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University

School of Rural Medicine

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# Western New South Wales Primary Health Network Movement Disorder Nurse Specialist Pilot Program

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## Note

This final report is to be read in conjunction with the following documents:

Rossiter, R. (2021). *Designing a safe and high-quality model of nurse-led care for people living with Movement Disorders in rural and remote New South Wales* [Commissioned by Western NSW Primary Health Network]. Charles Sturt University.  
<https://researchoutput.csu.edu.au/en/persons/rrossi01csueduau>

Rossiter, R. (2023). *Western NSW Primary Health Network Movement Disorder Nurse Specialist Pilot: Realist Evaluation*. Charles Sturt University.

# Executive Summary

## Background

The Western NSW Primary Healthcare Network Movement Disorder Nurse Specialist pilot program commenced in late in 2019. In the almost 5 years since this pilot program was commenced, multiple factors have impacted upon the program, these have been reported in detail in the Realist Evaluation completed in August, 2023. This report is designed to add to the 2023 Realist Evaluation and includes further data collected from two sites where the MDNS role remains active.

## Qualitative Descriptive Study

The aim of this study was to undertake a further examination of two Movement Disorder Nurse Specialist (MDNS) positions established as part of the larger Movement Disorder Nurse Specialist Pilot project that commenced in late 2019. The study utilised an over-arching case-study design. Two sites where the MDNS role remains active were sampled. A qualitative descriptive research approach was taken to data collection, analysis and interpretation of the data.

## Interpreting the Findings

In the case study site (Grenfell) with a population of 3,649 located in an Outer Regional Area (MMM5), the MDNS has one-day/week allocated to the role. This nurse remains active and has developed creative approaches to utilising the knowledge and skills learned during the education component of the MDNS Pilot. In addition to conducting individual assessments and referrals, the nurse conducts two group programs, one a Men's Exercise Group and the other a Dance Wise Exercise group. Participants from both groups emphasised the importance of being part of locally delivered group activities. Benefits derived from getting out of the house, socialising, and sharing experiences with other members of the community, some of whom have Parkinson's disease while the remainder are living with a range of diverse chronic health challenges limiting their mobility and physical functioning. They further identified the importance they attached to nurse's professional expertise combined with her status as a trusted 'local'. These factors are consistent with rurally focused research that has identified the importance of activities that are located close to home, accessible for those with decreased mobility, suited to the person's interests, health conditions and budget.

In the second case study site (Dubbo) with a population of 71,666 located in an Inner Regional Area (MMM3), the MDNS role incorporates a range of activities, engaging with both clinicians and people with Parkinson's disease and their carers in inpatient, outpatient and community settings. Although this location has a major referral facility for acute care services, access to specialist neurologists is extremely limited, as is access to allied health professionals. Participants identified the MDNS role as invaluable, while noting concerns about sustainability, ongoing funding and capacity to meet the needs of the region.

Both nurses described the significant challenges encountered in utilising the knowledge and skills they had obtained from their involvement in the MDNS Pilot program and identified organisational factors that contributed to these challenges.

## Reflections

The data from this small study are consistent with well-documented inequities in access to specialist neurological services experienced by rurally located people with Parkinson's disease and their carers and the need to expand the neurology support workforce.

Challenges arising from poorly integrated care and organisational factors, including roles not embedded as part of the ongoing staffing complement, insecure funding, lack of succession planning and systems issues were identified for both sites.

The MDNS Pilot program provided clinically relevant education designed to enhance the delivery of quality healthcare for people with movement disorders. However, unless these nurses are able to utilise their knowledge and skills and work to their full scope of practice, the provision of focused education programs is unlikely to deliver the anticipated improvements in healthcare delivery.

While there are 'pockets of excellence' in a few regional areas, the organisational and funding barriers to state-wide change serve to reinforce the need for a nationally coordinated approach to Parkinson's disease in Australia.

The 2022 World Health Organisation Technical Brief and the recently announced 2024 funding to the National Parkinson's Alliance to develop Australia's First National Parkinson's Action Plan both point to the importance of upskilling primary health care clinicians as a key action to improve access to evidence-based care both in metropolitan and regional, rural and remote Australia.

Given that Parkinson's disease is a progressive neurodegenerative condition, integrated care across the continuum of the disease trajectory is essential. This must include access to timely diagnosis, management with both pharmacological and non-pharmacological treatments, rehabilitation services and palliative care services.

## Recommendations

These recommendations are informed by the findings from this additional study, the 2023 Realist Evaluation, relevant research, the World Health Organisation Technical Brief and the activity underway currently to develop Australia's First National Parkinson's Action Plan.

- Given the imperative to upskill primary health care clinicians in recognizing, responding too and managing Parkinson's disease and other movement disorders, consideration should be given to consulting with the Australian Primary Healthcare Nurses Association (APNA) to develop a Parkinson's Disease/Movement Disorder on-line training module.

- This organisation has a nation-wide reach and is experienced in delivering on-line training for primary health care nurses .
- This would be an invaluable addition to the building capacity programs delivered by APNA and ensure primary healthcare focused care for people with Parkinson’s disease is accessible to nurses nationally.
- For Primary Healthcare Networks covering regional, rural and remote areas of Australia, it is recommended that attention be given to:
  - Facilitating access to education programs for primary healthcare nurses and allied health professionals to ensure more extensive knowledge of movement disorders
  - Developing health pathways to provide ready access to up-to-date evidence based information for general practitioners
  - Recognise the isolation experienced by individual clinicians where services for people with conditions such as Parkinson’s disease are delivered by one person
  - Ensure contingency and succession plans are in place to enable continuity of service delivery



# Background

The Western NSW Primary Healthcare Network Movement Disorder Nurse Specialist pilot program commenced in late in 2019 with the underlying premise that:

*Building registered nurse capacity (i.e., knowledge, skills, and competence specific to movement disorders) will result in improved care for people living with a movement disorder to care for people in underserved rural and regional settings [1].*

In the almost 5 years since this pilot program was commenced, multiple factors have impacted upon the program, these have been reported in detail in the Realist Evaluation completed in August, 2023 [1].

The graphic below is provided to orient the reader to the different phases of this project.

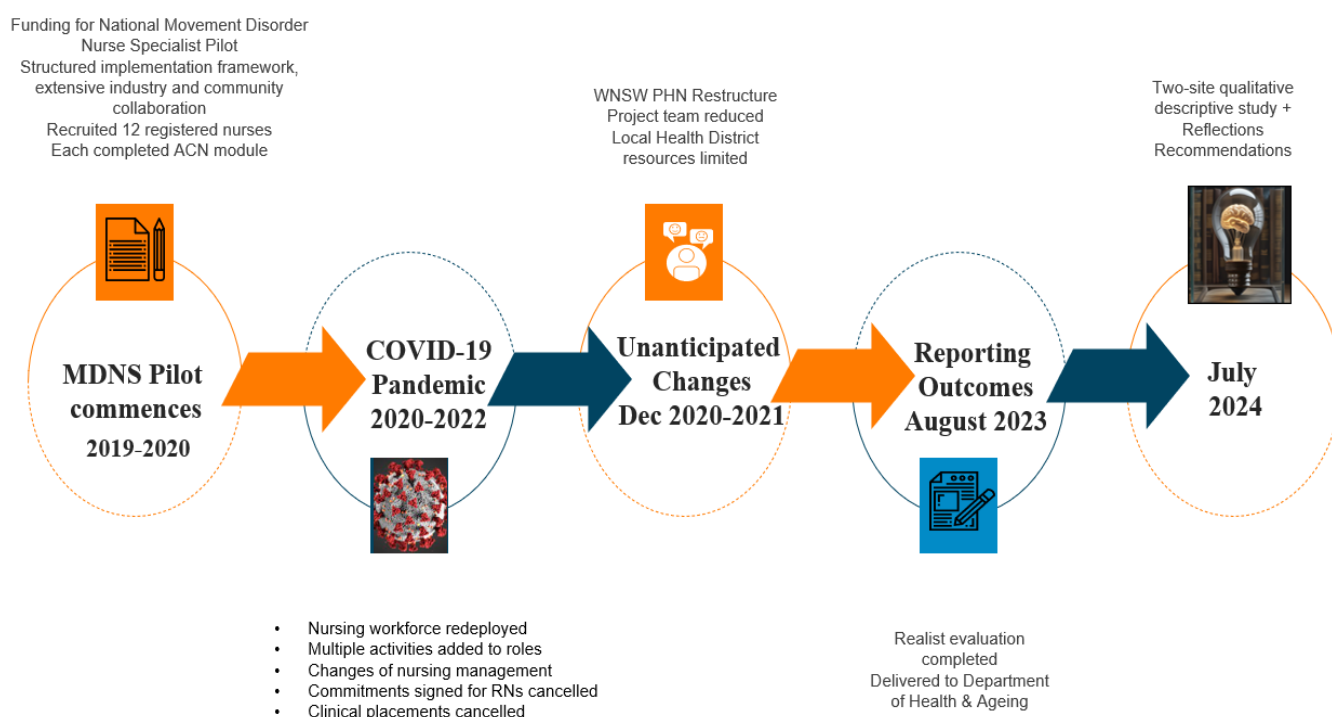


Figure 1: Overview of MDNS pilot timeline

This report is designed to add to the 2023 Realist Evaluation and includes further data collected from two sites where the MDNS role remains active.



# Qualitative Descriptive Study

## Aim

To undertake a further examination of two Movement Disorder Nurse Specialist (MDNS) positions established as part of the larger Movement Disorder Nurse Specialist Pilot project that commenced in late 2019.

## Objectives

To seek the perspectives of three distinct groups of the value and impact of the movement disorder nurse specialist (MDNS) role:

- Health professionals who have direct contact with the MDNS
- people diagnosed with movement disorders who have accessed the services provided by a MDNS
- carers and families of people diagnosed with movement disorders who had accessed the services provided by a MDNS

## Methodology

### Case study research design

Given the two markedly different sites in which this study was undertaken, this final evaluation is also suited to an over-arching case-study design, albeit on a smaller scale to the realist evaluation undertaken in 2023 [1]. This project design is underpinned by pragmatism and a constructivist perspective [2]. This design supports an exploration of factors both specific to each case and the broader contextual and organisational factors that impact upon each case [3].

### Case study selection

For this study, the selection of case study sites was purposive. Thus, the sites chosen were the two sites where:

- the Movement Disorder Nurse Specialist role continues,
- regular contact with the two nurses has continued with the Project Manager from WNSW PHN and
- the MDNS were eager to engage with further data collection

### Qualitative descriptive research

The approach to data collection, analysis and interpretation for this case-study research was what is broadly described as qualitative descriptive research [4, 5]. This approach focuses on a 'straight description and

comprehensive summary of the phenomenon of interest' and uses participants' language in the descriptions of the findings [4].

## Methods

This section describes the methods and tools utilised to collect the data for project.

### Recruitment

Participants were sought from the two sites indicated on the map below.

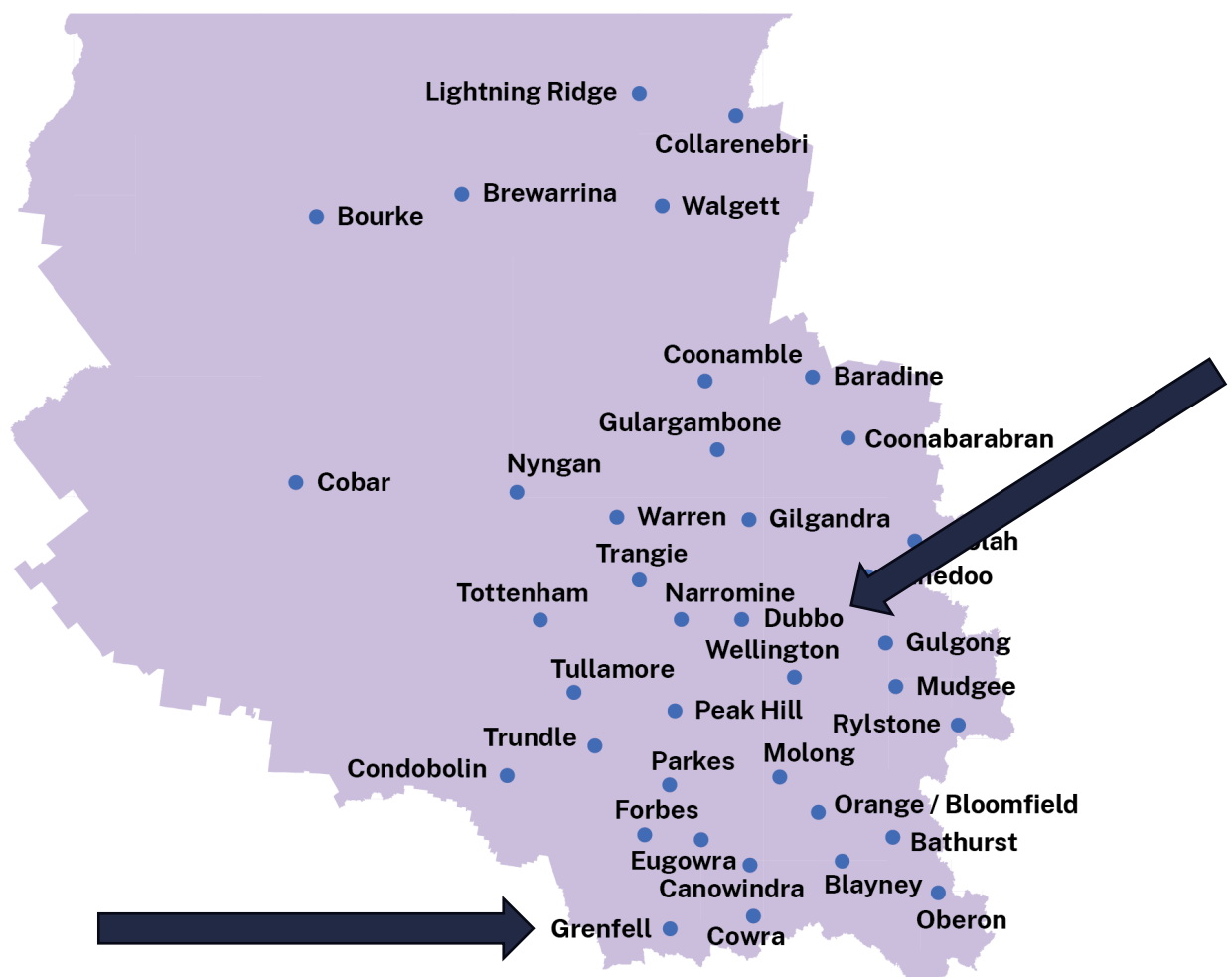


Figure 2: Western NSW Local Health District <https://www.health.nsw.gov.au/lhd/Pages/wnswlhd.aspx>

**Dubbo Case Study Site**

For the larger Dubbo Case Study site, several methods were used to recruit consumers of MDNS services and their carers including:

- Putting up information posters and distributing flyers about the study at the hospital based outpatients clinic where the MDNS is based;
- Enlisting the assistance of the communications manager at Parkinson’s NSW who emailed information to consumers and carers on the Organisation’s mailing list; and
- Direct recruitment by one of the research team who attended one of the Dubbo Parkinson’s Support Group meetings and distributed the Participant Information Sheets and Consent Forms. Interested participants would then be invited to contact the Research Assistant to arrange a face-to-face or online interview with the Chief Investigator.
- Health care providers working in the public and private healthcare systems who were actively engaged in providing care to people living with a movement disorder in Dubbo and surrounds were identified by the MDNS. The Research Assistant then emailed the potential participants inviting them to participate in a one-on-one online interview with the Chief Investigator.

**Grenfell Case Study Site**

A pragmatic approach was utilised to recruit consumer and career participants at the smaller Grenfell case study site. The Chief Investigator and Co-investigator attending several community based activities (Grenfell Men’s Group, Grenfell Community Health Dance Wise Exercise Group) conducted by the MDNS to recruit and speak with consumers and their carers. The visit also provided the opportunity for the Chief Investigator to meet directly with the MDNS.

**Data collection**

The data for this study were collected using three primary methods: semi-structured interviews, group interviews, and researcher observations. These methods enable detailed and nuanced information to be obtained from participants, providing an in-depth data set from a limited number of participants. Data collection was undertaken during April 2024.

Grenfell – site visit	Dubbo – semi-structured interviews
<ul style="list-style-type: none"><li>– Attended Men’s Exercise Group</li><li>– Dance Wise Exercise Group</li><li>• Interview with Movement Disorder Nurse Specialist<ul style="list-style-type: none"><li>– Face-to-face</li></ul></li></ul>	<ul style="list-style-type: none"><li>– Interviewed on-line</li><li>– Movement Disorder Nurse Specialist</li><li>– Neurologist</li><li>– Person with Parkinson’s disease</li><li>• Home visit to interview<ul style="list-style-type: none"><li>– Carer and Person with Parkinson’s disease</li></ul></li></ul>

*Table 1: Data Sources*

## Data analysis and interpretation

All interview data was transcribed and analysed using Yin's 5 Phases of Analysis [6]. This rigorous process enabled the identification of codes and themes that illustrate the participants' perspectives of the MDNS role. The interpretation of this analysis was undertaken iteratively throughout the coding process with reference to relevant empirical research and grey literature. The process of interpretation required frequent reference back to the initial design for the MDNS pilot [7] and subsequent reports documenting the evolution of the pilot project [1].

## Data limitations

This study employed rigorous methods to ensure the quality and trustworthiness of the data, however, despite active measures to recruit widely across the larger site (Dubbo), only a small number of people responded. The purposive sampling limits the generalisability of these findings to populations in other contexts [8]. Self-report data in interviews potentially introduces bias, as participants recall their past experiences without reference to contemporaneous reports. Additionally, the presence of the two researchers at one site may have influenced participants' behaviours and potentially altered the ways in which they spoke of the activities in which they were engaged.

## Ethics approval

Ethics approval to conduct this study was obtained from the Greater Western Area Human Research Ethics Committee (HREC) Approval Number: 2024/STE00646 (See Appendices 1 & 2: for a copy of the recruitment flyer and the Participant Information Sheet and Consent Form submitted to the HREC).

Site specific approval was obtained to allow data collection from Dubbo Health Service from which data collection was obtained for this two-site qualitative description study. This included the addition of Didiya Chennakkattel Issac as the Principal Investigator for this site to enable her to facilitate access to potential participants (See Appendix 3 for Notification of approval).

# Interpreting the data

This section presents the analysis and interpretation of the observational and interview data interwoven with reference to relevant medical, health management and social research specific to Parkinson's disease.

## Geographical location

The sites that are the focus of this report are each located within the WNSW Local Health District footprint (i.e. Part of the wider area covered by the WNSW Primary Health Network).

Location	Population*	Modified Monash Model[9]	ASGS Remote Australia (2016)[10]	Acute Care Services
<b>Grenfell</b> 360 kms to Sydney > 5 hours driving	3,649	MMM5	Outer Regional Code RA 3	Multipurpose Service
<b>Dubbo</b> 390 kms to Sydney >5 hours driving	71,666	MMM3	Inner Regional Code RA 2	Major referral facility

*Table 2: Case study sites*

**Please note:** Pseudonyms have been used throughout for participants attending each of the groups described below (indicated by \*).

### Grenfell

The MDNS role in this location is limited by time and funding constraints with one-day/week allocated to addressing the needs of people living with a movement disorder in this small community. Nevertheless, the MDNS (Belinda Bourne-Wilson) has remained active, developing creative approaches to utilising the knowledge and skills learned during the education component of the MDNS Pilot.

The researchers attended the two group programs delivered by the MDNS.

### MEN'S EXERCISE GROUP

An extensive literature details the importance of regular physical activity and exercise for people diagnosed with Parkinson's disease [11-13]. Apathy has been described as one of the non-motor symptoms highly prevalent in Parkinson's disease [14]. This symptom impacts on a person's capacity to self-motivate to exercise regularly, however engagement in group based activities has been described as helpful [15].

The Men's Exercise Group is conducted in the small 'gym' utilised by physiotherapists for rehabilitation programs delivered through Grenfell Multipurpose Service (<https://www.nsw.gov.au/departments-and-agencies/wnswlhd/service-directory/grenfell-health-service#toc-our-services>). The gym is fitted with a range of exercise equipment. Five to seven men attend weekly. Group members are aged between 70 and 92 years. While not all have a diagnosis of Parkinson's Disease, each person has a range of difficulties with balance and mobility and most have had several falls. One participant, John\*, (70-years-old) was diagnosed

with Parkinson's disease several years ago. He continues to work as a high school teacher in a school located 50 kilometres from his home. Since reducing his work hours to four days/week he has been able to attend the exercise group.

While John continues to enjoy his work, he acknowledges his increasing risk of falls and that he is becoming progressively more fatigued.

*I'm getting to the point where I feel I'm not doing my job as capably as I would like to.... So this might be my last year.... I think once I've finished I'll finish. I have had a couple of falls at school... I broke a rib once but I was knocked over by a kid accidentally. And landed on my chest and my elbows on the asphalt but the kids always say are you alright sir? Even a kid I might not know, says are you okay sir? You need a hand.*

For John having access to this group in his community had several benefits.

*It wasn't hard to come because I'd known Belinda when I was teaching here. I taught some of her kids and had met her parents... So I was quite comfortable knowing her previously... That's one of the useful things about being in a smaller community.*

John had previously been reviewed by the neurologist every six months in Orange, 150 kms from Grenfell.

*It used to be once every six months I haven't seen him for a year because I'll have an appointment and they'll say we've had to move it back or the doctor's on leave. So it's just as well Belinda's around.*

While Bert\* aged 92 has a formal diagnosis of Parkinson's disease and takes disease specific medications, he stridently refutes this, instead attributing his condition to 'being past his use-by-date'. Bill denies enjoying the group, simply stating that *"It's a hell of a lot better than sitting in your lounge room all day, every day."* Nevertheless he attends every week, talks with Belinda about any health concerns, for example, weight loss and accepts suggestions offered by the nurse.

The often jocular conversation, between participants where no topic seemed to be 'off-limits', included reference to personal experiences, health challenges, being a 'retired alcoholic', secrets to remaining married for more than 70 years, and shared memories of historical events. As researchers, this was an opportunity to observe both the significance of the group in providing social interaction, support and physical activity for older adults, as well as a space to speak openly of both the challenges and joys of aging, and maintaining relationships.

*'Of course, I'm going to fall if I've had a lot of grog on board'*

*Yeah, I fall sometimes, but I don't mind the falling, it's the stopping I don't like'*

While the focus of the activities would appear to be on physical activity alone, most of those attending were unlikely to engage with a 'disease-specific' support group or to self-initiate an assessment with the limited allied health services in this region. Belinda utilises the knowledge and skills that she acquired through the

educational component of the MDNS pilot program and undertakes regular assessments of each person's weight, medication management, changes in mobility, overall health status and engagement with specialist services. She ensures that the exercises and activities are individually tailored for each participant. This group provides a supportive space with a skilled clinician and other community members who are all supportive and understanding of each other's circumstances. It could be suggested that the real benefit of this group is connection and engagement combined with regular monitoring of symptoms and function.

#### DANCE WISE EXERCISE GROUP

Group based music therapy and dance have been shown to provide benefit for people with Parkinson's disease with the benefits extending beyond improvement in gait and mobility. [16, 17]. The interactions that are an integral component of group-based interventions may also improve mood and alertness and improved quality of life for people with Parkinson's disease [18]. Likewise, similar benefits are reported for older people with significant functional impairment and multiple comorbid conditions [19, 20].

Belinda was very aware that group activities for community members with a range of chronic conditions, including Parkinson's disease are limited in Grenfell. She thus sought additional training to enable her to offer a six-week dance program. Participants are led through a range of exercises, most of which are undertaken while seated, with some exercises with the person standing and holding the back of the chair (if able to do so). These activities are interspersed with 'brain training' described as important to keep 'stretching your brain'. Participants suggest songs that they would like included in the routine for the next week. The activities are designed to improve physical function, coordination, and flexibility as well as lift mood and promote general well-being.

In contrast to the Men's Exercise Group, this group is conducted in a large room within the Grenfell Community Hub. Sixteen women and one man were in attendance, those participating were living with a diverse range of chronic health conditions and often multi-morbidity. Some of the conditions identified included Parkinson's disease, recovering from a series of deep vein thromboses, fractured hip and ankle, cancer treatment for sarcoma and non-Hodgkin's lymphoma, post-stroke experiencing ongoing difficulties with balance and muscle weakness, recovering from a prolonged intensive care admission with Covid-19 and continuing long-Covid symptoms.

For those attending, the location in town serves to de-medicalise the activity, instead providing an opportunity to engage in an activity with health benefits while enjoying the social interactions with a group of people all of whom are affected with conditions impacting on their physical functioning. It could be suggested that the nature of this group also increases health literacy within a small community about how Parkinson's and other disorders affect individuals.

Of note, was the MDNS's pivotal role in actively engaging each of the participants and supporting the creation of a warm, welcoming and inclusive environment where group members were observed to share their stories and connect with each other. Previous research has identified factors specific to the instructor/facilitator including personality, professionalism, empathic and humanised approach that are key to participants remaining engaged with physical activities [21].



Participants reported the dance group as a fun and enjoyable experience in which they are engaged in continuous learning, skills development and new activities to keep their minds active and improve their cognitive function. Dance sessions of a similar structure to this program delivered to older people in an acute hospital setting were reported as having a positive impact, promoting movement and physical activity. The sessions were experienced as meaningful and enjoyable, which then encourages social interaction [22].

### PARTICIPANTS' PERSPECTIVES

Participants from both the Grenfell Men's Group and the Grenfell Community Health Dance Wise Exercise Group cited the importance of being part of these locally delivered group activities. They described the benefits derived from getting out of the house, socialising, and sharing experiences with other members of the community, some of whom have Parkinson's disease while the remainder are living with a range of diverse chronic health challenges limiting their mobility and physical functioning. They further identified the importance they attached to Belinda's professional expertise combined with her status as a trusted 'local'.

These factors are consistent with rurally focused research that has identified the importance of activities that are located close to home, accessible for those with decreased mobility, suited to the person's interests, health conditions and budget. Access to transport for those unable to drive was also an essential component to consider when providing activities such as these [23].

### THE MDNS PERSPECTIVE

The MDNS spoke of the frustration she experienced as she attempted to respond to the individual needs of people in the community with Parkinson's disease and other movement disorders. This proved especially challenging where extensive time was required to facilitate access to the extremely limited allied health and specialist neurological services. She described the assistance of Didiya, the MDNS based in Dubbo as invaluable, likewise, that of an occupational therapist who had been temporarily employed in a NSW Health funded role to coordinate care for people in some parts of the local health district. However, similar to the MDNS role in this location, funding and continuing of this service was under threat as well.

The group based activities served to support a number of people at the same time. While these two activities and the other services the MDNS provides were widely reported by the participants of each group as positive and impactful, Belinda perceived her knowledge and skills as limited. She also described feeling exhausted and needing a 'break', noting the lack of anyone to replace her when she takes leave. Another concern was her awareness that the funding for her one-day/week was not secured. A further source of frustration was the unsolved issue of reporting the activities specific to the MDNS role. Her understanding of this difficulty was the discrepancy between data collection for nursing activities and activities that are perceived as 'allied health' specific.

While Grenfell is identified as MMM5, the issues raised by the MDNS align with a number of those identified by nurses charged with providing primary health care in a remote setting [24]. These include a lack of physical resources, specialist health services and time, working alone, and a lack of shared understanding with managers. As a clinician deeply embedded in her local community and committed to addressing the

unmet needs she continually observed, she described a compromise where she attempts to do the best that she can with the limited personal and organisational resources available [24].

## Dubbo

Didiya, the MDNS in this location was described in the Realist Evaluation (2023) as an Exemplar of Success. The data collected in April 2024 provides a 'window' into the contextual and organisational challenges within which this nurse practices.

**Please note:** Pseudonyms have been used throughout this section for findings reported from interviews with a person with Parkinson's disease and carer (indicated by \*).

### ACCESS TO SPECIALIST AND ALLIED HEALTH SERVICES

While Dubbo is described as a major referral facility, access to specialist movement disorder neurologists is extremely limited. Public neurology services are limited to one neurologist who works part-time. Fly-in, fly-out neurologists provide limited private services, with only one whose subspecialty is movement disorders. It was noted that for each of these *'their books are closed or nearly closed'*. Those people who require specialist interventions (e.g., deep brain stimulation, insertion of a Duodopa pump) must travel to Sydney (at least five hours by road).

*... I think since 2019 this neurology position in Dubbo has been advertised and even today it's advertised without any response.*

While the part-time Dubbo-based neurologist was on maternity leave last year...

*...that 10 months period was covered by 7 different neurologists, flying in, flying out, different neurologists from Sydney. 2 weeks here, 2 weeks there.. I'm thinking of what this is like for patients, they see a different one every time.... Care coordination difficulties are massive*

Access to allied health professionals is likewise extremely limited with long waiting times.

*'...we've got no public speech pathology services at the moment at all. In Dubbo there's very limited physiotherapy and occupational therapy services... Really, it's very hard for us to get access, long waitlists and limited resources'*

Despite the contextual challenges in this location, the participants interviewed described the positive impact of the MDNS role.

### PARTICIPANTS' PERSPECTIVES

#### Neurologist

The neurologist noted that Didiya was employed in Dubbo as the EEG (electroencephalogram) nurse initially.

*“...when she mentioned that there was this project being launched so that she could learn more about movement disorders and hopefully set up a service here, I was super enthusiastic about it because I've seen these clinics working really well in tertiary settings and in Sydney...”*

The role was described as invaluable:

*She's providing this outpatient service, which is terrific, but then I think Didiya has been particularly innovative here in that she's focusing on an inpatient service as well. So she's identified what's important both for the patients themselves, but also for the confidence of the staff caring for people who have a movement disorder so that they are identified early in their presentation.*

*And so that she can do a kind of outreach service to go and check on them, check their medications are being administered correctly, check that they've got the correct medications in stock, make sure that if there's nurses involved, they get that education about the timing of the medications and how important it is not to miss them.*

*Now on our electronic medical record, people who have a diagnosis of a movement disorder get automatically flagged to her when they get admitted to hospital. That's a really big change.*

For the neurologist, this role supported the delivery of care beyond assessment and medication management for people experiencing a complex neurodegenerative condition. The importance of integrated care for this population has been well described [25].

*For the first time, I now have a service where I can offer newly diagnosed movement disorders patients more than just what I can do in my brief time with them, in which I have to do their whole assessment, review their medications, and try and provide education and support*

*And so it means that I can say look, if you've got more questions you can talk to Didiya... she'll have a comprehensive look at everything involved in your care.*

*It means I've got more to offer the patients and then it also hugely reduces my workload with movement disorders patients because before this service was in place, I had to try and do all of the education myself, which is very time consuming.*

*It means that for people who might have a small niggling concern in the six months between their visits to me, that maybe their GP doesn't know how to address, they have another point of call.*

Of concern, was the precariousness of the MDNS role, and the other demands on the nurse's time.

*It would obviously be better if we had a nurse who was a dedicated movement disorder nurse... but anyway we do with what we've got...She's wonderful...We're very grateful for her.'*

### Carer and person with PD

The interview with Susan\* and Grant\* was conducted at their home. Susan was diagnosed with Parkinson's disease 10 years ago (at the age of 66), by a Sydney based movement-disorder neurologist. The couple noted that marked symptoms were noticeable at work for some time prior to this. Susan spoke of the deterioration in her health as:

*"Last year was an absolute struggle - Parkinson's is taking more and more of me."*

Her mobility is now severely impaired, she has had multiple fractures, including a sacral fracture and more recently a 'broken neck'. Susan has difficulty swallowing, limited taste, and can no longer independently attend to basic self-care activities.

While the couple were grateful for the assistance they access via My Aged Care, the ongoing difficulties encountered when services are disconnected with no clear structure for communication between services. They described the trauma arising when Susan experienced an adverse reaction to two Parkinson's specific medications that resulted in tactile hallucinations. Attempts to contact the Sydney-based neurologist required contacting the Dubbo-based booking service. Despite the neurologist's advice to cease one of the medications and half the other, the residential aged care facility providing respite care for Susan refused to accept the e-mailed instructions from the neurologist. Grant was advised to contact the general practitioner to formally alter the medication chart. Such challenges are consistent with published reports [26].

Although, Susan is not a public patient, her neurologist is in private practice in Sydney. Didiya was described as an invaluable resource *"I've rung her when people don't seem to understand what is required"*.

### Dubbo Parkinsons Support Group leader

Parkinson's NSW coordinates the statewide network of Parkinson's Support Groups [27]. However, individual support groups are very much reliant on the volunteers who organise and lead the meetings usually held monthly [28, 29].

The current leader of the Dubbo Parkinson's Support Group was diagnosed with Parkinson's disease more than 10 years ago. He described accessing private neurological services every six months with a fly-in-fly-out neurologist. Since diagnosis, his condition has deteriorated a great deal, *"I've slowed down a lot...we battle a lot"* such that he has more recently needed to access short-term respite care.

The support group meetings are regularly attended by 25-30 people (people with Parkinson's diseases and carers). Given his deteriorating health, the leader stated:

*"It was getting too much, such that I wanted to give it away.... And one of the things that I had to do was to try and organize speakers...Didiya was able to step in and organize quite a lot of speakers, which is taking the pressure off me. I just had to issue the notification of the meeting and that's it now."*

The co-researcher for this project attended one of the meetings of this Dubbo group. Her observations highlight the importance of the MDNS's engagement with the group, noting the supportive nature of the

group meeting, the opportunities provided to share resources between attendees along with resources provided by the MDNS. Guest speakers provide focused condition specific education, enabling those attending to improve their health literacy and obtain additional skills to manage their condition. Didiya's attendance at the group enabled those attending to check in with her, enabling additional disease management support.

The beneficial role of support groups both for people with Parkinson's disease and their carers is described by the World Health Organisation as not only supporting 'learning and communication and providing emotional and social support'. The benefits extend to 'opportunities for local advocacy, combatting stigmatisation in communities and about educating people about PD' [29, 30].

### INITIATING IMPLEMENTATION OF EVIDENCE BASED PRACTICE (EBP) INTO ROUTINE CARE: NOT FOR THE FAINT-HEARTED

Providing education, training, clinical placement and other upskilling opportunities to registered nurses through the MDNS pilot project was viewed as one solution to improving access to specialised nursing care and health outcomes for people living in rural and remote communities with movement disorders, including those with Parkinson's disease [1].

However, despite increasing the capacity of these nurses to care for people living with movement disorders, MDNSs still face challenges and barriers to utilising their knowledge and skills in the workplace. This case study provides an example of the difficulties experienced by Didiya, a motivated and competent MDNS trying to incorporate evidence based practice into routine practice and highlights organisational factors that can impact the MDNS's ability to improve the care of people living with movement disorders.

Didiya had completed a clinical placement with Vince Carroll, Parkinson's Clinical Nurse Consultant (CNC) based in Coffs Harbour who works with the Mid North Coast Local Health District (MNCLHD) and adjunct lecturer [Vincent Carroll — Charles Sturt University Research Output \(csu.edu.au\)](https://www.csu.edu.au/research/output/vincent-carroll). Didiya had observed the clinical benefits of a project led by this CNC that was designed to address documented difficulties with medication management for people with Parkinson's disease admitted to hospital [31, 32]. **The project had resulted in** demonstrated improvements in clinical care, a marked decrease in prescriptions of contraindicated medications and a decreased length of hospital stay for people with Parkinson's disease [31].

#### **A Collaborative Clinical Practice Improvement Project [31, 33]**

**The outcomes resulted in a Parkinson's Disease (PD) 'flag' on Parkinson's patients' electronic medical record (EMR) when they presented to the emergency department. The flag automatically alerts both the community based MDNS and the hospital pharmacist when the person presents to the Emergency Department and is admitted to hospital. This triggers a range of alerts and interventions ensuring that:**

- **Parkinson's specific medications are available,**

- **Emergency Department medical officers are alerted to contra-indicated medications and have access to the MNCLHD 'Clinical guideline for the care and management of patients with Parkinson's disease at presentation and admission to hospital' [34]. This was distributed as a State wide Safety Notice March 2020[35] and further updated in 2023 [36]**
- **Nurses are alerted to the time-critical nature of specific medications.**

**Results showed a reduction in average length of hospital stay for Parkinson's Disease as a secondary diagnosis, from 9 to 6.2 days [33].**

As a result of the Parkinson's specific education and her clinical placement, the Didiya was deeply aware of the potential for adverse events when time-critical medication for Parkinson's disease is not ensured [32]. She recognized the importance of ensuring medication safety as outlined in the National Safety and Quality Health Standards [37]. In early 2023 Didiya had reported that she was

*"working on introducing systems improvements to the hospital EMR so that when a Parkinson's patient comes through the ED, a PD flag is triggered and the PD nurse, pharmacist and ED clinicians are alerted and thus able to initiate time critical medications" [1].*

Didiya noted that not only would the addition of the 'PD flag/alert' to the EMR improve health outcomes, it would enable capture of valuable information about people living with movement disorders in the local community.

During this interview, 12 months later, she noted that not only would the addition of the 'PD flag/alert' to the EMR improve health outcomes, it would enable capture of valuable information about people living with movement disorders in the local community. She then described the process that she had undertaken to finally achieve success.

*"I asked the project lead (LHD EMR team) to set it up so that we can trace these people, as we had no data. What are their major presenting problems and how can we stop unwanted hospital admissions?"*

Her reflections capture the frustrations and difficulties she experienced as she attempted to facilitate the implementation of the 'PD flag/alert'.

*"I went on placements and this LHD had this policy, or guideline on the intranet and when I talk to our LHD everything is so foreign and I don't know what stops them...They question then, how does Orange do it? How does Bathurst do it? Maybe we are innovative (within this LHD), but let's do this...Then they have to talk to the other person, then they do a MS Teams meeting, Round one, Round two and then they interview all these allied health people to be part of this, and finally it is done last week".*

It took both the persistence and many months of advocacy work by this MDNS to finally succeed in having the PD flag active in the EMR.

*'I think I'm notorious among the ED team now...I'm so demanding'".*



It is important to note that Didiya's focus on capturing information about people living with movement disorders in the local community is supported by a recent scoping review as an important activity [38]. This review concluded there is

*'A paucity of reliable prevalence data indicates the need for well-designed, country-specific epidemiological studies to be conducted to estimate the actual impacts of the disease to inform public health planning, particularly in regional, rural and remote areas where access to PD-specific care is already inequitable' [38].*

The issues contributing to the barriers encountered in this case study are unclear. Potential contributors could be one or more of the following:

- An organisational culture with limited leadership capacity or capability to support the translation of evidence into clinical practice [39, 40]
- Failure to respond to recommendations outlined in the Updated Safety Notice released by NSW Health in September 2023
- 'This Safety Notice includes additional medication management strategies to ensure safety for patients with Parkinson disease. These include broadened electronic Medication Management (eMM) system considerations as well as considerations for patients with swallowing difficulty' [41] (See Appendix 4).
- Overly complicated processes or structures to support the implementation of health technologies in enable evidence based clinical practice [42].

What this case study highlights is the complicated health context in which MDNSs operate and that equipping Registered Nurses (RNs) with the information, education and skills is still often not enough to implement evidence based Movement Disorder care and change clinical practice. This case study would suggest that strategies including measures to upscale and spread EBP across LHDs, train RNs in advocacy work and educating organisations about the benefits of implementing EBP in terms of improved clinical outcomes and resource management are required.

## Reflections

The findings from this additional round of data collection are consistent with a recent modelling of accessibility of adult neurological care in Australia assessing the capacity of the neurology workforce to meet estimated demand in 2020 and 2034. This modelling highlighted both the well-documented inequities in access to specialist neurological services experienced by rurally located people with Parkinson's disease and their carers and the need to expand the neurology support workforce [43].

Both of these MDNS roles are situated within services delivered by NSW health via Western NSW LHD. Although there are a number of HealthOne NSW Service locations in this LHD, where integrated primary and community health services have been established [44], neither of the case study sites examined for this

report are HealthOne sites [44]. Although the positive impact of these two roles are clear, with feedback from community members and the neurologist describing a range of benefits, there are a number of organisational factors that limit the capacity for each nurse to provide the services needed in their communities.

- Roles not part of ongoing staffing complement.
- Insecure funding
- Lack of succession planning
- Systems issues that impact on:
  - Efficient care delivery
  - Documenting the care delivered to enable accurate reporting of data

Access to clinically relevant education that both enhances delivery of quality healthcare and enables career development has been shown to be an integral component of recruiting and retaining healthcare professionals in rural areas [45]. Nevertheless, unless nurses and allied health professionals are able to utilise their knowledge and skills and work to their full scope of practice, the provision of focused education programs alone is unlikely to deliver the anticipated improvements in healthcare delivery [46-48].

While evidence-based neurological services are available to those residing in most metropolitan areas in Australia, albeit with lengthy waiting times for those who cannot afford to consult private neurologists, this is not the situation in many regional locations and the majority of rural and remote locations. Parkinson's NSW as the peak body has collaborated closely with clinicians and academic researchers to draw attention to the needs of people living with Parkinson's disease in regional, rural and remote areas of the state. The organisation funded initial research evaluating nurse-led models of care [49-51] and further research examining support group leadership models in rural NSW [29]. Continued anecdotal feedback from people with Parkinson's disease admitted to rural and regional hospitals that clinicians appeared to have limited awareness of Parkinson's disease highlighted the need to ensure that undergraduate curricula included this condition in subjects focused on neurological conditions. In response, a chapter focused on Parkinson's disease has been included in the third edition of a widely utilised nursing textbook [52]. Following an invitation from the editors of the Australian Journal of General Practice, two articles focused on increasing awareness of non-motor symptoms and communication and swallowing difficulties in Parkinson's disease were published [15, 53]. Concurrently, specialist Parkinson's nurses have identified the need for further research focused on the delivery of evidence-based nursing practice for people with Parkinson's disease [54-56].

Aligned with the examples of nurse-led research and advocacy efforts described above, there are 'pockets of excellence' in rural areas where innovative models of nurse-led team based care have been developed and co-funded with Parkinson's NSW. Successful improvements to clinical practice, including projects to ensure people with Parkinson's disease admitted to the Emergency Department and in-patient wards receive time-critical medications on time achieved in Coffs Harbour have inspired other MDNSs to attempt to replicate the intervention in other clinical settings both urban and rural.

These examples of collaborative efforts and focused activities designed to address the unmet needs of people with Parkinson's disease and the organisational and funding barriers to state-wide change serve to reinforce the need for a nationally coordinated approach to Parkinson's disease in Australia [29].

### Upskilling primary health care clinicians

In 2022 the World Health Organisation released a technical brief emphasising the need for an urgent public health approach to Parkinson's disease [30] with an emphasis on upskilling primary healthcare clinicians to recognise, diagnose, refer to specialist services (where available) and institute evidence-based care. The emergence of the Australian National Parkinson's Alliance in March 2024 further highlights the imperative for a nationwide response to addressing the impact of Parkinson's disease [57]. The subsequent announcement of funding to develop Australia's First National Parkinson's Action Plan signals the Commonwealth Government's recognition of the need for a coordinated response to care delivery and research focused on Parkinson's disease [58, 59]. The purpose of this national plan is to call for improvement in key areas that include:

- improved education and capability of the health, disability and aged care workforce
- earlier detection and diagnosis of Parkinson's, including more empathetic delivery of diagnosis and referral and access of a multi-disciplinary team
- better access to, and co-ordination of, evidence-based healthcare, resources, supports and treatments [39]

Of note, these key areas of focus are consistent with those identified by the WHO, i.e. to *'build the capacity of primary healthcare, social workers, rehabilitation and palliative care; and ensure education and training of primary health-care providers'* [30].

### Increased focus on integrated care for continuity across disease trajectory

While extensive research globally seeks to identify treatments to change the trajectory of Parkinson's disease, this is a progressive neurodegenerative condition. Thus, integrated care across the disease trajectory is essential [30]. To date, access to timely diagnosis, management with both pharmacological and non-pharmacological treatments, rehabilitation services and palliative care services is not readily available for most people living those in regional, rural and remote Australia.

The following actions recommended by the WHO to strengthen health and social systems are applicable to address the inequities experienced by those living in regional, rural and remote Australia:

- increase innovations for specialist support (e.g. telemedicine) to offer remote interdisciplinary support for people with PD,
- integrate diagnosis, treatment, rehabilitation and palliative services into interdisciplinary teams

- promote educational programmes within the PD interdisciplinary health and rehabilitation workforce and create networks for referrals;
- provide education and training of primary health-care providers, including allied health professionals, and shift tasks to community settings.

# Recommendations

To date, local health districts and primary health care networks have focused on developing and implementing local resources and programs. The MDNS Pilot has highlighted both the benefits and challenges encountered when seeking to improve access to movement disorder specific healthcare across the Western NSW Primary Healthcare Network.

The following recommendations are informed by the findings from this additional study, the 2023 Realist Evaluation, relevant research, the World Health Organisation Technical Brief and the activity underway currently to develop Australia's First National Parkinson's Action Plan

- Given the imperative to upskill primary health care clinicians in recognizing, responding too and managing Parkinson's disease and other movement disorders, consideration should be given to consulting with the Australian Primary Healthcare Nurses Association (APNA) to develop a Parkinson's Disease/Movement Disorder on-line training module.
  - This organisation has a nation-wide reach and are experienced in delivering on-line training for primary health care nurses [60].
  - This would be an invaluable addition to the building capacity programs delivered by APNA and ensure primary healthcare focused care for people with Parkinson's disease is accessible to nurses nationally.
- For Primary Healthcare Networks covering regional, rural and remote areas of Australia, it is recommended that attention be given to:
  - Facilitating access to education programs for primary healthcare nurses and allied health professionals to ensure more extensive knowledge of movement disorders
  - Developing health pathways to provide ready access to up-to-date evidence based information for general practitioners
  - Recognise the isolation experienced by individual clinicians where services for people with conditions such as Parkinson's disease are delivered by one person
  - Ensure contingency and succession plans are in place to enable continuity of service delivery

# Appendices

## Appendix 1: Recruitment Flyer



# HAVE YOU HAD APPOINTMENTS WITH THE MOVEMENT DISORDER SPECIALIST NURSE?

We are conducting a study to help us to understand your perspective and experience of having access to a Movement Disorder Specialist Nurse in your regional or rural location.

- Do you have a diagnosis of a movement disorder such as Parkinson's disease?
- Are you a family member or a carer for a person diagnosed with a movement disorder?
- Have you accessed the services of the Movement Disorder Specialist Registered Nurse?

The study involves a face-to-face, online or telephone interview that takes about an hour.  
To participate you must be 18 years or older.

## We would like to know what your experience has been!

Your participation will help us to evaluate the impact of the specialist skills provided by the registered nurse and what resources and support services are most useful.

To register your interest or find out more, please contact:

Name	Katie Prior
Position	Manager - Education Programs Western NSW Primary Health Network
Telephone	(02) 6831 0933
Email	<a href="mailto:Katie.Prior@wnswphn.org.au">Katie.Prior@wnswphn.org.au</a>

If you have questions and would like to speak to the Chief Investigator, please contact:

Name	Rachel Rossiter
Position	Associate Professor of Nursing, Faculty of Health and Science, Charles Sturt University
Telephone	(02) 6365 7245
Email	<a href="mailto:rrossiter@csu.edu.au">rrossiter@csu.edu.au</a>

This study has been approved by the Ethics Review Committee for Western and Far Western New South Wales Local Health Districts and Charles Sturt University's Human Research Ethics Committees. A person with concerns or complaints about the conduct of this study should contact the Executive Officer on 02 6330 5948 and quote reference ETH00160 or CSU Ethics and Compliant Unit on 02 6933 4123.

The conduct of this study in the WNSWLHD has been authorised by the RGO. Anyone with concerns or complaints about the conduct of this study may contact the RGO on (02) 6330 5948, email: [WNSWLHD-EthicsCommittee@health.nsw.gov.au](mailto:WNSWLHD-EthicsCommittee@health.nsw.gov.au) and quote reference: 2024/STE00646.

Master Version 2\_01\_V2 22/08/2022; WNSWLHD Version 1\_15/03/2024



## Appendix 2: Participant Information Sheet & Consent Form



### PARTICIPANT INFORMATION SHEET & CONSENT FORM

#### STUDY TITLE:

Views and perspectives of the Western NSW Primary Health Network  
Movement Disorder Nurse Specialist pilot project: A qualitative  
evaluation  
(Carer or Family Member)

#### INVESTIGATORS:

Rachel Rossiter	Co-ordinating Principal Investigator	Associate Professor of Nursing Charles Sturt University
Katie Prior	Assistant Researcher	Western NSW Primary Health Network Manager – Education Programs

**CONTACT PERSON:** Katie Prior, Manager, Education Programs  
WNSW Primary Health Network  
Phone: 02 6813 0833

#### 1. INTRODUCTION:

You are invited to take part into the research project named above. This Participant Information Sheet (PIS) will tell you about what is involved in the study and help you decide whether or not you wish to take part. Please read this information carefully. If there is anything you do not understand or if you feel you need more information about anything, please ask. Before you make a decision, please feel free to talk things over with a relative, a friend or your own doctor as appropriate.

#### 2. WHAT IS THE PURPOSE OF THIS STUDY?

Western NSW Primary Health Network (WNSW PHN) received funding from the Australian Government's Primary Health Care Quality and Coordination Program, to implement a Movement Disorder Nurse Specialist Pilot in our region. Charles Sturt University (CSU) has been commissioned by Western NSW Primary Health Network, to undertake an evaluation of the impact of movement disorder nurse specialist positions in regional, rural and remote NSW. These positions were established to enable people diagnosed with movement disorders such as Parkinson's disease (and associated conditions) to have access to a specialist movement disorder nurse who has the expertise and knowledge to educate and help people and their families manage the complexities of living with Movement Disorders such as Parkinson's disease. It is important that specialist positions such as these are carefully evaluated to assess whether the care provided is effective and to identify whether changes and improvements are needed. A very important component of this evaluation is to give the people for whom the service was initiated and their carers and family the opportunity to speak about their experience and perspectives of this nursing role.

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Information for Participants & Consent Form (Carer or Family Member) Master Version 3  
07/11/2022\_WNSWLHD Version 1\_15/03/2024

### 3. WHY HAVE I BEEN INVITED TO TAKE PART?

You are invited to take part in this study because you are over the age of 18 years, and you are a carer or family member of a person with a movement disorder who has accessed the services of the specialist movement disorder nurse. You will need to discuss with the person your desire to participate in this project and have their agreement for your participation.

### 4. DO I HAVE TO TAKE PART IN THIS STUDY?

Taking part in any research study is entirely voluntary. If you do not wish to take part, you do not have to. If you do decide to take part and later change your mind you can withdraw at any time without having to give a reason.

Please be assured that, whatever your decision, it will not disadvantage you or impact upon the care and treatment of the person who accesses the services of the specialist movement disorder nurse or upon your contact with the services.

If you do decide to take part, you will be asked to sign a consent form and given a copy to keep.

### 5. WHAT DOES PARTICIPATION IN THIS STUDY INVOLVE?

If you agree to take part, you will be asked to let an interviewer from the research team talk to you in person, over the telephone or by Zoom, at a time and place that is easily accessible for you. The interview may last between 45-90 minutes.

The interview will begin with asking some standard questions about how long you have been a carer or family member for a person living with a movement disorder. Topics that may then be discussed include:

- Your experience of the program thus far
- Differences that you have noticed between the previous care available and what is now available
- The impact that accessing the specialist movement disorder nurse services has had for the person for whom you care and for you as a carer or family member
- Ways in which your location in NSW impacts on access to specialist services and supports for you as a carer or family member
- Ways the program could be improved

The interview will be audio-taped so that it can be transcribed into writing. It can be stopped at any time if there is any interruption, or if you need a break. If you would like to review the transcript of your interview, this can be provided for you once the transcription has been completed. The transcription will be sent to you by Rachel Rossiter, and you will have two (2) weeks to return the transcription with any changes that you would like to make. If a response is not received within the two weeks, we will understand that you are satisfied with the transcription.

### 6. WHAT ARE THE POSSIBLE RISKS AND DISADVANTAGES OF TAKING PART?

There is a potential risk associated with participating in this evaluation. You may potentially find talking about your experience and perspectives of your involvement in accessing the services of the specialist movement disorder nurse and supporting the person with a movement disorder for whom you care to be difficult. The interview may raise questions which could provoke a range of uncomfortable emotions, such as sadness, anxiety, frustration, and fear. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset during the interview or feel uncomfortable, we will take a break or stop completely – it will be up to you. The interviewer

Page 2 of 5

Information for Participants & Consent Form (Carer or Family Member) Master Version 3  
07/11/2022\_WNSWLHD Version 1\_15/03/2024

is an experienced researcher and will check with you before the interview that you are comfortable to proceed and that you have support available for you after the interview if necessary. You can nominate a support person to be with you during the interview if you wish.

If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge. You can also contact Lifeline (telephone number: 13 11 14) at any time.

#### 7. WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

We cannot promise that you will receive any benefits from this research; however, possible benefits of participating in this research will be that you can have your experiences and perspective heard in a way that could influence the future development of specialist nursing positions such as these. Your experiences and perspectives may also be helpful for others who could benefit from similar specialist nursing roles.

#### 8. WHAT WILL HAPPEN TO MY INFORMATION?

By signing the consent form, you consent to the research team collecting and using personal information about you for the research project. Your privacy and confidentiality will be protected at all times. We will not use your real name in any written or verbal reports of this study, in presentations or publications. All responses will be treated confidentially. All recorded and transcribed data will be de-identified. You will be given a pseudonym that will be used instead of your real name if anything you tell the interviewer is quoted. Your de-identified information will be used for the purpose of this research study and a summary of the findings from this study will be included in the NOUS International Management Consultancy report commissioned by the Australian Government Department of Health and Aged Care to undertake a broad evaluation of all the pilot projects underway across Australia. Your identity will only be disclosed with your permission, except as required by law. For example, researchers are required to report if a participant is believed to be at risk of harm.

Your data will be stored for at least 5 years after the study finishes.

If you withdraw from the study, we will not collect any more information about you. We would like to keep the information we have already collected about you to help us ensure that the results of the research project can be measured properly. Please let us know if you do not want us to do this.

#### 9. COSTS: Participation in this study will not cost you anything, nor will you be paid.

#### FURTHER INFORMATION

When you have read this information, Katie Prior will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Associate Professor Rachel Rossiter [rrossiter@csu.edu.au](mailto:rrossiter@csu.edu.au) Ph: 02 6365 7245. This information sheet is for you to keep.

This study has been approved by the Greater Western Area Human Research Ethics Committee. If you have any concerns or complaints about the conduct of the research



Charles Sturt  
University



Health  
Western NSW  
Local Health District

study, you may contact the Executive Officer of the Ethics Committee, on (02) 8330 5948 [WNSWLHD-EthicsCommittee@health.nsw.gov.au](mailto:WNSWLHD-EthicsCommittee@health.nsw.gov.au) and quote reference: ETH00160.

The conduct of this study in the Western New South Wales Local Health District has been authorised by the Research Governance Officer (RGO). Anyone with concerns or complaints about the conduct of this study may contact the RGO on (02) 8330 5948, email: [WNSWLHD-EthicsCommittee@health.nsw.gov.au](mailto:WNSWLHD-EthicsCommittee@health.nsw.gov.au) and quote reference: 2024/STE00646.



Charles Sturt  
University



Health  
Western NSW  
Local Health District

*Views and perspectives of the Western NSW Primary Health Network Movement  
Disorder Nurse Specialist pilot project: A qualitative evaluation*

**PARTICIPANT CONSENT FORM**

I .....[name]  
of .....[address]

have read and understood the Information for Participants for the above-named research study. I understand that I will not be identified in any presentations or publications arising from this research.

- I have been made aware of the interview procedure involved in the study, including any known or expected inconvenience, risk or discomfort and of their implications as far as they are currently known by the researchers.
- I agree to the interview being recorded.
- I freely choose to participate in this research study and understand that I can withdraw at any time.

Name (Please Print): .....

Signature:..... Date: .....

### Appendix 3: 2022/ETH00160: Addition of a New Site - (154895) – Approved

2022/ETH00160: Notification of an amendment to a research study - Addition of a New Site - (154895) - Approved

N

no\_reply@regis.health.nsw.gov.au

To

Rossiter, Rachel

Cc

Phillips, Rosemary

😊

↩ Reply

↩ Reply All

➡ Forward

📧

⋮

Fri 1/03/2024 7:40 AM

Action Items

Date of Decision Notification: **01 Mar 2024**  
**Greater than low risk review pathway**

Dear Rachel,

Thank you for submitting a Notification of an amendment to a research study - Addition of a New Site with ID (154895 for the following study:

**2022/ETH00160:** Views and perspectives of the Western NSW Primary Health Network Movement Disorder Nurse Specialist pilot project: A qualitative evaluation

The Amendment has been reviewed on 01 Mar 2024, by the Executive Officer as delegated by the HREC Chair and has been approved.

**Notification of an amendment to a research study - Addition of a New Site with form ID 154895**

- Dubbo Health Service

PI name:

- Didiya CHENNAKKATTEL ISSAC

PI email: [didiyacissac@gmail.com](mailto:didiyacissac@gmail.com)

The following documentation is included in this approval:

- PI CV

It is noted that the Greater Western Human Research Ethics Committee is constituted in accordance with the National Statement on Ethics Conduct in Human Research, 2023 (NHMRC).

**This email constitutes ethical and scientific approval only.**  
This project cannot proceed at any site until separate research governance authorisation has been obtained from the Institution at which the research will take place.

Please contact us if you would like to discuss any aspects of this process further, as per the contact details below.

Regards,  
**Phil Sanders**

Manager, Research Ethics and Governance |  
Research Governance Officer  
PO Box 143, 39 Hampden Park Road, Bathurst. 2795  
Tel (02) 6330 5948 | [Phil.Sanders@health.nsw.gov.au](mailto:Phil.Sanders@health.nsw.gov.au)

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### Safety Notice 025/23

#### Recommendations for local governance committees cont.

- Ensure staff have access to education on how to manage patients with Parkinson disease, and encourage uptake. An e-Learning module is available for this purpose from My Health Learning (Course code: 283839943).
- Liaise with local eMM teams to optimise configuration of the eMM system, for example:
  - Use of automated Parkinson disease icon alerts within Emergency Department and ward electronic systems, to alert clinicians to a patients' arrival and admission.
  - Use of electronic consultation order (or equivalent) to expedite Parkinson disease specialist nurse review.
  - Displaying Parkinson medicines with generic (active ingredient), brand name and specific formulation (e.g., immediate or extended release), to minimise risk of selection error at the point of prescribing and administration.
  - Ensuring processes are in place for high level frequency and timeliness of levodopa Parkinson medications (e.g. 6 times per day). Adjust the timing of nursing overdue alerts to trigger at an appropriate interval (e.g., after a 15-minute delay), rather than according to default settings (e.g., 60 minutes).
  - Pop-up alerts when prescribing time-critical medicines that provide instructions on how to avoid prescribing contraindicated medications to patients on levodopa-based medications; adjust the order to non-standard administration times; and remind nurses to check the patient specific administration times as these may sit outside the regular administration medication times.
  - Inclusion of standardised additional information on medication orders for time-critical medications (e.g., **"Time-critical: must be administered at prescribed time"**).

NSW Health. (2023). *Safety Notice 025/23 UPDATED – Medication management in Parkinson disease*. NSW Health. <https://www.health.nsw.gov.au/sabs/Documents/2023-sn-025.pdf> (p.3).



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