

Parkinson's Disease Movement Disorder Nurse Specialist Demographic Survey 2021

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Abstract

Parkinson's disease is a common neurological condition. Patients benefit from patient centred care provided by a Parkinson's disease or movement disorder nurse specialist. This study is the second in a series of annually recurring publications to progressively monitor the growth and development of the PDMDNS profession in Australia. Results will firstly; provide evidence to support the PDMDNS professional body in Australia to advocate for adequate resources, sufficient training and appropriate levels of qualifications and pay grades, secondly; assist in identifying gaps in the provision of services to people living with PD.

Keywords: Parkinson disease, Parkinson's disease, Parkinson disease nurse, Parkinson's disease nurse, demographic survey, workforce, Australia

Introduction

Parkinson's disease (PD) is a common chronic neurological condition with 1 in 177 people in Australia living with the disease, as at 2019 (Ayton et al 2019). It is possible the incidence will be higher in those who recover from COVID-19 (Beachamp et al 2020, Eldeeb et al 2020). Many live with the disease for over 20 years (Deloitte 2015) with 20% disabled by the disease requiring continuous care (Williams et al 2017) at an estimated average lifetime financial cost of \$161,300 per patient over the average 12 year life span, (Deloitte 2015).

Due to the complex nature of the disease, people living with PD ideally have a team of health care professionals involved in their care, including neurologists, PD nurse specialists, general practitioners, and multiple allied health professionals (Bhidayasiri et al 2020). With many involved it is vital that people living with PD receive patient centred care, defined as 'providing care that is respectful of, and responsive to, individual patients needs and preferences' (Lim et al 2017).

PD and movement disorder nurse specialists (PDMDNS) provide patient centred clinical care, assessment, advice and education which reduces physical and psychological morbidity and results in improved health outcomes (MacMahon and Thomas 1998). Nursing led patient centred care provided by one PD nurse has been shown to enable people living with PD to live independently in the

community, prevent hospitalisations, and delay nursing home admissions with cost benefits to the community of \$482,333 per year (Rossiter et al 2019).

This study is the second in a series of annually recurring publications to progressively monitor the growth and development of the PDMDNS profession in Australia. These publications will firstly; provide evidence to support the PDMDNS professional body in Australia to advocate for adequate resources, sufficient training and appropriate levels of qualifications and pay grades, secondly; assist in identifying gaps in the provision of services to people living with PD.

Study Objectives

The primary objective was to collect demographic information pertaining to PDMDNS positions in Australia including the population, geographic location, level of education and the clinical experience of the nurses.

The secondary objectives were firstly, to explore the nature of work that the PDMDNS are engaged in and the long-term sustainability of this subspecialised nursing workforce.

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Secondly, to analyse data to identify gaps in service provision to people living with Parkinson's disease in Australia. Thirdly, to compare data collected in 2020 with data collected in 2021. This information will aid in workforce planning related to funding, education and advocacy.

Study Design

The study and its design were initiated solely and independently by the Australasian Neuroscience Nurses Association (ANNA) Movement Disorder Chapter (MDC) with no financial funding and/or conflict of interests. The ethics application was submitted to and approved by Northern Sydney Local Health District Human Research Ethics Committee 2019/ETH12872: Parkinson's Disease Movement Disorder Nurse Specialist Demographic Survey as a low or negligible risk project.

Data was collected through an anonymous online multiple choice survey produced using the website <https://www.surveymonkey.com>. The survey included a series of qualitative, multiple choice questions designed to sample a cohort of PDMDNS across all states in Australia, including years of service, employer types and levels of education. This survey was emailed to PDMDNS contacts known to the ANNA MDC but only the recipients who were employed as a specialty nurse working directly with people with PD in Australia were included. The data collected was compared to data collected using the same design in 2020.

Study Results

Between April and July 2021 150 surveys were distributed, 88 responses were received, 59 responses met the inclusion crite-

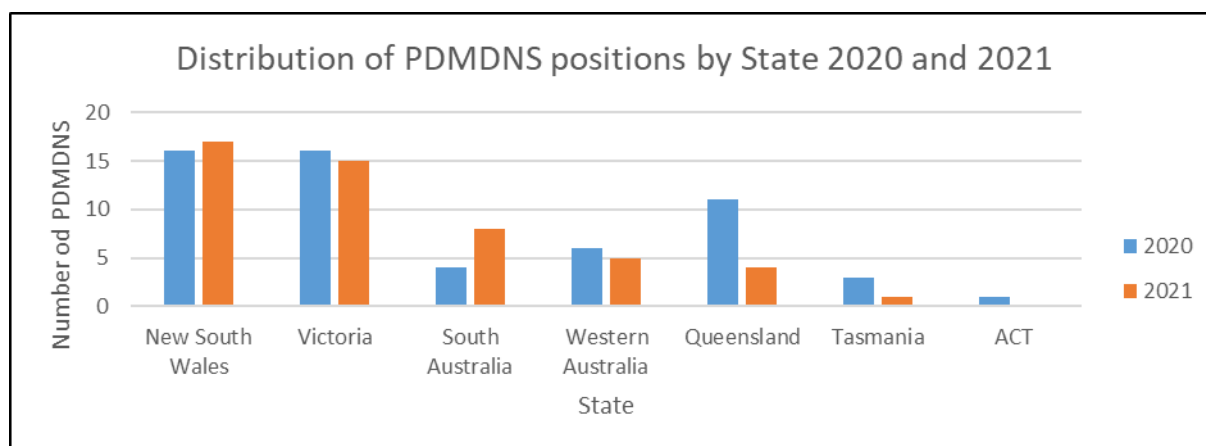
ria and 50 surveys were fully completed (n=50). Responses were included if the respondent identified themselves as being employed as a specialty nurse working directly with people with PD in Australia. Data collection was initially limited by a slow response rate; consequently the survey link was recirculated until the number of responses was comparable with the number received in 2020. In 2020, 70 responses were received, 61 met the inclusion criteria, only 57 surveys were fully completed. Only fully completed survey responses were included for analysis, 2020 n=57 and 2021 n= 50.

Distribution of PDMDNS positions by state and region

Of the 50 complete responses, New South Wales had the most PDMDNS positions with 34% (n=17), Victoria 30% (n=15), South Australia 16% (n=8), Western Australia 10% (n=5), Queensland 8% (n=4), Tasmania 2% (n=1). There were no PDMDNS employed in the Australian Capital Territory (ACT) or the Northern Territory. Queensland had the largest reduction in the number of PDMDNS from 11 in 2020 to 4 in 2021, followed by Tasmania with 3 in 2020 to 1 in 2021. South Australia was the only state with an increase in the number of PDMDNS, 4 in 2020 and 8 in 2021. (Figure 1.)

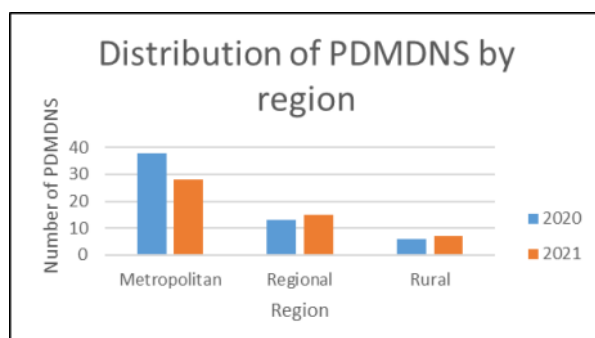
The anonymity of responses required for ethical data collection removes the ability to confirm who did not have the opportunity to participate in the survey. We conservatively estimate there are approximately 10 PDMDNS's known to the ANNA MDC who did not complete the survey in New South Wales, Queensland and Tasmania metropolitan areas.

Figure 1. Distribution of PDMDNS positions by State 2020 and 2021



The majority of PDMDNS are based in metropolitan areas 56% (n=28) with 30% (n=15) based regionally and 14% (n=7) in rural areas. There was 27.5% reduction in the number of metropolitan nurses from 40 to 29 nurses. (Figure 2)

Figure 2. Distribution of PDMDNS by region



The metropolitan regions remain better resourced than the regional and rural areas, and this is consistent between all states except for Tasmania, where the number of regional nurses is higher than the number of metropolitan nurses. Of the 17 PDMDNS in New South Wales 47% (n=8) are metropolitan, 35% (n=6) are regional and 18% (n=3) are rural. New South Wales lost 2 metropolitan positions but gained 1 position in both the regional and rural regions. Of the 15 PDMDNS in Victoria 47% (n=7) are metropolitan, 27% (n=4) are regional and 27% (n=4) are rural. Victoria lost 5 metropolitan nurses and gained 2 in both the regional and rural regions between 2020 and 2021. Of the 8 PDMDNS in South Australia 88% (n=7) are metropolitan, 13% (n=1) are regional. South Australia gained 4 metropolitan positions. Of the 5 PDMDNS in Western Australia 80% (n=4) are metropolitan, 20% (n=1) are regional, with little change from 2020. Of the 4 Queensland PDMDNS 50% (n=2) are metropolitan, 50% (n=2) are regional. Queensland lost 5 metropolitan positions and 1 regional

position. The only PDMDNS in Tasmania is regional having lost 2 positions, 1 metropolitan and 1 regional. The Australian Capital Territory no longer has a PDMDNS. (Table 1.)

Table 1. Distribution of PDMDNS by state and region

State and Region	2020	2021
New South Wales	16	17
Metropolitan	9	8
Regional	5	6
Rural	2	3
Victoria	16	15
Metropolitan	12	7
Regional	2	4
Rural	2	4
South Australia	4	8
Metropolitan	3	7
Regional	1	1
Western Australia	6	5
Metropolitan	5	4
Regional		1
Rural	1	
Queensland	11	4
Metropolitan	7	2
Regional	3	2
Rural	1	
Tasmania	3	1
Metropolitan	1	
Regional	2	1
ACT	1	
Metropolitan	1	
Grand Total	57	50

Table 2. Distribution of PDMDNS positions by employer

Employer	2020		2021	
	%	n	%	n
State Department of Health	51	29	46	23
Consumer Organisation	7	4	16	8
Pharmaceutical Industry	21	12	16	8
Primary Health Network	4	2	10	5
Private Practice	5	3	6	3
Private Hospital	4	2	2	1
University or Educational Institution	2	1	2	1
Other	7	4	2	1
Total	100	57	100	50

Distribution of PDMDNS positions by employer

The largest employer of PDMDNS remains the state based Department of Health which employed 46% (n=23) of the positions, down by 6 positions from 2020. Consumer Organisations and the Pharmaceutical Industry is the second highest employer with 16% (n=8) each. However, Consumer Organisations doubled in the number of positions from 4 to 8 positions and the Pharmaceutical Industry lost 4 positions. Other employers include Primary Health Networks 10% (n=5) an increase of 3 positions, Private Practice 6% (n=3), Private Hospitals 2% (n=1) and University or educational institutions 2% (n=1). The other category included not for profit organisations not classified as a consumer organisation. (Figure 3)

Workforce Stability

Permanency of funding

Funding arrangements for 2021 indicate that 54% (n=27) of PDMDNS positions are permanently funded, a reduction of 22% (n=6) from 2020. 44% (n=22) of PDMDNS are not permanently funded. The remaining 2% (n=1) respondent did not feel the question was applicable to their position. (Table 3)

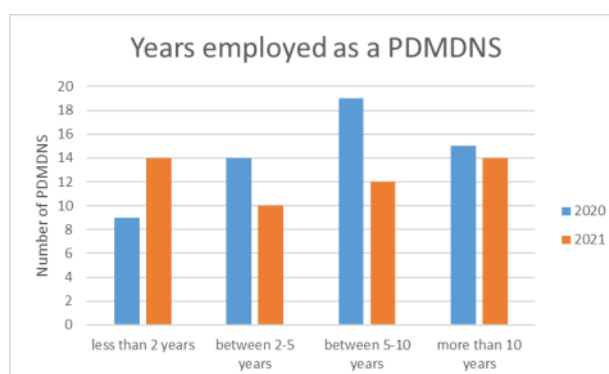
Table 3. Position is permanently funded

Position is permanently funded	2020		2021	
	%	n	%	n
Yes	58	33	54	27
No	33	19	44	22
Not Applicable	9	5	2	1
Total	100	57	100	50

Years of Experience

The survey identified that in 2021, 28% (n=14) PDMDNS had had been employed for less than 2 years, 20% (n=10) had between employed for 2-5 years, 24% (n=12) had between employed between 5 and 10 years' and 28% (n=14) had been employed between 2 and 5 years. There were 5 new PDMDNS in 2021 with less than 2 years' experience. A total of 12 more experienced PDMDNS have left the profession, 2-5 years' experience (n=4) and between 5-10 years of experience (n=7) more than 10 years (n=1). This trend indicates a loss of overall experience of 14% from the workforce, with the loss of experience dominated by the demographic with 5+ years of experience. Figure 3.

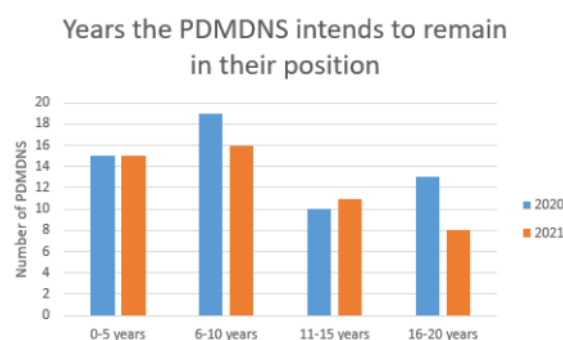
Figure 3. Years employed as a PDMDNS



Intention to stay

Workforce stability forecasts a fairly consistent workforce into the future with approximately two thirds of the workforce planning to stay for more than 5 years, 32% (n=16) of PDMDNS intending to stay for 6-10 years 22% (n=11) intending to stay for 11-15 years, and 16% (n=8) intending to stay for 16-20 years. Although the reduction of 7% (n=5) in the 16 – 20 years and 1% (n=4) in 6-10 years may indicate an overall reduction in the years PDMDNS intend to stay in their position, however 2 years of data does not yet indicate a trend. (Figure 4)

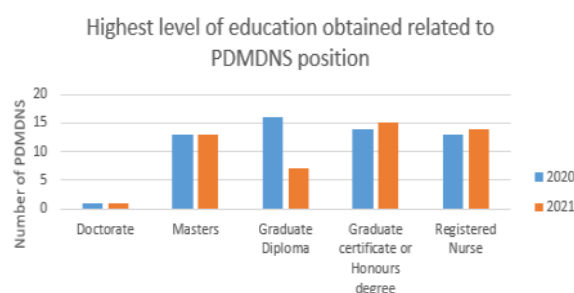
Figure 4. Years the PDMDNS intends to remain in their position



Education and Grading

Highest level of education obtained related to the PDMDNS position

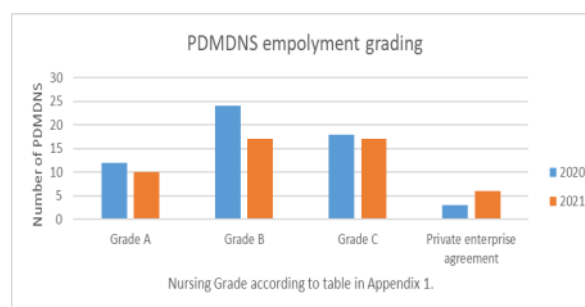
Many PDMDNS hold post graduate qualifications. A Graduate Certificate or honours degree is the most common post graduate qualification with 30% (n=15) followed by a Master's Degree 26% (n=13), Graduate Diploma 14% (n=7), and holding a Doctorate 2% (n=1).

Figure 5. Highest level of education obtained related to the PDMDNS position

The majority of PDMDNS were not enrolled in tertiary study 72% (n=36) in 2021. However the number of people enrolled in tertiary study increased by 27% (n=3). PDMDNS enrolled in a graduate certificate or honours degree (n=5). Alternatively, in 2021 6% (n=3) were enrolled in a master's degree or a graduate diploma, 4% (n=2) were enrolled in the Australian College of Nursing Parkinson's Care unit, 2% (n=1) were enrolled in a certificate IV workplace training and assessment course. (Table 4)

Nursing grading and pay scale

There was a 100% increase in the number of private enterprise agreements in 2021 (n=3 in 2020, n=6 in 2021). 20% (n=10) of the positions are graded as a registered nurse (or Clinical Nurse Specialist in New South Wales), reflecting competent but not specialised nurses and is consistent of the level of tertiary education and experience discussed above. There was a 29% decrease (from 24 to 17) in the number of PDMDNS in Grade B, recognised as experienced nurse specialists equivalent to clinical nurse specialists, grade 1-2 Clinical Nurse Consultants I 34% (n=17) of respondents were Grade C, graded as expert nurse specialists or advanced practitioners, Clinical Nurse Consultant level 3, or Nurse Practitioner. Overall there is a decrease in the grades attributed to advanced practice consistent with the level of education and experience discussed above.

Figure 6. PDMDNS employment grading
Respondents were also given the opportunity

to indicate if they feel the rate they are paid adequately reflects the level of expertise to which they work. The majority 66% (n=33) agree that their level of pay reflects their level of expertise. There was a 50% reduction (n=22 to 11) of PDMDND who disagree that their level of pay reflects their level of expertise. (Table 5).

Table 5. the proportion of Nurses who agree their level of pay reflects their level of skill.

Row Labels	2020	2020	2021	2021
Agree	51%	29	66%	33
Neither agree nor disagree	11%	6	12%	6
Disagree	39%	22	22%	11
Grand Total	100%	57	100%	50

Discussion

The outcome from the 2021 survey highlighted several key elements of this longitudinal study. Firstly, it is an encouraging and positive outcome that there has been an increase in the number of PDMDNS in the regional and rural areas which was previously identified as an underserved area. Unfortunately, in the metropolitan areas, there has been a reduction in number and permanency of funding for PDMDNS.

Table 4. PDMDNS Enrolled in Tertiary Study

Post Graduate Study	2020		2021	
	%	n	%	n
Doctorate	4%	2	0%	0
Masters	7%	4	6%	3
Graduate Diploma	5%	3	6%	3
Graduate Certificate or Honours degree	4%	2	10%	5
Australian College of Nursing Parkinson's Care unit	0%	0	4%	2
Cert IV Workplace training and assessment	0%	0	2%	1
Not currently enrolled in any tertiary studies	81%	46	72%	36
Total	100%	59	100%	51

The data supports anecdotal experience in the field. There has been a significant loss of experienced PDMDNS but a substantial increase in new and inexperienced PDMDNS. This is most likely the result of the increase in the new positions in the regional and rural areas generated from the federal funding injected into the primary health network (PHN). With the injection of new PDMDNS, it is also rewarding to see the increase in nurses acquiring and securing post-graduate qualifications.

The above observations from the 2021 demographic survey have highlighted some really positive changes in the landscape of the field of Parkinson's Disease and Movement Disorders Nursing with the newer nurses enrolling in study to support the acquisition of skills. However, while these new nurses work to become advanced practice nurses the more senior and experienced advanced practice nurses must work to prioritise training, mentoring and support for the influx of new PDMDNS entering the field.

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