STANDARDS FOR PRACTICE
Parkinson's Disease and
Movement Disorder Nurse Specialists
2017
First Edition

Australasian Neuroscience Nurses' Association:
Movement Disorder Chapter

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1. Executive summary

The Movement Disorder Chapter of the Australasian Neuroscience Nurses'
Association (ANNA) was developed in 2016 due to the expansion of this nursing
specialty. This chapter identified the need to expand on the current ANNA
Professional Standards for Neuroscience Nurses (2013) in order to clearly identify
and recognise the movement disorder nurse specialist. The first edition of the
standards for practice for Parkinson's Disease and Movement Disorder Nurse
Specialists was produced for Australian and New Zealand nurses. We recognise that
further work needs to be done to acknowledge the Treaty of Waitangi, Nursing
Council of NZ and the HPCAA (health practitioners competency assurance act). It is
clear this is an exciting step for this nursing speciality which will require revision in
the future as it continues to expand.

2. Glossary

DAT	Device Assisted Therapies
HP	Health Professional
MDT	Movement Disorder Team/Multidisciplinary Team
PD	Parkinson's disease
PDMDNS	Parkinson Disease Movement Disorder Nurse Specialists
PWP	Person with Parkinson's disease

3. History of the role of the Parkinson's Disease Nurse in Australia

Sally-Anne Wherry,

The role of the Movement Disorders Nurse Specialist (PDNS) was first established in Australia in 1997. The Parkinson's Society of Western Australia (PWA) lobbied the State Government to fund and support a pilot role for one Parkinson's Disease Nurse Specialist through the Western Australian Department of Health. This position was modelled on the PDNS roles in the United Kingdom (2010, McLeod). The development of the UK model has been integral to this specialist role.

In 1989 the role of the Movement Disorders Nurse Specialist (PDNS) was first established within the National Health Service (NHS), UK. Since then, PDNS positions expanded throughout the UK and globally and have become a recognised nursing specialty (2010, McLeod).

The National Institute for Health and Clinical Excellence (NICE) produces clinical guidelines as requested by the Department of Health, UK. These guidelines are internationally recognised for the rigorous process used in their development, centred on the best available evidence, including the views of a range of stakeholders 2014, NICE). These guidelines support the development of PDNS roles for people with Parkinson's. In June 2006 the NICE Clinical Guideline 35 for Movement Disorders was issued, resulting in the development of the NHS good practice guide for neurological conditions which emphasised the importance of specialist nurses (2006, NICE).

Following these development, competencies were refined by the Royal College of Nursing, UK, in conjunction with the Parkinson's disease Nurse Specialist Association (PDNSA) and the Parkinson's disease Society, now recognised as Parkinson's UK. These competencies were then released as the 'Competency framework for nurses working in Parkinson's disease management' (Royal College of Nursing 2016).

Whilst these developments moved forward in the UK, Australia's specialist nursing positions slowly expanded. Following the initial pilot position in 1997 the WA Government granted further funding to create a second position in 1998. In 2007, members of the PWA, through member donations and bequests funded a third PDNS position (2010, McLeod).

In May 2008, the Government of Western Australia (WA) developed a 'Parkinson's Disease Services Model of Care,' (2008, Department of Health WA) and adopted the 2006 NICE Guidelines as the best practice framework for the delivery of Parkinson's disease Services.

The PWA funded PDNS position received full financial support from the WA Government in July 2010 after successful lobbying from the PWA (2010, McLeod). There are currently four PDNS servicing the Perth Metropolitan areas (2012, PWA).

Following the evidence from the WA service, Parkinson's Australia issued an initiative to Australian political parties in the lead up to the 2010 Federal election, which highlighted four major challenges that people with Parkinson's, their families and their carers faced (2010, Parkinson's Australia):

1. Limited services that focus specifically on Movement Disorders
2. Lack of awareness and knowledge in health, aged care and the general community of the condition and its impacts
3. Lack of appropriate services for people with early onset Parkinson's
4. Cost restrictions on access to effective treatment options

The initiative was designed to achieve two outcomes:

1. Improve the quality of life for all Australians with Movement Disorders, enable people to continue in employment, to live at home longer and reduce hospitalisations
2. Produce substantial downstream savings in hospital and aged care costs, as well as productivity benefits for government

One of the main proposals of this initiative included applying to the Federal government for funds to employ over 50 Specialist Neurological Nurse Educators across Australia (2010, Parkinson's Australia):

"This would significantly improve the quality of life for people with Parkinson's, Motor Neurone Disease and other neurological conditions whilst reducing government health care costs. These nurse educators can contribute to better management of treatment, and through information and referrals, reduce the impact of symptoms, and hospital and aged care admissions. There are potential savings of up to $100,000 per annum for every person who remains in the community rather than residing in an aged care facility... The challenge of service gaps for those with neurological conditions (like Parkinson's) is exacerbated in regional and remote areas, where Parkinson's is more prevalent (20% higher), as there are no neurologists based in these areas, neurological nurses would provide and essential service to those who cannot afford to travel regularly to the city."

In August 2010, a press release by the Royal College of Nursing Australia (RCNA) officially announced the establishment of the RCNA Movement Disorders and Nursing Faculty (2010, RCNA). This highlighted that "Parkinson's and movement disorders nurses play a pivotal role in developing care and treatment strategies for individuals with progressive neurological conditions, often delivering care over the person's lifetime" (2010, RCNA).

In 2008, the Faculty of Movement Disorder Nurses was launched within the Royal College of Nursing, leading to the development of a strong community of Parkinson's Nurses across Australia. In 2013, the RCNA and The NSW College of Nursing (TCoN) were unified into the Australian College of Nursing (ACN) and the Faculty became a

Community of Interest. The Steering Group for the Community of Interest identified the need for a professional identity, and the development of nurse competencies for nurses working with people with Movement Disorders (ACN, 2014). This working party continued to explore options to develop an organisational structure that would allow the Australian Parkinson's nurses to develop a professional framework and career pathways. In 2016, the Australasian Neuroscience Nurses Association launched the inaugural Movement Disorders Chapter, emphasising the expansion of this nursing speciality across Australasia.

4. The diversity of the role of the Parkinson's Disease and Movement Disorder Nurse Specialist.
Janet McLeod

Parkinson's disease is a multifaceted condition affecting all aspects of life thus bringing a huge long term impact on both the person with the diagnosis and their partner and family. While the introduction of levodopa in the 1960's changed the life expectancy and quality of life of those affected by the disease process it was the introduction of the Parkinson's Nurse Specialist almost three decades later which transformed the management of Parkinson's from a medical model to a collaboration of professionals and those living with Parkinson's.

In Australia the role of the PDMD Nurse Specialist is as diverse as the presentation of the condition. An Australian survey of 53 nurses identified specialist nursing positions across the nation (excluding the Northern Territory). The variability of responsibilities and the diversity of settings was revealed.

The survey results indicated 36% of the 53 respondents were MDNS with 21% employed by PD associations in community roles. 16% of the respondents included DAT and pharmaceutical nurse specialists. The survey outcomes also demonstrated that Parkinson's Nurse Specialists or Movement Disorder Specialist Nurses are employed in both the public and private sectors, with ongoing funding a common concern to all (ADD survey reference).

The survey also identified the diversity of nursing qualifications, revealing a high level of qualifications. The nurses surveyed included three Nurse Practitioners, two with PhD degrees and ten Masters of Nursing. The remaining 38 held a Bachelor of Nursing. Collectively, many had completed additional studies, including a Diploma in Parkinson's disease and the GP online Parkinson's Course, available through Parkinson's Australia.

It is essential to continue to expand these diverse specialist nursing roles which provide complex care for all people living with Parkinson's Disease from diagnosis to death. To ensure this model of care is maintained both professional and financial investment in nursing services is paramount. This in turn will reduce the growing burden of an aging population on our health care systems.

5. The future of Parkinson's Disease and Movement Disorder Nursing in Australia

Amy Jones,

The total health costs of PD to the Australian economy in 2011 was 775.4 million with 478.5 million incurred as direct health care costs predominantly incurred through hospital admission, aged care costs and pharmaceutical costs (Deloitte Access economics, 2011, p. ii) . The Australian government provided no funding to support Australian PD nurse position and in 2011 there were only 33 PD nurse specialists, all funded privately; compared with 264 in the UK (Group, 2016). It is calculated that a single PD nurse saves £60 000 in consultant fees, £80 000 in emergency admissions and £194 000 on days spent in hospital (Moonan, 2011).

In order for PD nurses to fulfil their future role, health services need to recognise the burden that PD places on our economy by incorporating PD into the national chronic disease strategy. In doing so this will make PD a priority, mobilise funding and drive collaboration in development of strategies, policy directions, research priorities, education, services and community awareness to better support people living with Parkinson's (Parkinson's Australia Action Framework, 2016, p. 4).

Several studies indicate that people with PD have poor health literacy regarding symptoms of PD and how treatment works. Health literacy plays a significant role in determining the choices people make to maintain health and prevent chronic illness (Thornton, Bentley, & Kavanagh, 2009; Velardo, 2015). As the prevalence of PD increases with our aging population and with increasing health care costs, specialist PD nurses are a strategy that can be used to reduce the burden of care and economic costs.

Parkinson's Australia has published several papers including "A call to action in Parkinson's" (2014); "Parkinson's nurse specialist position paper" (2014); "Making Parkinson's a priority action framework" (2015); 'Living with Parkinson's disease an updated economic analysis" (2014). These papers continuously highlight that people living with PD are poorly supported in the healthcare system due to inadequate knowledge about PD among healthcare staff for treating and recognising the complex interplay between symptoms and treatment of PD. People living with PD have poor access to specialist health care and support; PD nurse specialists fill a crucial gap by providing education to health care colleagues, advocating for better acute care management practices, implementing policy and developing medication management protocols.

PD nurses reduce the burden of care by employing chronic disease management strategies that promote health literacy and self-efficacy by employing specialist knowledge in medication management, education, patient/carer counselling, screening and rehabilitation referrals (Bhidayasiri et al., 2016). Also, in a health care system where patients are only able to access specialist care, provided by a neurologist, every 6 months; PD nurse specialists are a critical point of care to

manage complex idiosyncratic medication regimes and timely support in times of crisis (Parkinson's Australia Action Framework, 2016, p. 4).

WHO indicate that chronic disease places a greater burden on already struggling acute care models of care and that health services need to reorientate away from acute care models and move towards chronic management (WHO, 2002). As health care systems move away from a model of acute care towards a model of chronic care, PD nurses will have an increasing role in the community to develop and deliver chronic health care models of care and develop strategies that promote self-management in chronic conditions, such as PD. Increasingly telehealth is being used in Australian healthcare as a way to reduce travel costs and improve health care access in remote regions of Australia (Making Parkinson's a priority action framework, 2015). PD nurse specialists should have an increasing role and support from health departments for developing and implementing chronic health care models and help improve access to specialist care in remote regions of Australia. In order to provide high quality, efficacious and efficient health services, PD Nurse specialists need to be provided with opportunities and access to funds for researching PD specific nurse interventions.

Lastly, PD nurses need training in synthesising, designing and carrying out research in order to prove the efficaciousness of their interventions and care models, to ensure their practice is evidence based. Furthermore, educational pathways need to be developed by educational intuitions to ensure PD nurses are adequately prepared for their role in symptom assessment, treatment management, patient education, chronic care management and health service delivery. This has the added benefit of making the specialty attractive and an achievable career path.

6. The development of the Standards for Practice framework
Sue Williams,

This document has been developed with reference to
  I.   Nursing and Midwifery Board of Australia (NMBA) "Registered Nurse and Nurse Practitioner Standards for Practice" 2014,
 II.   Benner's "From Novice to Expert: excellence and power in clinical nursing practice" 1984,
III.   Parkinson's Disease Nurse Specialist Association (PDNSA) United Kingdom's "Competencies: A competency framework for Nurses working in Parkinson's Disease Management" 2016iv.
 IV.   Professional Standards for Neuroscience Nurses, Australasian Neuroscience Nurses Association (ANNA), 2013

As regulated health professionals in Australia PDMDNS's are responsible and accountable to the NMBA. The national Registered Nurse (RN) standards for practice

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underpin current practice. (NMBA RN 2014) These NMBA standards for practice have informed the development of these Standards of Practice.

Nurse Practitioners (NP) provide higher levels of clinically focused nursing care. The NP scope of practice is built on the platform of the RN scope of practice providing nursing care which is regulated, and assumes additional responsibilities and accountabilities. (NMBA NP 2014)

Benner's Stages of Clinical Competence recognise the acquisitions and development of a skill as a nurse passes through five levels of proficiency: novice, advanced beginner, competent, proficient and expert. This document recognises that a nurse freshly employed as a new PDMDNS will be, in Benner's terms, a novice or advanced beginner. They may have no experience in the situations in which they find themselves, they require support and supervision as their knowledge develops. (Benner 1984)

A new PDMDNS is required to work toward achieving a level consistent with Benner's competent, proficient and expert skill level of nursing. The competent nurse has two to three years of experience. They can demonstrate efficiency and confidence in their actions within a suitable timeframe and independently. The proficient nurse learns from experience and recognises when the clinical picture changes. The expert nurse has developed an intuitive grasp of clinical situations underpinned by a holistic model. They have a deep understanding of the situation and a high level of proficiency, which aids decision making in situations where the nurse has limited experience. (Benner 1984)

Parkinson's Disease Nurse Specialist Association (PDNSA) United Kingdom's "Competencies: A competency framework for Nurses working in Parkinson's Disease Management" 2016 refers to three levels of skill; competent nurse, experienced specialist nurse and expert nurse. These terms align with the UK's health care assistants Skills for Health, Career Framework for Health (2005), including:
- Level 5 – registered competent nurse defines the entry point for registered nurses into the PD specialty, they are developing their knowledge and skills.
- Level 6 – experienced specialist nurse has developed their knowledge and skills demonstrating mastery and understanding.
- Level 7- expert specialist decision nurse
- Level 8 – consultant nurse are regarded as a specialist or expert practitioner, they coordinate comprehensive care of patients, working autonomously according to local protocols.

Table 1. Aligning grades of nursing specialisation across Australia and New Zealand illustrates how the terms Competent Nurse, Experienced Specialist Nurse, and Expert Nurse used in this document align with the terms used in the above documents, and pay scales in various states.

NMBA standards for practice 2014	RN standards for practice	RN standards for Practice	RN standards for practice NP standards for practice
New South Wales	Registered Nurse, Clinical Nurse Specialist	Clinical Nurse Consultant level 1,2	Clinical Nurse Consultant level 3, Nurse Practitioner Yr 1 and 2
Queensland	Nurse Grade 5 Registered Nurse	Nurse Grade 6, Clinical Nurse	Nurse Grade 7, Clinical Nurse Consultant Nurse Practitioner
Victoria	Registered Nurse	Clinical Nurse Specialist	Nurse Practitioner Yr 1 and 2
South Australia	RN level 1	RN Level 2 (Clinical Nurse)	RN Level 3 (Clinical Nurse Consultant) Nurse Practitioner
Western Australia	RN Level 1 -2	Senior registered Nurse level 1-4	Senior registered nurse level 5-6 Nurse practitioner
Australian Capital Territory	Registered Nurse Level 2	Registered Nurse Level 3 Clinical Nurse	Registered Nurse Level 3 Nurse Practitioner (registered Nurse level 4, grade2)
Tasmania	RN Level 2		RN Level 3 (Clinical Nurse Consultant)
Northern Territory	Nurse 3-4	Nurse 5-6	Nurse 7-8
New Zealand	Registered Nurse	Clinical Nurse Specialist	Nurse Practitioner Yr 1 and 2
Benner's stages of clinical competence (1984)	Competent Nurse	Proficient Nurse	Expert Nurse
PDNSA Competencies: a competency framework for nurses working in Parkinson's disease management	Competent nurse	Experienced specialist nurse	Expert specialist nurse
Parkinson's Disease and Movement Disorder Nurse Specialist Standards for Practice. ANNA MDC	Competent Nurse	Experience specialist nurse	Expert specialist nurse
Corresponding level of post graduate education	Bachelor of Nursing, working towards post graduate education	Graduate Certificate Working towards Masters or Doctorate	Masters Doctorate

7.   How to use the Standards for Practice framework

This document is for nurses working with people with Parkinson's disease and may apply to other movement disorders. These standards for practice can be used in the following ways:
- Performance management
- Revision of existing position descriptions
- Development of new job descriptions and scopes of practice
- Facilitate continuing professional development
- Recognition of PDMD nurse specialists level of expertise

In Australia the NMBA RN and NP are the only recognised terms that are used consistently across Australia. Different states have different terms to indicate varying levels of skill and remuneration. This document provides terms of reference for PDMDNS to support evidence of expertise.

PDMDNS using this framework can map evidence against each competency to support and demonstrate achievement. This evidence will be articulated against local requirements for position grading and reaccreditation.

Due to the diverse nature of these roles the evidence to support the level of expertise will be varied. Examples may include:
- Case presentations that demonstrate knowledge of the disease, assessment skills, clinical interventions, patient education, and multidisciplinary team participation.
- Audit and review of written documentation e.g. patient notes, letters and reports.
- Self-assessment through observation and critical analysis of every day practice by the individual.
- Written testimony of the PDMDNS's clinical practice by colleagues and supervising medical practitioners.
- Certificate of attendance at, and an evaluation of the learning outcomes of study days and courses.
- Demonstration of evidence of informed practice, with supportive literature, eg the development of protocols, guidelines, policy development.
- Active involvement in clinical supervision, and mentorship.
- Demonstrated ability to build and deliver a quality service.
- Leading or participating in local education opportunities for patients, carers and colleagues.

Evaluation of the Standards for Practice framework.
These standards of practice will be reviewed in line with developments in practice across Australia and New Zealand.

The Parkinson's Disease and Movement Disorder Nurse Specialist Standards for Practice 2017 have been principally developed by the Movement Disorder Chapter

Committee. Expert contribution has been sought through its development. The final draft was sent out for comment from the wider PDMDNS community.

The effectiveness of the framework will be measured in 2018 by a focus group evaluating
1. If and how it is being used,
2. Ease of use and any problems that arise
3. Gaps in information

Outcome measures of the development of the framework would include
1. Base line self-assessment survey of a representative group to establish an existing level of competence according to the framework
2. This survey would also indicate gaps in competence and inform the development and delivery of education and training for Parkinson's nurses.
3. Repeat self-assessment survey of a representative group to demonstrate a higher level of competence x years later

8. The Standards for Practice

Standard 1. Knowledge of Parkinson's disease.

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse / Nurse Practitioner*
Pathophysiology • Developing knowledge of the aetiology of and incidence of PD, • Developing knowledge of the anatomy, pathophysiology, the function of the basil ganglia, the dopamine neuron, Braaks hypothesis. • Recognises how aging and co-morbidities impact on PD	**Pathophysiology** • Links the pathophysiology of PD and aging to management options. • Educates the multidisciplinary team, PwP, and their careers of the aetiology, pathophysiology of PD. • Explains the clinical implications of the pathophysiology of PD	**Pathophysiology** • Provides education regarding new theories and research developments in the aetiology, pathophysiology of PD. • Expands their level of knowledge to include critical analysis. • Explains anatomy and pathophysiology in relation to device therapies.

Disease Progression
 	
• Considers the progression of PD by acknowledging the different needs of people during the 4 clinical stages.
 	
  1. Diagnosis
  2. Maintenance
  3. Complex
  4. Palliative
	Disease Progression
	
	• Links the pathophysiology to the stage of disease.
	
	• Taylors management to the stage of disease and liaises with HP's
	
	• Describes the pathological differences underlying Parkinson's disease and Parkinsonism
		Disease Progression
		
		• Prepares people with Parkinson's disease, and their carers for the next stage of disease.
		
		• Works with other HP's to provide adequate services and support for the future care needs, preventing the need for crisis management.
		
		• Discusses end of life issues with people with PD and their carers

Clinical Phenomenology and Symptomatology • Develops knowledge of 1. The motor symptoms 2. The non-motor symptoms 3. The neuropsychiatric symptoms 4. Atypical Parkinson's syndromes (PSP, MSA,	**Clinical Phenomenology and Symptomatology** • Assesses and describes 1. The motor symptoms 2. The non-motor symptoms 3. The neuropsychiatric symptoms 4. Atypical Parkinson's syndromes (PSP, MSA,	**Clinical Phenomenology and Symptomatology** • Assesses, describes and diagnoses* or assists in the diagnosis of 1. The motor symptoms 2. The non-motor symptoms 3. The neuropsychiatric symptoms

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse Nurse Practitioner*
CBD, PDD, DLB 5. Terminology; off, tremor, rigidity, akinesia, bradykinesia, on, dyskinesia, dystonia,	CBD, PDD, DLB • Uses correct terminology when discussing and explaining phenomenology and symptomatology • Links the Phenomenology and symptomatology to the clinical care needs of the PwP and carer and refers to HP's accordingly using evidence based practice	4. Atypical Parkinson's syndromes (PSP, MSA, CBD, PDD, DLB • Educates HP on the phenomenology and symptomatology • Works with other HP to design and implement care pathways in anticipation of potential problems for the PwP. • Works to develop evidence based management protocols • Understands the wider political environment and how it impacts on service provision and design

Assessment Tools
 	
• Shows awareness of the need to use validated standardised tools to assess PwP
 	
• Developing knowledge of tools available to assess movement disorders;
  1. Unified Parkinson's Disease Rating Scale (UPDRS)
  2. Carer questionnaires
  3. Cognitive assessments
  4. Gait assessments
 	
• Understands the value of video to record the PwP clinical symptoms and the ethical and legal issues associated with its use.
	Assessment Tools
	
	• Uses and interprets results from a range of tools, and discusses the implication for management options.
	
	• Working towards proficiency in the UPDRS.
	
	• Understands the common limitation of the clinical use of tools.
	
	• Uses video
	  1. To track changes in clinical symptoms over time
	  2. To educate HP's
	  3. Responsibly, ethically, and legally according to local guidelines.
		Assessment Tools
		
		• Identifies and critically analyses tools appropriate for specific clinical measurement.
		
		• Understands the significance of reliability and validity of data related to clinical outcome measures.
		
		• Is proficient in the UPDRS as demonstrated by completion of the MDS online assessment.
		
		• Identifies gaps in service provision and initiates strategies to address them using quantitative and qualitative outcome measures.

Develop knowledge • Identifies and attends recognised training courses for management of PwP. • Dedicates time for study and professional	**Develop knowledge** • Maintains professional development through access to national study days and courses. • Shows knowledge of best	**Develop knowledge** • Contributes to the professional development of other PDMDNS at regional and national study days and courses.

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse **Nurse Practitioner***
networking • Working towards post graduate education.	practice through participation in local and national specialist networks. • Achieved Graduate Diploma level education. Working towards Masters in PD/MD	• Attends and participates in educational opportunities at a national and international level. • Positioned to offer mentoring / work place experience opportunities for PDMDNS's working toward higher degree

Standard 2: Accountability and professional development

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse / Nurse Practitioner*
Scope of Practice • Works with in the scope of practice of an RN. • Works within the scope of the Code of Conduct of their employer. • Discusses the scope od professional practice in their current role.	**Scope of Practice** • Identifies areas of practice that may require the development of policies or guidelines to ensure their practice remains within the scope of an RN. • Works with others to develop policies or guidelines that define the scope of practice of an PDMDNS • Shows awareness of the codes of practice of other HP's and where the line is for duty of care • Discusses with HP's where the lines of responsibility are.	**Scope of Practice** • Develops policies or guidelines that outline the scope of practice for the PDMDS. • Demonstrates understanding and maintains the lines of responsibility and accountability for PDMDS medical practitioners and other HP's • * Works within the scope of practice of the NP
Accountability for Service • Develops and manages own workload. • Identifies when it is appropriate to seek support	**Accountability for Service** • Demonstrates ability to prioritise and manage service workload in response to changing clinical and service needs. • Demonstrates ability to work using different service models.	**Accountability for Service** • Maintains a strategic overview of the service, Identifying alternative models to managing workload. • Recommends redesigns to service models that recognises budgetary needs for growth.
Documentation • Maintain accurate clinical records, applying knowledge of data protection and patient confidentiality. • Developing knowledge of how scores from validated tools enhance documentation of clinical outcomes	**Documentation** • Documentation reflects knowledge of PD, providing clear communication of assessments, concerns, implemented care plans and recommendations. • Improves communication between the different HP's involved in the care of the PwP	**Documentation** • Develops documentation processes that improve communication between HP's in the primary, secondary and tertiary services.
Evidence based practice • Accesses and works to	**Evidence based practice** • Uses own clinical expertise,	**Evidence based practice** • Identifies gaps in the

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse Nurse Practitioner*
evidence-based best practice guidelines where available. • Seeks support as required	and evidence based practice along with the local clinical governance framework to advise others on the management of PD • Identifies gaps in the evidence base and collaborates with others to address them.	evidence base and initiates strategies to address them. • Works collaboratively with local and national bodies to develop best practice guidelines
Informed Consent • Adheres to principles of informed consent • Confirms PWP consent to be filmed before recording clinical symptoms	**Informed consent** • Assesses PWP and carer literacy levels, their primary language to monitor their understanding of the information required to give informed consent. • Acquires formal PwP consent to record clinical symptoms according to local requirements.	**Informed consent** • Advises, supervises and coordinates colleagues on the ethical issues of informed consent.
Relationships with Industry • Shows awareness of pharmaceutical and commercial involvement in PD management • Identifies local policy to guide their relationship with industry • Is aware of the role of Medicines Australia in establishing the ethical standards for industry • Shows awareness of the Therapeutic Goods Administration and its role in recommending medication and their clinical indications.	**Relationships with Industry** • Develops and maintains professional relationships with commercial organisations for the benefit of the PwP. • Understands the Medicines Australia Code of Conduct and how it applies to the role of the PDMDNS • Understands and aligns medication management to the Therapeutic Goods Administration.	**Relationships with Industry** • Uses experience and expertise to influence Pharmaceutical and commercial industry to improve patient care. • Understands and interprets the Medicines Australia Code of Conduct, and ensures they are acting in accordance with it. • Understands and aligns medication management to the Therapeutic Goods Administration and critically interprets their recommendations.
Reflective practice • Recognises the importance of clinical supervision and attends regularly. • Identifies critical incidents and discusses the learning points	**Reflective practice** • Improves their practice and service provision by reflecting on positive and negative clinical experiences. • Provides mentorship for	**Reflective practice** • Maintains personal clinical supervision and reflective practices. • Initiates and provides skilled supervision for members of the team and

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse / Nurse Practitioner*
	less experienced nurses	other PDMDNSs • Supports and guides other nurse mentors
Reflective practice • Recognises the importance of clinical supervision and attends regularly. • Identifies critical incidents and discusses the learning points	**Reflective practice** • Improves their practice and service provision by reflecting on positive and negative clinical experiences. • Provides mentorship for less experienced nurses	**Reflective practice** • Maintains personal clinical supervision and reflective practices. • Initiates and provides skilled supervision for members of the team and other PDMDNSs • Supports and guides other nurse mentors

Standard 3: Promotes patient independence

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse Nurse Practitioner*
Advocacy • Acts as an advocate for PwP and carers at a team level to remove barriers to care and services	**Advocacy** • Acts as an advocate for PwP and carers ensuring their voice is heard at a local health service level. • Collaborates with Parkinson's Australia and the state based affiliates to develop services and resources for PwP and carers	**Advocacy** • Advocates on behalf of PwP and carers at a governmental level to ensure resources and services are developed to meet the needs of this population •
Service Development • Develops awareness of issues related to service development.	**Service Development** • Provides opportunities for PwP to contribute to the development of local services	**Service Development** • Uses qualitative tools to identify the needs of PwP as part of service development.
Time management • Manages time effectively by assessing the urgency of patient contact/ phone calls	**Time management** • Sets realistic expectations regarding availability for anxious or dependent PwP and carers.	**Time management** • Identifies reasons for a PwP's anxiety or dependency and develops strategies to alleviate them.
Self-Management • Builds a professional relationship built on trust • Develops an understanding of strategies used to self-manage PD	**Self-management** • Provides the PwP, carers with information and strategies to support self-management • Support, or contributes to a self-management program	**Self-management** • Empowers the PwP and carers to identify and reach realistic goals of self-management • Designs and runs a self-management program
Knowledge base • Demonstrates knowledge of the physiological, social and spiritual needs of PWP and the ability to recognise and describe signs of common problems that may compromise self-care	**Knowledge base** • Identifies the physiological, social, spiritual, psychological, and cultural needs of Parkinson's disease and normal aging. • Provides the PwP and carers the information and tools they needs to make informed decisions	**Knowledge base** • Critically appraises the available research and evidence base to ensure best practice in managing PD and normal aging. • Identifies areas for research into self-care or the PwP and carers inability to self-care • Participates in developing and publishing the

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse **Nurse Practitioner***
		evidence base and best practice guidelines.
Nursing Interventions • Uses advocacy, interpersonal and listening skills to enable PwP and carers to express their needs and receive appropriate care. • Maintains the safety, privacy, respect and dignity or the PwP and carers. • Demonstrates relevant current knowledge of health promotion. • Assesses the PwP ability to manage their own care independently or with their carer, and implements strategies or services to ensure their needs are met.	**Nursing Interventions** • Provides information and support to empower the PwP to make decisions related to their PD. • Conducts comprehensive holistic assessments to identify changes in the patient condition and refers to appropriate HP's. • Demonstrates ability to implement treatment plans within local guidelines or policies. • Implement knowledge and skills of effective health promotion to meet the needs of Parkinson's disease	**Nursing Interventions** • Critically assesses, plans, implements and evaluates planned care that meets the holistic needs of PwP. • Initiates decision making based on expertise and experience to achieve best outcomes • Recommends or initiates* a range of investigations related to the changing needs and condition of the PwP • * Demonstrates autonomy of practice and decision making in meeting the needs of the PwP
Management • Provides support and advice for PwP to be cared for in the environment of their choice, adapted to suit their needs • Communicates and collaborates with multiple services, placing the PwP and carers at the centre of decision making •	**Management** • Engages and develops collaborative relationships with multiple local services • Identifies, acknowledges and promotes activities the benefit the PwP and carers, including exercise, medical and complimentary therapies	**Management** • Critically analyses the legal, moral and ethical issues related to PD to develop and improve care, policies, and strategies at local, state and national levels • Effectively champions the needs of PwP through patient advocacy and active empowerment.

Standard 4: Assessment and management of PD

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse / Nurse Practitioner*
Developing knowledge	**Developing expertise**	**Demonstrating Expertise**
Assessment	**Assessment**	**Assessment**
• Recognises and describes phenomenology and symptomatology during clinical assessment of the PwP.	• Demonstrates ability to identify, and describe phenomenology and symptomatology during clinical assessment of the PwP	• Demonstrates advanced assessment skills by identifying changes in phenomenology and symptomatology associated with the clinical progression of PD
• Identifies the changing physiological, psychological, social, cultural, developmental, sexual and spiritual needs of the PwP and carers.	• Demonstrates knowledge of the changing physiological, psychological, social, cultural, developmental, sexual and spiritual needs of the PwP and carers.	• Recognises, and prioritises the management of symptoms in clinical evidence based practice.
• Has up to date information about common motor and non-motor symptoms, and potential side effects of medication.	• Provides HP's, PwP and carers with up to date information about common motor and non-motor symptoms and potential side effects of medication	• Acts as a resource to colleagues, influencing local work practices, policies and guidelines.
• Discusses and responds to the changing clinical needs of PD and normal aging	• Provides HP's with education and resources to guide management of PD	• Questions and reviews practice and responds innovatively
•	• Identifies and acts when phenomenology and symptomatology are uncharacteristic of normal PD. Eg PSP, MSA, CBD, PDD, DLB,	• Demonstrates self-awareness by challenging own practice and seeking improvement.
	• Anticipates the changing physiological, psychological, social, cultural, developmental, sexual and spiritual needs of PD and normal aging and monitors them accordingly.	• Prepares the PwP and carers to respond to the changing physiological, psychological, social, cultural, developmental, sexual and spiritual needs expected with PD progression and normal aging.
	• Responds to the changing needs of PwP by generating appropriate treatment options in consultation with medical team and refers to services to	

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse Nurse Practitioner*
	enhance outcomes.	
Assessment tools • Has knowledge of clinical rating scales used in PD. • Seeks direction and guidance to use assessment tools.	**Assessment tools** • Correctly uses appropriate clinical rating scales when assessing a PwP.	**Assessment tools** • Critically analyses assessment tools for their specificity and sensitivity and understands their limitations when applied clinically.
Communication and documentation • Developing skills in communicating assessment results such as patient history, description of phenomenology and symptomatology through discussions with colleagues and written documentation	**Communication and documentation** • Demonstrates the ability to discuss and document patient history, assessment findings, outcomes for implemented care plans and further recommendations. • Recognise changes to cognition as disease progresses and tailors education and communication accordingly	**Communication and documentation** • Demonstrates expertise when discussing and documenting patient history, assessment findings, outcomes for implemented care plans and further recommendations. • Analyses communication strategies and tailors them according to patient needs.

Standard 5: Medications

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse / Nurse Practitioner*
Developing knowledge	**Developing expertise**	**Demonstrating expertise**
• Developing knowledge of the oral and non-oral medications used to treat PD • Developing knowledge of the medications contraindicated in PD • Consolidating knowledge of the significance of medications on time to the clinical outcomes for PwP. • Consolidating knowledge of the complexity of regimes	• Discusses and explains the oral and non-oral medications use to treat PD • Educates HP and screens treatment regimens for medications contraindicated in PD • Educates PwP, Carers and HP on the significance of medications on time and the clinical outcomes for the PwP	• Develops medication policy at local and national levels • Advises and supports the PwP, carer and HP in the management of medications. • Assess effectiveness, benefits and side effects of medication regimes, and recommends changes based on clinical evidence, extensive knowledge and experience. • * Nurse Practitioners prescribe ongoing medications and changes to medications in the existing regime according to their local policy and guidelines
Practice	**Practice**	**Practice**
• Works within their scope of practice by identifying and adhering to their role in relation to medication management • Ensures the administration of medication is done in accordance with local policy and guidelines. • Provides support and information to PwP and carers regarding the provision of medication	• Educates and equips Pwp and carers to manage their own medication regime, enabling them to observe and report back with the benefits and side effects. • Takes a medication history 1. Establishes whether medications are being taken correctly and identifies any reasons for non-compliance. 2. Reviews the effectiveness of the medications on symptoms and overall condition. 3. Discusses with medical team recommendation for changes to the medication regime	• Collaborates with PwP and carers to develop individual clinical management plans. • Works with local drug committees to develop protocols and shared care guidelines • * Applies evidence base and local formularies in prescribing practice • Monitors prescribing practice through follow up and within clinical management plan, and makes referrals back to medical practitioner where appropriate.

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse / Nurse Practitioner*
Device Assisted Therapies • Develops an understanding of the role of device assisted therapies and the role of continuous delivery and stimulation. • Refers PwP and carers to resources and information as directed by the medical team • Participates in the initiation, titration and management of device assisted therapies as appropriate to their PDMDNS role	**Device Assisted Therapies** • Demonstrates an understanding of the role and management of device assisted therapies and the role of continuous delivery and stimulation by providing education to HP's, PwP and carers. • Prepares and educates PwP and carers for device assisted therapies as when by the medical team • Manages initiation, titration and management of device assisted therapies, in accordance with local policies and guidelines. • Provides ongoing support, assessment and advice to the PwP and carers once established on the device assisted therapy.	**Device Assisted Therapies** • Develops and delivers education packages for HP's, PwP and carers on the role of device assisted therapies and the role of continuous delivery and • Identifies when device assisted therapies are of benefit to the Pwp and carers making recommendations and discussing with the medical team. • Provides ongoing support, assessment and advice to the PwP and carers once established on the device assisted therapy, making adjustments as directed within the RN scope of practice. • *Initiates titration and management of device assisted therapies, as per the NP scope of practice.
Accountability • Documents and maintains accurate records across multiple settings.	**Accountability** • Documents and maintains accurate records across multiple settings.	**Accountability** • Documents and maintains accurate records across multiple settings.

Standard 6: Managing the complexity of Parkinson's Disease

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse Nurse Practitioner*
Multidisciplinary Team • Identifies and establishes working relationships with HP's and volunteers with expertise in Parkinson's disease • Understands the role of the PDMDNS as part of the multidisciplinary team across multiple settings	**Multidisciplinary Team** • Identifies gaps in local service provision and works with others to expand services to meet the needs of PwP and carers. • Developing own leadership skills. Is recognised as a pivotal member of the MDT. • Establishes professional networks within their local area service and the wider state community	**Multidisciplinary Team** • Leads MDT projects to develop new working practices that include HP's, volunteers and community services. • Initiates new networking opportunities on a local, state and national basis.
Non motor symptoms; Neuro psychiatric • Recognises Depression, Dementia, Anxiety, sleep disorders, hallucinations and impulse control disorders and reports them to the medical team • Shows awareness of how these affect the PwP and carers, and advises accordingly	**Non motor symptoms; Neuro psychiatric** • Assess PwP for psychological symptoms using tools. Eg MOCA. Adenbrooks • Provides support and advice to PwP and carers to help them manage these symptoms • Discusses symptoms and management with medical team and refers appropriately to mental health or dementia teams • Educates carers and HP's on the management of neuro psychiatric non motor symptoms	**Non motor symptoms; Neuro psychiatric** • Advises other members of the MDT about the management of neuropsychiatric symptoms • Plans and manages the needs of PwPa and carers associated with neuro psychiatric complications. • Educates peers othe HP's on the management of neuro psychiatric non motor symptoms of PD.
Motor and non-motor fluctuations • Is aware of motor and non-motor fluctuations and end of dose problems. • Demonstrates awareness of the physiology relating to fluctuations • Demonstrates ability to evaluate the current medical plan and feedback	**Motor and non-motor fluctuations** • Demonstrates ability to work within set guidelines and protocols for the management of motor and non-motor fluctuations. • Demonstrates ability to interpret data collected from assessment tools and electronic equipment to	**Motor and non-motor fluctuations** • Independently interprets the findings of investigations. • Demonstrates ability to articulate the evidence base and change practice accordingly • Accepts referral from other

Competent Nurse	Experienced Specialist Nurse	Expert Specialist Nurse / Nurse Practitioner*
to the treating physician. • Identifies tools and electronic equipment available to monitor motor and non-motor fluctuations.	make changes to treatment within agreed guidelines or protocols. • Demonstrates ability to supervise and teach junior colleagues. • Demonstrates ability to communicate the issues identified related to motor and non-motor fluctuations to PwP, carers and HP's involved in their care. • Recognises biphasic and Tardive dyskinesia and discusses appropriate management strategies with the medical team	HP's • Identifies appropriate services and products to meet Pwp and Carers needs • Facilitates the development of new services to meet the PwP and carer needs. • Develops training programmes, guidelines and protocols to manage motor and non-motor fluctuations in Pwp.

Mobility and falls
 	
• Demonstrates awareness of contributory factors that cause PwP to fall.
• Maintains basic awareness of falls assessments and prevention.
• Works with MDT to optimise mobility and minimise falls
• Accesses local falls prevention programs.
	Mobility and falls
	
	• Assesses and identifies environmental, physical and pathological factors that cause falls in PwP
	  • Falls history,
	  • Gait balance
	  • Musculoskeletal
	  • Fear of falling,
	  • Visual or cognitive impairment
	  • Medication review
	  • Environmental hazards
	  • Continence assessment
	• Refers to MDT and falls prevention programs
	• Educates and advises PwP, carers and HP's on falls management in PD
		Mobility and falls
		
		• Identifies gaps and leads the development of local and regional initiatives to ensure falls in PwP are managed effectively.
		• Develops and monitors the implementation of care pathways and policies for falls identification and management in PD.

Timeline

Phase	Description	Commenced	Who
1.	Agreement to proceed	May 2014	Sally-Anne Wherry, Sue Williams
2.	Development of scoping document	July 2014	Sally-Anne Wherry
3.	Assessment of current PDNS roles within Australia	2016	Janet McLeod
4.	Assessment of evidence related to scope of role within PDNS	May 2017	Sue Williams
5.	Development of PDNS Competencies	May 2017	MDC ANNA committee
6.	Send out for comment	Sept 2017	Sue
7.	Development of Survey to collect workforce demographics, Consider Ethics approval		
8.	Promotion of Competencies through: 1. PDNS Meetings 2. peer reviewed publications	September 2017	
3.	Attraction of funding to further research role scope and benefits to patients		

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