotherapy intervention for people with Parkinson's disease.

Table 39 C	omparison	between p	atients that	remained i	in the MD	NS pilot	and in	the 2015	study
in the Neth	erlands								

Demographic	2015 Comparative Study in the Netherlands ¹³² : Intervention (patients)	2015 Comparative Study in the Netherlands: Control (patients)	MDNS pilot
Age (years)	71	70	72.1
Female	22 per cent	59 per cent	43 per cent
Disease duration (years)	6	6	8.9

This study analysed the impact of providing occupational therapy to people with Parkinson's disease.

Table 40 Comparison between patients that remained in the MDNS pilot and in the 201	12 study
in the UK	

Demographic	2012 Comparative Study in the UK ¹³³ (demographic details for both intervention and control groups)	MDNS pilot
Age (years)	71	72.1
Female	52 per cent	43 per cent

¹³² Sturkenboom, I. H., Hendriks, J. C., Graff, M. J., Adang, E. M., Munneke, M., Nijhuis-van der Sanden, M. W., & Bloem, B. R. (2015). Economic evaluation of occupational therapy in Parkinson's disease: A randomized controlled trial. Movement disorders : official journal of the Movement Disorder Society, 30(8), 1059–1067. https://doi.org/10.1002/mds.26217

¹³³ Fletcher, E., Goodwin, V.A., Richards, S.H. et al. An exercise intervention to prevent falls in Parkinson's: an economic evaluation. BMC Health Serv Res 12, 426 (2012). https://doi.org/10.1186/1472-6963-12-426

Demographic	2012 Comparative Study in the UK ¹³³ (demographic details for both intervention and control groups)	MDNS pilot
Disease duration (years)	8.8	8.9



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