2022 Annual Demographic Survey of Parkinson's Disease and Movement Disorder Nurse Specialists

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Background

Parkinson's disease (PD) is a neurodegenerative condition that is the most common form of movement disorder. Caring for people with Parkinson's requires the skills and expertise of a Parkinson's disease and movement disorders nurse specialist (PDMDNS) (Bramble, Carroll, & Rossiter, 2018). The World Health Organisation has identified the importance of monitoring health workforce demographics and distribution trends in order to effectively plan for health care needs (WHO 2016). This is the third publication of an annual series reviewing the longitudinal trends of the PDMDNS workforce in Australia (Williams et al. 2021, Williams et al.2023).

Primary Objective

The primary objective of this study 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 for the third consecutive year, 2022.

Secondary Objectives

The secondary objectives were firstly to explore the nature of work that the PDMDNS are engaged in and secondly the long-term sustainability of this subspecialised nursing workforce. Thirdly, to analyse data to identify gaps in service provision to people living with Parkinson's disease in Australia. Fourthly, to compare data collected over three consecutive years and determine if any trends are emerging. 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 conflicts of interest. 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.

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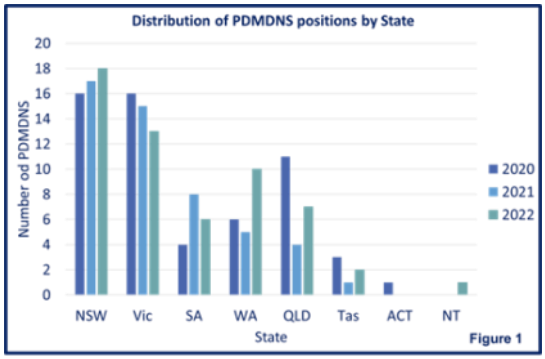
Data was collected through an anonymous online survey produced using the website https://www.surveymonkey.com. The survey included a series of quantitative, multiple-choice questions and one qualitative free text question designed to sample a cohort of PDMDNS across all states in Australia, including 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 in the analysis. The data collected was compared to data collected using the same survey design in 2020 and 2021.

Results

The survey link was emailed out to 202 nurses with an interest in PDMDNS known to the Movement disorder Chapter of the Australasian Neuroscience Nurses Association on 17th August 2022 and a reminder was sent on the 6th September 2022. The survey link was closed on 19th September 2022. A total of 85 responses were received, and of these 68 responses met the inclusion criteria, identifying themselves as employed as a PDMDNS working in Australia or as participating in the Western New South Wales Primary Health Network Movement Disorder Nurse Project. 57 surveys were fully completed (n=57). This was comparable with responses included for analysis in previous years, 2020 n=57 and 2021 n= 50.

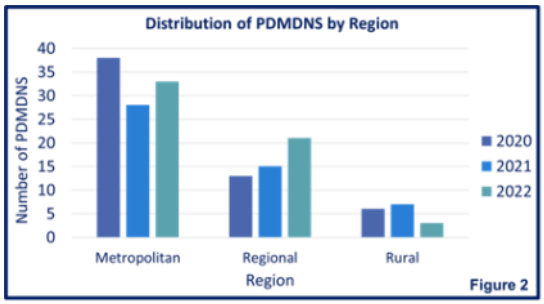
Distribution of PDMDNS by State, Region and Employer

Figure 1 Distribution of PDMDNS positions broken down by state.



NSW continues to lead the number of reported PDMDNS positions with 33% (n=18) in Australia. Western Australia also recorded the largest increase in PDMDNS from 5 to 10. Northern Territory recorded its first PDMDNS position. Unfortunately, QLD and Victoria have seen a marked decrease in reported PDMDNS positions .

Figure 2 Distribution of PDMDNS positions broken down by region



It was encouraging to witness the increase in reflected PDMDNS positions in both metropolitan and regional positions. This is most likely a direct result of governmental funding that was injected into primary health networks Australia wide and NSW local health districts.

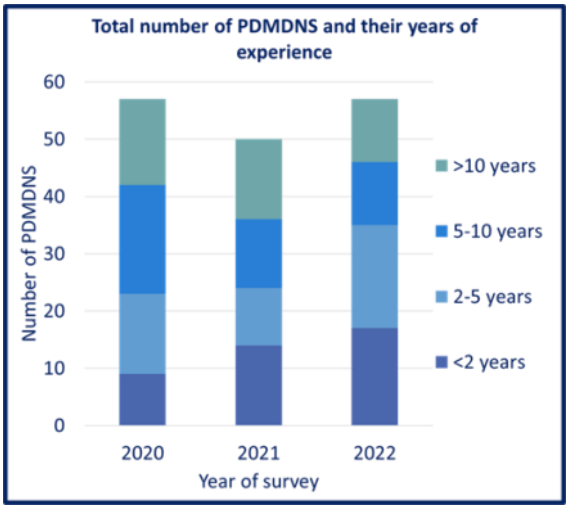
Table 1 Distribution of PDMDNS positions by employer.

Employer	2020		2021		2022	
	%	n	%	n	%	n
State Department of Health	51%	29	46%	23	47%	27
Pharmaceutical Industry	21%	12	16%	8	23%	13
Consumer Organisation	7%	4	16%	8	16%	9
Primary Health Network	4%	2	10%	5	5%	3
Private Practice	5%	3	6%	3	4%	2
Private Hospital	4%	2	2%	1	2%	1
University or Educational Institution	2%	1	2%	1	0%	0
Other	7%	4	2%	1	4%	2
Total	100%	57	100%	50	100%	57

The majority of PDMDNS positions held by responding members are employed by a State Departments of Health followed by nurses employed by the pharmaceutical industry.

Workforce Mobility

Figure 3 Total number of PDMDNS and their years of experience



It was noted that in 2022, 62% of responding PDMDNS have less than 5 years' experience. This is due to the reduction in PDMDNS with over 5 years' experience as they leave the profession.

Table 2. Permanency of funding.

Position is permanently funded	2020		2021		2022	
Yes	58%	33	54%	27	53%	30
No	33%	19	44%	22	40%	23
Not Applicable	9%	5	2%	1	7%	4
Grand Total	100%	57	100%	50	100%	57

In 2022, 53% of PDMDNS roles reflected in the survey responses are permanently funded with 40% not funded. There has been a decrease in the number of reported permanently funded positions over the past 3 years (Table 2). It is important to note that a lack of permanent funding did not impact the reason for leaving for 89% of the participants (Table 3).

Figure 4 How long to PDMDNS intend to stay in their position.

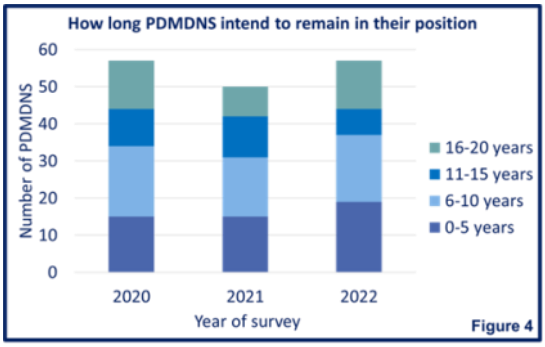


Table 3 Reasons the PDMDNS intends to stay in their position for the intended years.

Years intended to stay in PDMDNS position 2022	Career Development	Funding	Retirement	Other
0-5 years	4	3	11	1
6-10 years	5	3	6	4
11-15 years	1		5	1
16-20 years			11	2
Grand Total	10	6	33	8

Figure 4 shows in 2022, 23% (n=13) of responding PDMDNS intend to stay for 16-20 years with 12% intending to stay for 11-15 years. 33% of responding PDMDNS intend to leave within 5 years and another 33% intend to leave between 6-10 years. Table 3

highlights the reasons with 11% (n=6) noted funding to be an issue, 14% (n=8) gave other reasons. Retirement at 59% (n=33) is the most likely reason for PDMDNS leaving their positions.

Education levels and employment

Figure 5 Number of PDMDNS with post graduate qualifications.

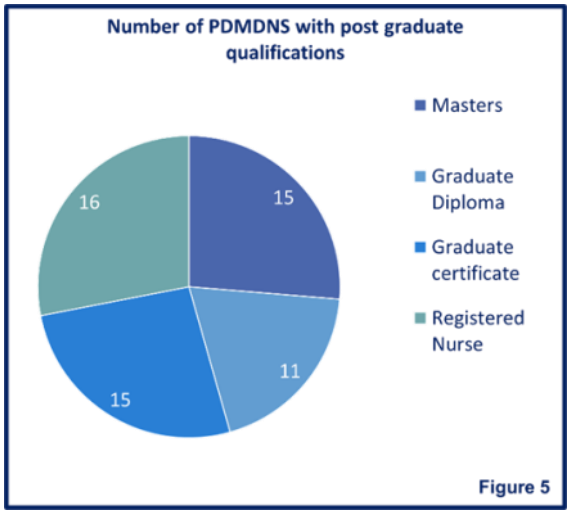
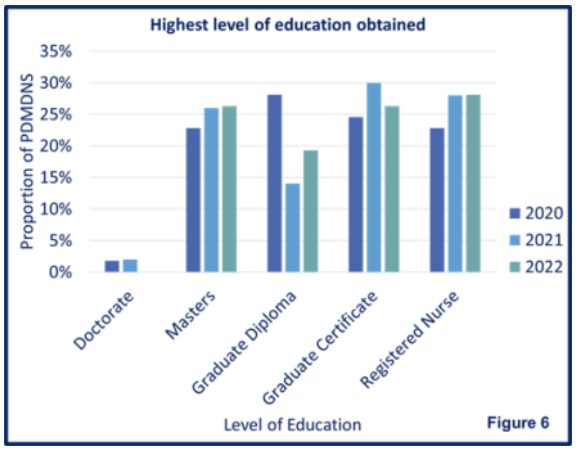


Figure 6 Highest level of education obtained.

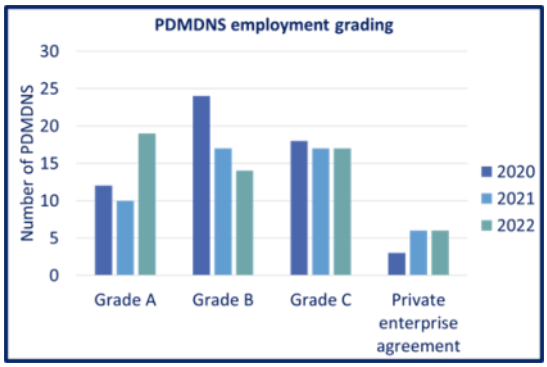


In 2022, 72% of PDMDNS who completed the survey have completed some form of post graduate studies (Table 4). 28% (n=11) of responding PDMDNS are currently enrolled in post graduate studies related to their PDMDNS position. Four are enrolled in a masters and 7 are enrolled in a graduate certificate of honours degree.

Table 4 Number of PDMDNS currently enrolled in tertiary study related to their PDMDNS position.

Currently enrolled in post graduate studies related to the PDMDNS position	2020	2021	2022
Yes	11	14	11
No.	46	36	45
Grand Total	57	50	56

Figure 7 PDMDNS Employment Grading.



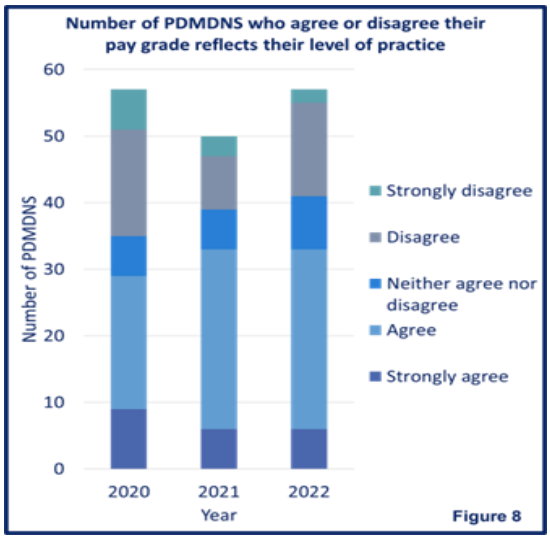
Grade A indicates the competent nurse. In most states, this is graded at a registered nurse level. Grade B is the grading used for experienced or intermediate levels of specialist nurses and in most states, the would be the listing for a Clinical Nurse Specialist level. Grade C is the listing for expert specialist nurses such as Nurse Practitioners or Clinical Nurse Consultants. In this year's survey, 34% (n=19) of responding PDMDNS nurses are employed as a Grade A, compared to 20% (n=10) in 2021. 25% (n=14) of PDMDNS are employed as a Grade B down from 34% (n=17) in 2021. Grade C and Private Enterprise agreements have both remained stable with n=17 and n=6 respectively. (Figure 7)

The increase in the number of PDMDNS employed as a Grade A is consistent with the

influx of new less experienced nurses to the specialty (Figure 3) and the levels of education (Figure 6).

Figure 8 Number of PDMDNS who agree or disagree their pay grade reflects their level of practice

The majority of responding PDMDNS (58%



n=33) agree with their grading and pay scale (Figure 8). Further analysis showed of the 16 PDMDNS who disagree that their pay grade does not reflect their level of pay, 62% (n=10) have been working in the for position for over 5 years, 31% (n=5) for over 10 years. 4 of them are still employed at a Grade A level.

Study Limitations

The aim was to include as many PDMDNS in Australia as possible in this study. The invitation to participate is emailed broadly amongst those known to the ANNA MDC. However, it is likely that there are PDMDNS who either did not receive the invitation or choose not to participate in the survey, which can make interpretation of the data difficult in some circumstances. Anecdotally we conservatively estimate there are at least 10 PDMDNS unaccounted for. The ANNA MDC recognizes the challenge it is to continue to capture all the PDMDNS, however it is necessary for all PDMDNS to be included to provide an accurate reflection of the workforce on the ground, but will continue to work towards supporting and resourcing as many as possible.

Discussion

The long-term sustainability of this subspecialised workforce looks positive with the majority of the nurses intending to remain in their position until they retire. This is particularly significant as the nursing workforce in general recovers from the onslaught of the COVID-19 pandemic (Anderson et al 2023). The influx of new PDMDNS into new positions indicates this is a desirable area of expertise and practice. The influx of less experienced nurses replacing retiring or PDMDNS leaving the speciality is consistent with demographic changes in Australia's regulated health professionals in general. (Anderson et al 2023)

The New South Wales (NSW) Health Department has provided all 15 Local Health Services with funding to improve Parkinson's services particularly to the benefit of people living with PD in regional and remote areas (NSW Government media release 2021). While most services have created or expanded PDMDNS full time equivalent, not all have, and many of these new positions were still being filled at the time of data collection. This will be reviewed in next year's survey.

The high level of post graduate education

and multiple years of experience also describes an advanced level of clinical practice. The continued increase in the number of Industry nurses reiterates the importance of incorporating industry nurses into the ecosystem of the field of PDMDNS . It is also a reflection that all nurses regardless of their employment arrangement benefits and should continue to be associated with the peak professional body of the specialty such as the Movement Disorder Chapter (MC) of Australasian Neuroscience Nurses Association (ANNA).

It is concerning that so many positions are still not permanently funded, with no guarantee these positions will continue to exist. The growth of new PDMDN positions and PDMDNS with less than 2 years' experience, and the significant loss of experienced positions means that education and mentoring of these new nurses is crucial. Care needs to be taken to ensure the advanced practice PDMDNS are not 'burnt out' during this transitional period. Attention should be placed on succession planning, empowering others to contribute to the PDMDNS community of practice and to cultivate the next generation of expert PDMDNS as we plan for the retirement of our PDMDNS population.

Conclusion

Surveying PDMDNS remains an important annual exercise. The longitudinal nature of the data describes the population, geographic location, level of education and clinical experience of the PDMDNS workforce in Australia. This informs professional organisations, such as the ANNA to target education, resources, materials and establish mentoring networks to ensure all PDMDNS are able to work to the highest level of professional clinical practice.

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