



Evidence based models  
that support best  
practice nursing services  
for people with  
Parkinson's disease in  
regional NSW:

An integrative literature  
review

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## **II. Executive Summary**

This literature review aims to provide evidence specific to the role of the specialist community-based neurological nurse in the care of people living with Parkinson's disease (PD). The information provided and summary of findings provide evidence to support the advocacy role of Parkinson's NSW with State and Federal Governments, as they seek to draw attention to the deficit in specialist neurological nursing services in rural and regional areas of NSW.

PD is a chronic, neurodegenerative, incurable, complex and disabling neurological condition with no known cure. In Australia and worldwide, the prevalence of PD compared with other neurological conditions is only exceeded by dementia. Reports from Deloitte Economics (2011) and Parkinson's Australia (2014) provide clear evidence of the increasing prevalence of PD as the population ages; 80% of people living with PD are aged over 65 years and the remaining 20% are of working age (15–64 years). For this group, the capacity to work and live independently is lost, with each person becoming increasingly dependent on support and care from family and caregivers. It is noteworthy that the high prevalence of PD is comparable with or exceeds that of a number of diseases and injuries identified as national health priority areas in Australia, such as cancer and cardiovascular disease.

PD places a high burden on the person with the disease, their caregiver, family and society. The median time from onset of PD to death is 12.2 years, but many people live with the condition for more than 20 years. In Australia, an estimated 89% of those with PD live most of these years at home, with the remaining 11% living in residential facilities. The high cost of this condition to individuals and society is such that the World Health Organization's policy framework emphasises the need for positive and proactive government policies with clearly identified links to healthcare organisations and the community. Provision of effective

responses to the needs of people living with PD has been the focus of attention in some countries. In the UK, well-developed policies formed jointly by government and nursing bodies have increased the scope of the PD nurse specialist, meaning cost-effective primary health services are available for people with PD. To date, no such policy framework has been developed in Australia. The absence of well-developed policies and lack of a coherent approach to providing integrated specialist nursing care is particularly noticeable in regional, rural and remote areas. People living in these areas have lower health-related quality of life and poorer management of PD when compared with those living in urban areas.

## Summary of Findings

- Fifteen evidence-based models of primary care from five countries (the UK, the Netherlands, the US, Canada and Australia) have been selected as frameworks to advocate for developing the specialist PD nursing role in rural and remote areas.
- Models developed to date have been in response to; the increasing prevalence of PD, the protracted period of time people with PD remain at home (requiring increasing levels of care from caregivers and family) and the need to more effectively use technological advances to enable cost-effective options that can provide the best quality of life for clients<sup>1</sup> and carers<sup>2</sup>.
- Research evidence supporting the development of specialist PD nursing models of practice focuses on improving quality of life and outcomes for people living with PD in seven areas: 1) a comprehensive chronic care model of person-centred care; 2) early intervention, specialist treatment, community rehabilitation and support; 3) working within multidisciplinary teams across the continuum of disease progression; 4) supporting

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<sup>1</sup> Terminology used to denote the person who is the focus of health care varies according to a range of factors, including setting (e.g. inpatient care, community care) and service and service user preference. Throughout this document the terms client/s and/or patient/s are used interchangeably.

<sup>2</sup> Likewise terminology denoting a person who provides care may be identified as a carer and/or a caregiver.

family and carers; 5) palliative care; 6) telemedicine; and 7) neurological assessment.

Specialist PD nurses play a critical role in regular monitoring and consistent assessment of people with PD using validated instruments that measure symptom changes, quality of life and caregiver burden.

- When building the case for specialist PD nurses in rural and remote areas, appropriate measures of sustainability, equity of access and cost effectiveness related to the condition must be identified. The feasibility of effective models of nursing care currently used in regional and remote contexts can then be evaluated and cost savings identified. This will enable the development of clearly articulated proposals and advocacy endeavours to government and service providers.
- In Australia, major outcome measures using a prevalence rate model (as identified by Deloitte Economics) are direct health system costs, loss of productivity, informal care costs, other financial costs (e.g. medications and health aids) and burden of disease. The largest identified costs are acute care and nursing home costs and indirect costs from lost productivity. Major drivers of increasing costs are disease progression and severity, and the impact of dysfunction in motor and cognitive capacity.
- Nurse-led management strategies and therapeutic measures that minimise the impact of disease progression and maximise quality of life (e.g. timely diagnosis, provision of support for informal carers to reduce caregiver burden, equitable access to medications and therapies, avoidance of hospital admissions and delayed admission to residential care) should therefore help contain acute and residential care costs and expenses arising from incremental changes related to disease progression. It is also important to link quality and effectiveness of service provision to consistent measures of assessment, both for people living with PD and caregivers.

- Measures of sustainability are an important consideration for recruitment and retention strategies for rural and remote nurses. Additional costs associated with ongoing professional development and role-specific education, financial incentive programs and workplace infrastructure need to be included when developing specialist PD nursing positions. Strategies require a combined public and private sector response, and should be developed with a regional focus that considers the specific characteristics of that region.

### **III. Literature Review Overview**

#### **Background**

This literature review aimed to provide research evidence specific to the role of the specialist community-based neurological nurse caring for people living with Parkinson's disease (PD).

The information provided and summary of findings will support Parkinson's NSW in its advocacy role to the State and Federal Governments in seeking measures to address the current deficit in specialist neurological nursing services in rural and regional areas of NSW.

The prevalence of PD in the world's most populous nations is expected to double by 2030 (reaching 8.7–9.3 million), and is generally higher in rural and remote areas than in metropolitan areas (Del Brutto, Santibáñez, & Santamaría, 2013; Peters, Gartner, Silburn, & Mellick, 2006). This, together with the impact of population ageing on the prevalence of PD, means that access to specialist neurologist care for people with PD will worsen if no changes are made to current models of care (Deloitte Access Economics, 2011; Schneider & Biglan, 2017). PD is now the second most common neurological disease (secondary to dementia) in Australia, and there is urgent need for a global public policy approach (Deloitte Access Economics, 2011; World Health Organisation (WHO), 2006). In Australia, PD is more common than prostate, bowel and many other cancers, all of which are currently identified as national health priority areas. Neurological disease is second only to cardiovascular disease as a major cause of disease burden among Australians aged 65 years and older (Australian Institute of Health and Welfare (AIHW), 2016a; Parkinson's Australia, 2014).

Although PD is described as a neurological disease, it has been more recently classified by the American Psychiatric Association as a neurodegenerative condition with both motor and non-motor symptoms (American Psychiatric Association, 2013; Parkinson's Australia, 2014). Because of its chronic progressive nature, insidious onset and no known cure, PD is one of

the most challenging conditions for specialist physicians to treat, and requires a multidisciplinary management approach (Parkinson's Australia, 2014). The median time from onset to death is 12.2 years, although many people with PD live with the disease for over 20 years. It is conservatively estimated that in 2011, more than 64,000 Australians were living with PD; an estimated 57,400 (89%) living in the community and the remaining 6,600 (11%) residing in nursing homes or aged care facilities (Deloitte Access Economics, 2011). Few available studies have focused on the point at which a person with PD is no longer able to stay at home. However, one study reported significant predictors for nursing home placement were age, Parkinson's-related dementia, functional impairment and hallucinations (Aarsland, Larsen, Tandberg, & Laake, 2000).

The complexities and chronic progressive nature of PD highlight the need for specialist nurses who can address the gaps in primary health service provision (Carroll, 2017; Dodd, 2014; Parkinson's Australia, 2014). In 2011, there were 33 specialist Parkinson's nurses in Australia compared with 264 in the UK and 90 in the Netherlands for similar populations, and still no nurses are funded by the Australian Government (Deloitte Access Economics, 2011; Dodd, 2014). A key positive step for the future of people living with PD relates to sufficient funding for the education of specialist PD nurses, supported by sustainable, funded employment for 51 specialist PD nurses in urban and regional areas (Dodd, 2014; Parkinson's Australia, 2014). The lack of access to regular specialist services in Australia, including specialist PD nurses, is further compromised for people in rural and remote areas, which increases the risk for complications including falls, decreased quality of life (QoL), increased admissions to acute and long-term care and potentially a shortened life span (Deloitte Access Economics, 2011; Dodd, 2014; Harris & Fry, 2017).

Government policies and focus identify the need to improve services in rural and remote areas for people with chronic conditions such as diabetes, coronary vascular disease, chronic

obstructive pulmonary disease and mental illness (Australian Health Ministers' Advisory Council, 2017; Hopkins et al., 2016). While these measures are much needed, conditions such as PD are not identified or targeted in these initiatives, placing greater burdens on society, people with PD, their caregivers and families (Parkinson's Australia, 2014).

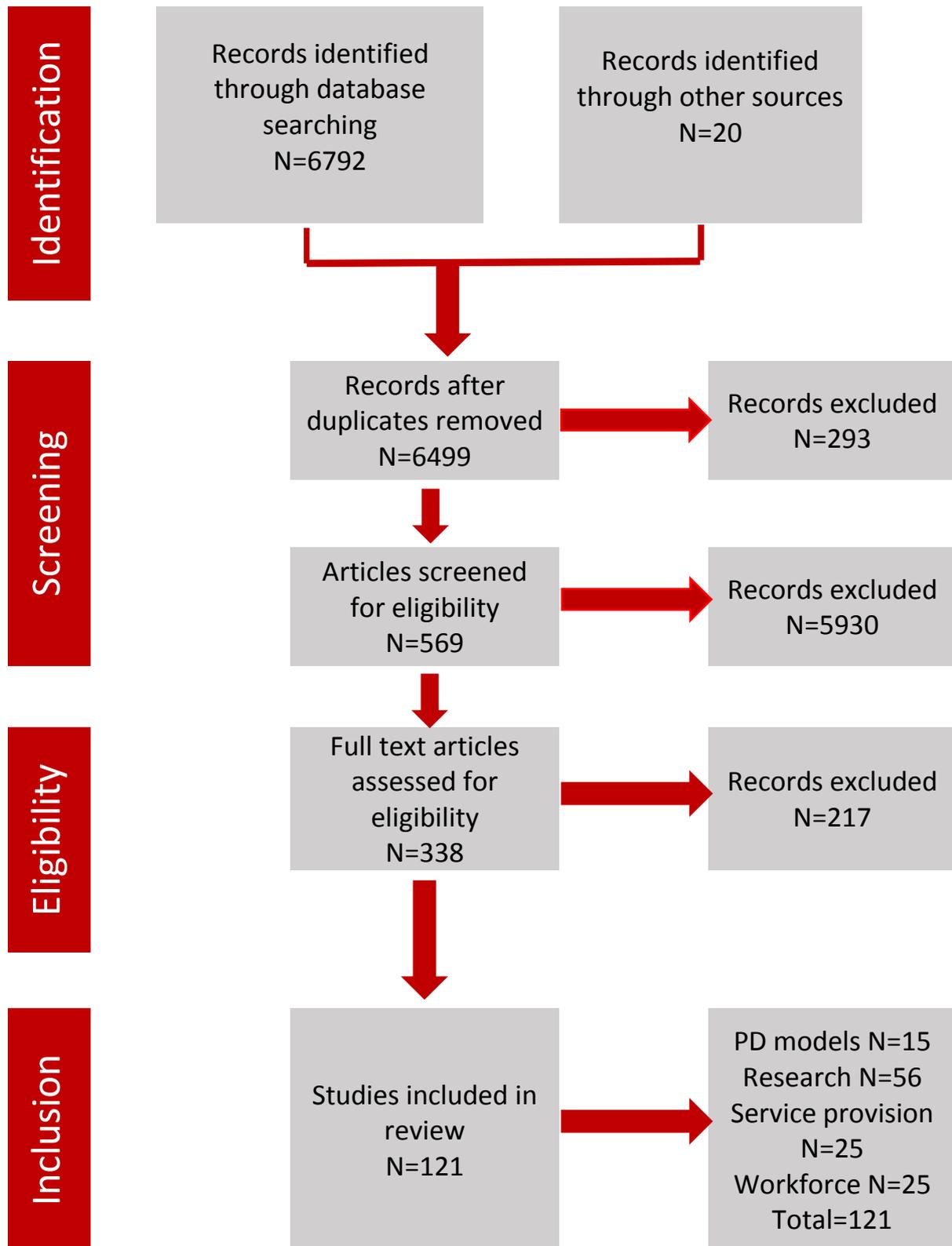
## Design and Methods

The objective of this review is to examine both Australian and international literature published in English between 1997 and 2017 that reported on:

1. Models of primary and specialist nursing care developed for community care for people living with PD.
2. Models that have potential to be sustainable when implemented in rural and remote contexts.

The publication flowchart and steps in the literature search are detailed in Figure 1. This review was guided by the four-stage integrative review framework developed by Whitemore and Knafl (2005). The search terms and concepts used in the literature search are summarised in Table 1.

**FIGURE 1: LITERATURE SEARCH PUBLICATION FLOWCHART**



## Selection of Models for Inclusion in the Review

Inclusion of studies in this literature review was based on concepts derived from the research aim, target population, healthcare problem and sampling frame, as summarised in Table 1 (Whittemore & Knafl, 2005).

Specific inclusion criteria for selecting the 15 models were:

- Implemented as an evidence based model of primary care for people living with PD;
- Developing an evidence base for structuring a regional model for people living with PD;
- Included multidisciplinary, interdisciplinary and/or specialist nursing care services for people living with PD;
- The model provides a framework for neurological nursing models of practice in rural and remote areas;
- Studies that (when evaluated) have potential to achieve improved outcomes for people living with PD, achieving cost effectiveness and sustainability for specialist PD nurses in rural and remote contexts.

Exclusion criteria were:

- Insufficient evidence to indicate the model supported the specialist PD nurse role;
- Insufficient evidence base to enable the structuring of a regional model for people living with PD;
- The model did not include a framework for neurological nursing models of practice in rural and remote areas;

- Insufficient evidence to indicate potential for improved outcomes for people living with PD and achieve cost effectiveness and sustainability for specialist PD nurses in rural and remote contexts.

**TABLE 1. SEARCH CONCEPTS AND TERMS**

Concept	Key words
<b>Models of primary care</b>	“Parkinson* Disease” AND Model AND (Primary OR Specialist OR Nurse) AND Care
<b>Research evidence, rural and remote areas</b>	“Research evidence” AND Rural OR Regional OR Remote
<b>Evidence of sustainability and effectiveness in rural and remote contexts</b>	“Outcome measures” AND Effective Service AND Evaluate AND Family “Specialist community service” “Support groups” AND Effective (Neurological OR Specialist OR Nurse) AND (Rural OR Regional OR Remote) AND Recruitment AND Retention*)
<b>Databases</b>	CINAHL, SCOPUS, Psychinfo, MEDLINE, Cochrane and JBI
<b>Limits</b>	1997–2017, English

## **IV. Models of Primary Care and Specialist Nursing Care Services for People Living With PD**

### **Introduction**

As described in Section III, most people with PD reside in their homes with family members who provide physical, emotional and financial support (Deloitte Access Economics, 2011; Martinez-Martin et al., 2005). Nurses are in a crucial position to partner with people living with PD and their family members for better self-management of PD and improved QoL (Parkinson's Australia, 2014). It is also imperative that specialist nurses work with researchers to develop the evidence base for advanced models of care that address client needs across the trajectory of PD, from the time of diagnosis to palliative and end-of-life care (Ju Young & Habermann, 2017).

Rural nurses in the 21st century must be able to contribute to the design, implementation and enhancement of services by partnering with clients, peers, community organisations, other health service providers and government. There is evidence in the literature that similar demographic trends emerged in relation to population mix and diversity in rural and remote areas in Australia, the US and Canada (Bushy, 2002). There are also similar trends towards decentralisation of financial management of health resources from federal to state governments. However, funds do not always flow on to rural communities, leaving a paucity of resources to sustain quality healthcare delivery systems (Bushy, 2002; Deloitte Access Economics, 2011; Dorsey et al., 2016). In all three countries, the development of innovative models that enable access to multidisciplinary health professional services and use current and emerging technologies (e.g. telemedicine), is a priority for healthcare in rural and remote areas (Dorsey et al., 2016; van der Marck & Bloem, 2014).

## International Development of the PD Nurse Specialist

Internationally, the role and scope of the PD nurse specialist is expanding to address the increasing need for primary healthcare services for people living with PD. The following sections provide a review of PD nurse specialist models in the UK, the Netherlands, the US, Canada and Australia. These models are summarised in Table 2 (see Summary of Models, page 27-30).

### UK Models

During the last 20 years, several models of nursing provision for people living with PD have been piloted in the UK. PD nurses are now established as specialist practitioners with advanced skills in clinical leadership, case management, education and the evaluation of care across the trajectory of PD (MacMahon & Thomas, 1998; Osborne, 2009; Parkinson's Disease Nurse Specialist Association, 2016). The UK model is aligned with the King's College model for hospital care (Martin & Mills, 2013). Nurses in the UK are employed by a hospital trust and/or community services. The latest available figures from Parkinson's UK indicate that 80% of people living with PD have access to specialist nurses (Dodd, 2014). The accredited competency framework for this role was developed by the Royal College of Nursing (Parkinson's UK, 2011). The PD nurse specialist uses knowledge, skills and best practice to meet the needs of people living with this chronic, debilitating condition (Parkinson's Disease Nurse Specialist Association, 2016). As researchers work with practitioners to build the evidence base, neuropsychiatric models of PD have been identified as better reflecting the complexity of the problems arising in PD. Therefore, general agreement in the UK is that models of care based on a multidisciplinary, holistic, person-centred approach similar to those in place for people living with other neurodegenerative conditions (e.g. dementia) should be adopted (Gibson, 2017; Thyrian et al., 2017). A recent

model developed for people in regional areas of the UK (see Section VI p.49 for more detail) aims to use smartphone technology to improve self-management and medication adherence for people living with PD (Lakshminarayana et al., 2016).

PD care in the UK is monitored against the 2017 UK Parkinson's Audit Patient Management: Elderly Care & Neurology Standards and Guidance (2017). These standards provide guidance for the assessment and management of patients with an established PD diagnosis, and comply with national guidelines including the National Institute for Health and Care Excellence (NICE) PD guideline and the National Service Framework for Long Term Neurological Conditions (National Institute for Health and Care Excellence (UK), 2017).

## Netherlands Model

The major development in the Netherlands since 2004 has been implementation of the ParkinsonNet program, a low cost, evidence-based model of integrated care. This model aims to enable connectedness, training, transparency and a team approach using a web-based system (Bloem & Munneke, 2014). Other aspects of the model are nurse-led clinics, greater in-reach into acute and residential aged care facilities and education about self- management for people living with PD (Bloem & Munneke, 2014). Another important feature of ParkinsonNet was the establishment of an information technology platform, including a dedicated website with a search engine and web-based communities run by both patients and health professionals (Bloem & Munneke, 2014; Bloem et al., 2017). Of note, the ParkinsonNet community, which comprises healthcare professionals, patients and caregivers, aspires to empower patients' decision-making (No authorship indicated, 2014).

In recognition that this comprehensive approach is likely to be feasible for other countries, an international collaboration has been established across Europe and Canada to improve community care for people living with PD. A similar approach has potential to be considered

in developing a model for Australia (Carroll, 2017; Dodd, 2014; Keus, Oude, Nijkrake, Bloem, & Munneke, 2012). More recent developments in the Canadian model (still at the clinical trial phase) are focused on improving QoL and cost effectiveness through primary, secondary and tertiary assessment (Van der Marck et al., 2013) (See Table 2 and Section VI).

## US Models

This review identified a number of evidenced-based models of care developed in the US in response to the increasing prevalence of PD and the ageing population. The key role of specialist PD nurses as leaders and managers in the care of people living with PD is evident in the reviewed models (Bunting-Perry & Vernon, 2007; Pretzer-Aboff & Prettyman, 2015). In rural and regional areas, model development has focused on addressing barriers to access related to geographic isolation, which are similar to those encountered in rural and remote Australia (Bushy, 2002; Dorsey et al., 2016; Schneider & Biglan, 2017; Vaughan et al., 2017). This has resulted in a number of innovative models in individual regions or states that include at least one aspect of telehealth, including telehealth diagnostics, videoconferencing, smartphone applications and online assessment (Bunting-Perry & Vernon, 2007; Dorsey et al., 2016; Heldman et al., 2016; Pretzer-Aboff & Prettyman, 2015; Schneider & Biglan, 2017). However, there is no evidence to date that US models have informed model development in Australia.

The first model to be developed in the US for people living with PD was a nurse-led PD model of care (see Table 2). Since the early 2000s, neuroscience nurses across the US have facilitated palliative care for people living with PD using this nurse-led model of care in combination with an advanced care planning process. Helping provide the client and family with a good experience at the end of life has traditionally been within the scope of practice of

US neuroscience nurses through advocacy for the principles and philosophy of palliative care (Bunting-Perry, 2006; Pretzer-Aboff & Prettyman, 2015).

As access to telehealth has increased, specialist PD nurses in the rural state of Delaware developed a hybrid of the Pretzer-Aboff and Prettyman PD Model of Integrative Holistic Healthcare. This hybrid model incorporates synchronous videoconferencing and telehealth technology, and supports remote access to movement disorder specialists and clinical psychologists located geographically distant from the region (Pretzer-Aboff & Prettyman, 2015). This dynamic, nurse-led model can provide blended face-to-face office visits with telehealth visits on the same day, thereby responding to patients' needs as they evolve over time (Pretzer-Aboff & Prettyman, 2015) (see Table 2).

Researchers and practitioners across the US have developed a study protocol aimed at developing the evidence-base for Connect.Parkinson (a virtual house call program), and evaluated the feasibility and effectiveness of using technology to deliver care into the homes of people living with PD (Dorsey et al., 2016) (see Table 2). The trial also served as a model for increasing access and delivering patient-centred care at home for individuals with other chronic conditions. That study found that remote enrolment in this care model was feasible, but may be affected by differential access to the Internet (Achey, Beck, et al., 2014; Dorsey et al., 2016). These technologies have potential to improve care for disparate populations with PD in the US, including those who are geographically isolated and those who are unable to travel (Heldman et al., 2016) (See Section V and VI for further discussion). Evidence to date suggests that patient management aided by telehealth diagnostics provides outcomes comparable with those attained by standard care delivery.

In regional Southeastern Massachusetts, the Affiliated Community Visiting Nurse Association, Inc., a non-profit home healthcare agency with community-based branches,

claims to have created the first known nurse-led interdisciplinary home healthcare program specifically for people living with PD and associated disorders (Vaughan et al., 2017). Evaluation of this model is currently at the clinical trial stage (see Table 2). Other relevant work in its infancy in the US includes developing and trialing remote physical assessments of people living with PD by physiotherapists to enable the provision of tele-rehabilitation for people in rural and remote communities (T. Russell, Hoffmann, Nelson, Thompson, & Vincent, 2013). Advances in wearable technology may also allow the objective assessment of motor performance, both in home and clinic environments, and have been used to explore motor impairments in PD (Toosizadeh et al., 2015).

## Australian Model Development

In Australia, legislative frameworks governing nursing scope and practice clearly detail the postgraduate skills and qualifications required of an advanced practice nurse. Under these frameworks, a PD nurse specialist should have post-graduate neurological skills and training (Nursing and Midwifery Board of Australia (NMBA), 2016). Such training and expertise in a specific area of specialist practice is congruent with the scope of practice identified for a clinical nurse specialist (CNS) and clinical nurse consultant (CNC). Working within the CNS and CNC scope (domains of practice in NSW Health), the PD nurse specialist has capacity to clinically manage patients, recognise acute changes and deterioration, provide education, undertake nursing assessments, make nursing decisions and referrals, analyse and interpret clinical data and contribute to policies affecting the patients for which they care (Carroll, 2017; NSW Health, 2017). The PD nurse specialist also conducts nurse-led clinics and works within a multidisciplinary team, receiving referrals from and referring to other clinicians (Carroll, 2015; Dodd, 2014). PD nurse specialists should also have capacity to disseminate up-to-date knowledge of the disease and available therapies, including information regarding

developing research directions, to consumers, carers and other health professionals (Carroll, 2015). An integral aspect of the PD nurse specialist role is provision of psychological and emotional support. This aspect of care provision, coupled with ready access and ease of contact, has been rated as one of the most beneficial features of the PD nurse specialist role (Parkinson's NSW, 2016).

In 2014, a report by Tasmanian Churchill Trust Recipient and registered nurse, Anne Dodd, asserted that moving toward an innovative nursing-led model in Australia should include maximising the scope of the CNS role. She recommended: the inclusion of nurse-led clinics, particularly in rural and remote areas; greater in-reach into acute facilities; increased provision of education to healthcare professionals in generalist roles; and in-reach into residential aged care facilities to support the care of people living with PD with complex, advanced disease and enable collaboration with palliative care (Dodd, 2014). However, Dodd also argued that developing the PD nurse specialist model in Australia can only be achieved by increasing the capacity of the service through increased government investment (Dodd, 2014). Therefore, in the Australian context, increasing the number of PD nurse specialists is critical to providing equity of access for people living with PD and their families, particularly in rural and remote areas, together with promotion of a client-centred self-management model of care and timely interventions that improve QoL (Dodd, 2014; Parkinson's Australia, 2014).

In 2011, the Tasmanian Department of Health directly employed three CNCs in each of the State's area health services. These CNCs specialise in service provision for people living with PD (Dodd, 2014). The key activities outlined for the CNCs were to run monthly outreach PD clinics conducted by a specialist physician, and work collaboratively with general practitioners (GPs), allied health services, government and non-government organisations to improve the safety and quality of healthcare provision (Dodd, 2014). In 2015, the Tasmanian Government further proposed that this nurse-led model be extended so the CNC has capacity

to work with people living with PD and their healthcare team across all settings (Nursing and Midwifery Board of Australia (NMBA), 2016). This proposed model aligned with the UK 2006 NICE guidelines that identify advanced clinical assessment and evidence-based treatment of PD as part of the UK PD nurse specialist role. The NICE guideline for the diagnosis and management of PD in primary and secondary care recommends that people should have referral to a PD specialist. A PD nurse is identified as one of the specialist options, and the guidelines recommend one PD nurse for every 300 people with PD (Dodd, 2014). This model, proposed for implementation in Tasmania, was informed by and closely follows the role of the UK PD nurse specialist, and aligns with the King's College Hospital model of care (see Table 2). This model has been evaluated and demonstrated marked cost savings (see Section VI p.48) (Martin & Mills, 2013).

In Victoria, a multidisciplinary movement disorder nurse (MDN) model was operationalised across acute, sub-acute and ambulatory services in the regional area of Goulburn (see Table 2). The MDN model is underpinned by diagnosis and management in primary and secondary care, and places the client at the centre of care (Parkinson's Victoria, 2016). The current MDN program aims to expand the service, and provide a strong basis for future advocacy initiatives and duplication in other rural health settings in the state.

On the Mid-North Coast of NSW, the local health district nurse-led model of care is a PD CNC (neurology) role. The CNC works across the continuum of care, from community settings and aged-care facilities to acute care hospitals, and is responsible for a multidisciplinary PD clinic and providing regular nurse-led clinics (see Table 2). A multidisciplinary team approach is adopted for assessment and review, involving (as required) the GP, a range of allied health professionals (physiotherapists, occupational therapists, speech pathologists, dieticians, pharmacists and counsellors) and PD-specific supports, such as those provided by coordinators of PD support groups and the Parkinson's

NSW information and counselling line. Governance for this role is provided by regular oversight from the Parkinson's Nursing Service Advisory Committee, comprising management, program partners, Parkinson's NSW, the North Coast Primary Health Network, the local health district, senior nurse managers and representatives of local PD support groups (Carroll, 2015). Further initiatives to be included in the model are: 1) a greater focus on non-motor assessment in people living with PD; 2) increased knowledge of advanced therapies in people living with PD; 3) a network of nurses around the world; and 4) development of clinical guidelines to care for patients admitted to hospital with PD who are unable to swallow safely (Carroll, 2017; Dodd, 2014).

In the Hunter New England district of NSW, effort has been made to develop an evidence-based nurse-led clinic for people living with PD (Gow, Collins, Giles, & O'Brien, 2014). Clients are sent a self-reported questionnaire before their first appointment, and regional patients are provided with a tablet for videoconferencing on a regular basis, supported by a NSW telemedicine platform (Gow et al., 2014). Identified benefits include improved QoL and clinical outcomes, improved access to specialists and allied health and better opportunities for understanding the condition (see Table 2) (Gow et al., 2014).

In the Australian Capital Territory (ACT), a nurse-led PD service was introduced at Canberra Hospital and Health Services in 2012 with the primary objective of improving the care and self-management of people living with PD and related disorders (B. Jones et al., 2016). Other objectives of the service include improving the QoL of people living with PD, reducing caregiver burden, improving knowledge of PD among healthcare professionals and reducing unnecessary hospital admissions (B. Jones et al., 2016) (see Table 2). Evaluation of the service has identified positive impacts (see Section VI p.54).

PD nurse specialists have been operating in Western Australia (WA) since 1998. This community-based nursing service is funded jointly by the Department of Health WA and charitable trusts (Department of Health Western Australia, 2008). In 2008, a comprehensive plan was published outlining an integrated PD services model of care for older people that would build on existing infrastructure (Department of Health Western Australia, 2008). Model development was informed by the 2006 NICE guidelines and health outcome and economic data (P. Hobson, Roberts, & Mearar, 2003; Jarman, Hurwitz, Cook, Bajekal, & Lee, 2002). This model describes the PD nurse specialist service as an integral component of the overall model of care. The role description includes; coordination of care, conducting holistic assessments, monitoring wellbeing and response to treatment, referrals to other health and social care professionals, providing education to other health and social care professionals and education and counselling for people living with PD and their carers (Department of Health Western Australia, 2008, p. 42). Parkinson's WA describes the nurse specialist role as innovative and successful, and reports presenting the model at both national and international conferences (<https://www.parkinsonswa.org.au/nurse-specialists/>). To date, outcome data and evaluation of the nursing model have not yet been published in peer-reviewed journals. In the Northern Territory, Queensland and South Australia, there are no formal networks identified for PD nurse specialists.

Other nursing support services provided in rural and remote areas by and for nurses include:

- 1) information and counselling services provided by peak PD bodies within each state (e.g. Parkinson's NSW, Parkinson's Victoria);
- 2) nursing support from pharmaceutical companies, either by phone or home visits, in the area of advanced therapies such as duodopa and apomorphine;
- 3) education by pharmaceutical companies for nurses, GPs, neurologists and carers in regional and remote areas; and
- 4) duodopa and apomorphine outreach (while the

data are international, the service is commonly provided in Australia) (Bhidayasiri et al., 2016; Ianseck & Morris, 2013).

## Summary of Nurse-led Models of Care

In summary, the development of nurse-led models of primary healthcare both nationally and internationally has been in response to the increasing prevalence of PD, the length of time people living with PD remain at home with carers, technological advances and more cost effective options that provide the best QoL for clients and carers. In the US, which has a similar geographical and governance structure to Australia, there has been a focus on development of a range of telehealth models for people living with PD in regional areas.

Fifteen evidence-based models of primary care from five countries (the UK, the Netherlands, the US, Canada and Australia) have been selected as frameworks to advocate for the development of the specialist PD nursing role in rural and remote areas (see Table 2, pp. 27–30).

**TABLE 2. MODELS OF PRIMARY AND SPECIALIST NURSING CARE FOR PARKINSON'S DISEASE**

Study (country)	Model title	Aim	Model structure	Description of major attributes	Stage	Outcome measures
Bunting-Perry (2006) (US)	PD model of care	Support for people living with PD from diagnosis through bereavement	Evidence-based principles of palliative care Balance of life-prolonging therapy and palliative care	Nurse-led model Palliative care Individual care planning Advance care planning	Implemented	Quality of life
Keus et al. (2012); Bloem and Munneke, (2014); Bloem et al. (2017) (Netherlands)	ParkinsonNet	Improve community care for people living with PD	Evidence-based model of integrated care Tertiary referral centre Web-based system	Nurse-led clinics Evidence-based guidelines Regional focus Training: specialist expertise in PD Multidisciplinary Empower client decision making	Implemented	Improved self-management Reduced costs
Van der Marck et al. (2013) (Netherlands, Canada)	ParkinsonNet	Improve quality of life	Developing evidence base for integrated approach to care and assessment	Primary, secondary and tertiary assessment to measure quality of life Extension of ParkinsonNet (Netherlands)	Clinical trial phase	Quality of life Tertiary outcomes
Martin and Mills (2013) (UK)	King's College Hospital model of care	Deliver advanced therapies for complex PD Encourage self-empowerment through access to person-centred care	Accredited National Parkinson Foundation Centre of Excellence	NICE-approved nurse-led clinics to empower people living with PD Tertiary focus but linked to primary care Quarterly patient-led expert patient groups Complex therapies including apomorphine, DBS and duodopa	Implemented	Cost savings Reduced unplanned hospital admissions and readmissions Reduced cost of apomorphine tests

Study (country)	Model title	Aim	Model structure	Description of major attributes	Stage	Outcome measures
Gow, Collins, Giles and O'Brien (2014) (NSW)	Nurse-led clinic for people living with PD	Improved access to services in the Hunter region of NSW	Aligned with evidence of success of nurse-led clinics Managing outpatient follow-up Reduce hospital visits	Regional focus Extend scope of practice of PD registered nurses Telehealth	Implemented	Improved quality of life Improved access to allied health and specialists
Dodd (2014) (Tasmania)	CNC model Neurological support	Provide advanced clinical leadership	Aligned with evidence based models and NICE Guidelines (UK) CNC employed by Tasmanian Department of Health	Regional focus Nurse-led outreach clinics Multidisciplinary Advanced clinical assessment	Implemented	Improved healthcare outcomes
Pretzer-Aboff and Prettyman (2015) (US)	Model of Integrative Holistic Healthcare	Improve access to specialist care in the Delaware region	Hybrid of evidence based integrative holistic healthcare model Telehealth clinic blended with onsite nurse-managed health centre Synchronous videoconferencing and telehealth technology	Regional focus Nurse-led model Patient-centred Multidisciplinary Regional access to movement disorder specialist and clinical psychologist	Implemented	Improved response to individual patient needs Improved access to specialised, multidisciplinary and advanced care
Jones et al. (2016) ACT	Nurse-led PD service	Improve care and self-management for people living with PD	Based on principles of patient-centred service delivery.	Regional focus Nurse-led service Multidisciplinary Linked to chronic care program	Implemented	Positive impact on healthcare service provision for people living with PD

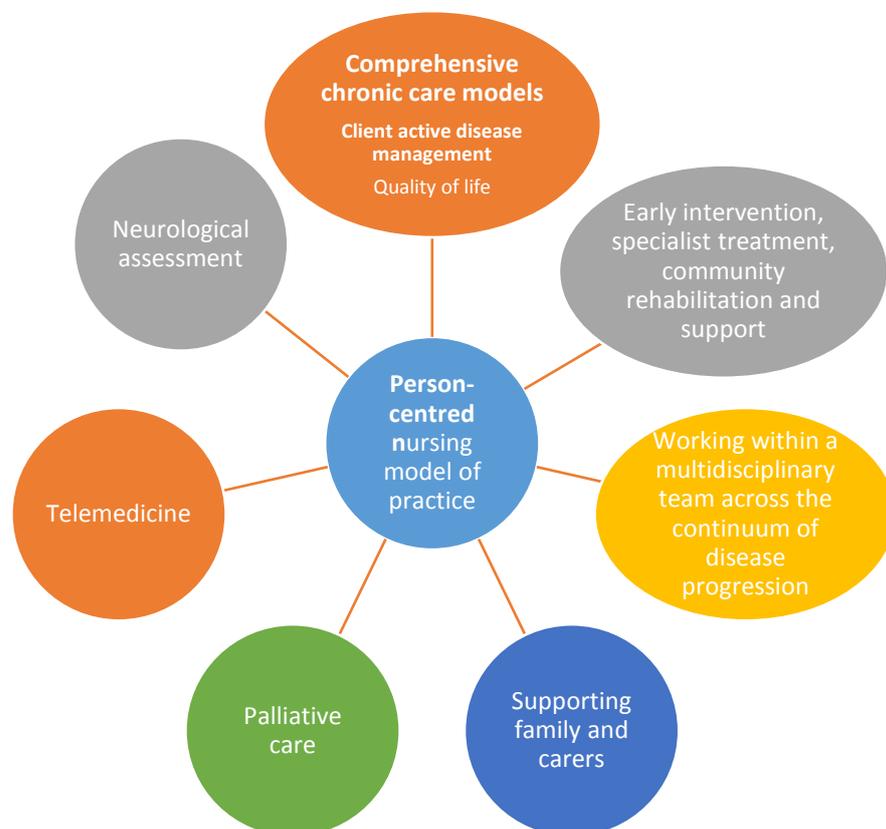
Study (country)	Model title	Aim	Model structure	Description of major attributes	Stage	Outcome measures
Parkinson's Victoria (2016)	MDN model	Service expansion Future advocacy initiatives Duplication in other rural health settings	Aligned with evidence base Support people living with PD in local communities Link with other Goulbourn Valley health programs	Regional focus Multidisciplinary Diagnosis and management in primary and secondary care	Implemented	Improved self-management Reduce travel Improved quality of life
Carroll (2017) (NSW)	CNC model: advanced model of care	Ease the symptoms and burdens of people living with PD, carers, families and the community	Evidence-based model Innovative and personalised care systems	Regional focus Nurse-led clinics Multidisciplinary Evidence-based (Kings College Hospital Parkinson's Centre of Excellence)	Implemented	Ease symptoms and burdens for people living with PD and carers Improved clinical assessment of non-motor symptoms Reduce costs due to hospital admissions and poor medication adherence
Vaughan et al. (2017) (US)	Interdisciplinary home health program Emory PD Comprehensive Care Clinic	Further test the model through a randomised controlled trial	Developing evidence base 2-day interdisciplinary comprehensive care clinic where practitioners communicate directly with each other	Regional focus Inter-disciplinary team based assessment Assessment through Unified Parkinson's Disease Rating Scale	Clinical trial stage	Higher quality care Better assessment of motor and non-motor symptoms Cost effectiveness later in disease process
Dorsey et al. (2016) (US)	Connect. Parkinson	Evaluate feasibility of the model Improve care for disparate PD populations	Developing evidence base A virtual house call program Telehealth diagnostics	Regional focus Using technology to deliver care into homes of people with PD.	Feasibility stage	Increased access to patient-centred care at home May be affected by differential access to the Internet

Study (country)	Model title	Aim	Model structure	Description of major attributes	Stage	Outcome measures
Lakshminarayana et al. (2016) (UK)	Parkinson's Tracker App	Support self-management of PD	Developing evidence for smartphone application to enhance medication adherence and clinical consultation	Regional focus Using technology to improve self-management for people living with PD by increasing medication adherence and self-management	Clinical trial stage	Quality of clinical consultation Medication adherence
Schneider and Biglan (2017) (US)	Telemedicine delivered care	Improve access to neurologist care	Developing evidence for real-time, synchronous videoconferencing	Regional focus Using technology to deliver medical care	Trial and feasibility stage	Barriers include legal and technological issues and reimbursement
Gibson (2017) (UK)	A biopsychosocial model of PD	Provide multidisciplinary, holistic PD services	Developing an evidence-based biopsychosocial approach to care of people living with PD Adapted from dementia model of care	Nurse-led Includes psychological and social factors Addresses lived experience of patients	Trial and feasibility stage	

## V. Research Evidence Supporting Neurological Nursing Models of Practice in Rural and Remote Areas

In this section, research demonstrating improved outcomes for people living with PD is examined, with attention directed to how aspects of management and care can be integrated into existing nursing models of practice, as summarised in Figure 2.

**FIGURE 2: NURSING MODEL OF PRACTICE**



Research discussed here focuses on aspects of the nursing model of practice (illustrated in Figure 2) as follows.

1. Comprehensive chronic care models;
2. Early intervention, specialist treatment, community rehabilitation and support;
3. Working within a multidisciplinary team across the continuum of disease progression;

4. Supporting family and carers;
5. Palliative care;
6. Telemedicine;
7. Neurological assessment.

A range of assessment tools, rating scales and measures have been developed and validated for use by researchers and clinicians to evaluate the impact of treatment and management interventions (See Appendix 3 for more information about commonly used tools). These tools focus on several main areas:

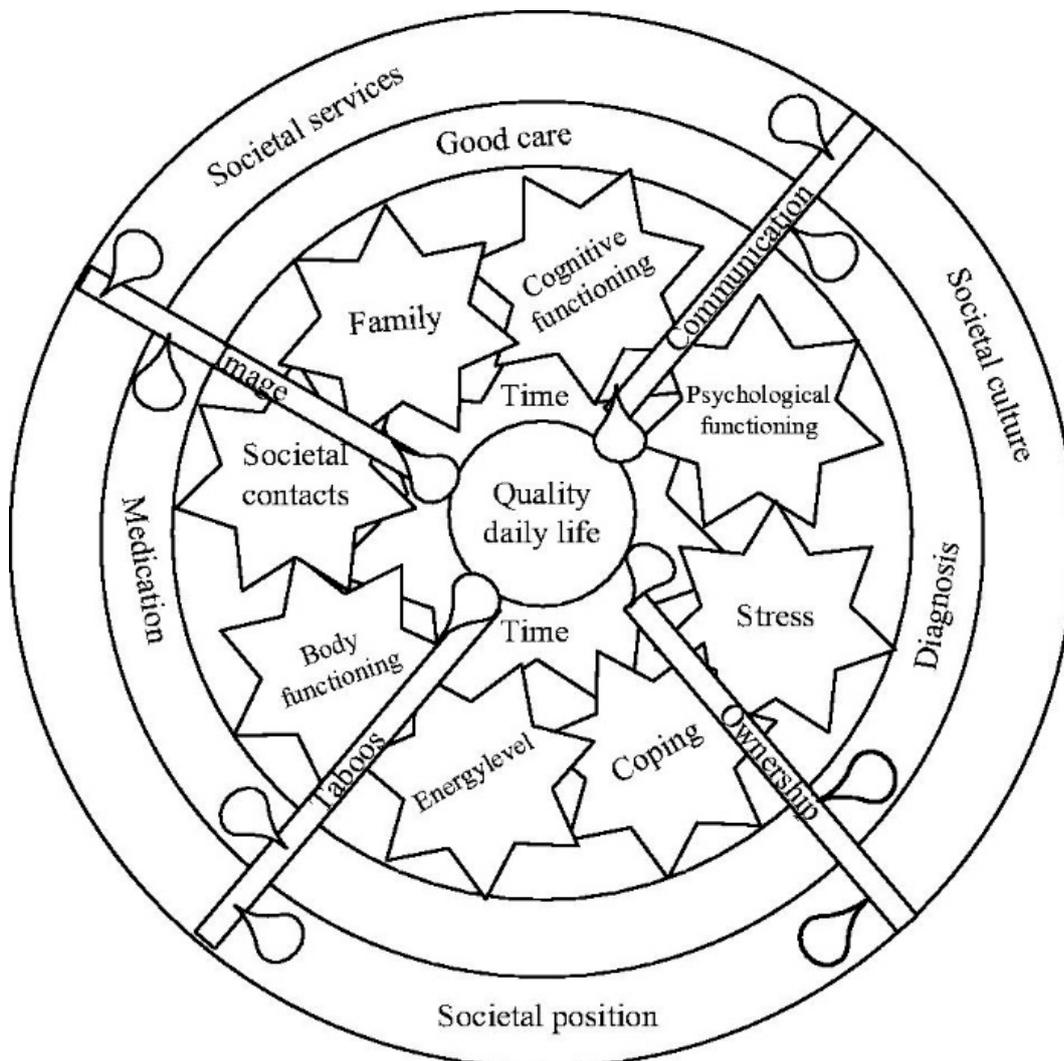
1. Motor symptoms such as tremor, rigidity, balance and dystonia. Tools include components 2–4 of the Movement Disorder Society-sponsored revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS) and the Hoehn and Yahr staging scale;
2. PD-related complications including falls and aspiration pneumonia.
3. Non- motor symptoms including depression, anxiety, apathy, sleep disturbances, constipation, pain, postural hypotension, cognitive changes and sexual dysfunction. The Non-Motor Symptoms Questionnaire was developed specifically to assess this aspect of PD;
4. Quality of life tools such as the Parkinson's Disease Quality of Life, Health-Related Quality of Life (HRQoL) and the Quality of Life in Neurological disorders (Neuro-QoL) are used to assess this aspect of living with PD.

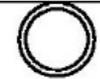
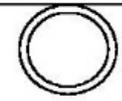
## Comprehensive Chronic Care Models

Using a comprehensive chronic care model builds on current medical and rehabilitation models by integrating the concept of person-centred chronic care, particularly for older people living with PD; that is, living with a chronic illness and adding two extra dimensions of wellness or QoL and client-active disease management (see Figure 2) (Achey, Beck, et al., 2014; Giroux & Farris, 2008). The inclusion of active management and functional independence concepts (even in the context of functional decline) allows for inclusion of measures to assess and maximise QoL in a neurodegenerative condition such as PD (Giroux & Farris, 2008).

Research supports the argument that in PD, chronic care models should use an integrated approach to care. An integrated approach addresses both the individual management of symptoms within the client's control and the psychosocial aspects of PD that impact on people living with PD and carers (Navarta-Sanchez et al., 2016). Evidence demonstrates that education for people living with PD focused on self-management as a positive intervention produces outcomes directly correlated with better HRQoL. Studies using patient-reported QoL measures (Dauwese, Hendrikx, Schipper, Struiksma, & Abma, 2014; Shimbo et al., 2004) have demonstrated improvements in QoL from the perspectives of people living with PD (see Figure 3).

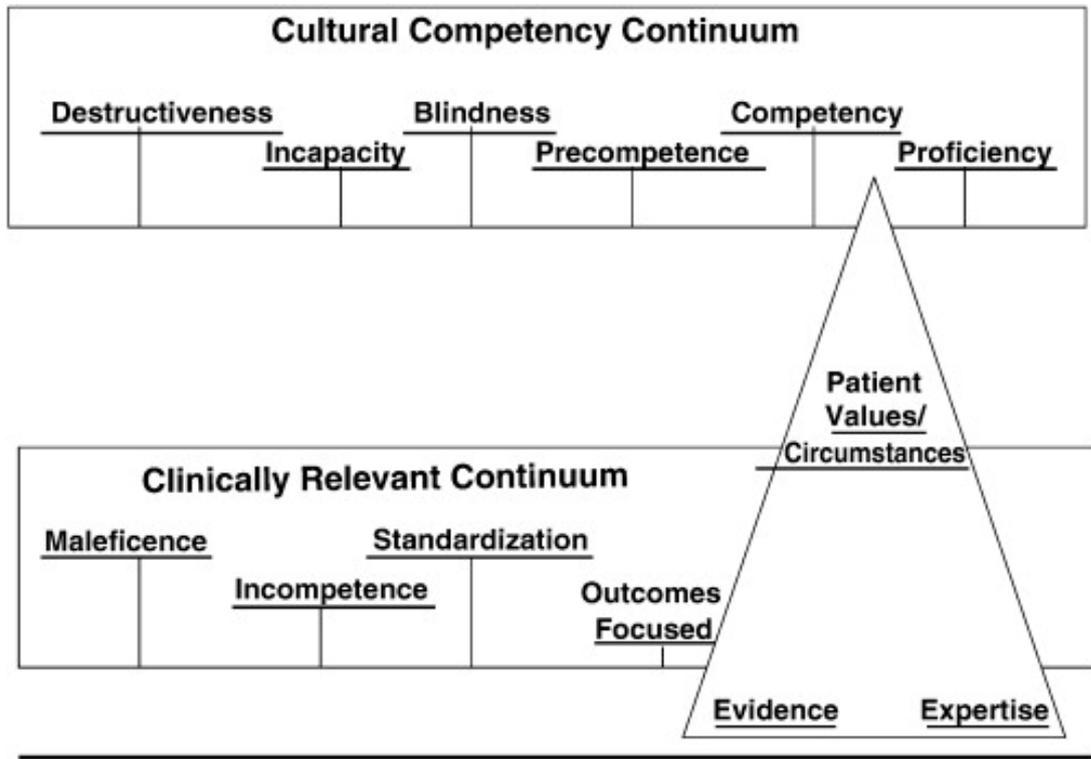
**FIGURE 3: CLIENT PERSPECTIVES OF QUALITY OF LIFE**



	This axis within the middle of the wheel illustrates the central cluster for living with PD (QoL and time).
	Lubricant (crossing cluster) which drips through the whole wheel (influencing and connecting the outer layer (societal cluster), care cluster, inter- and intra-personal cluster and axis of the figure).
	Arms of the clock, connecting the lubricant with the other layers
	These star categories (tracing wheels) are all a part of the inter- and intra-personal cluster. They turn around the axis and influence each other.
	Care ring: directly influencing the inter- and intra-personal tracing wheels and directly (dripping as lubricant) and indirectly (via the inter- and intra-personal cluster) influencing the axis in the middle (QoL).
	Societal ring: directly influencing the care ring and directly (dripping as lubricant) and indirectly influencing the inter- and intra-personal tracing wheels and axis in the middle (QoL).

The comprehensive chronic care model has been further developed through the integration of the clinically relevant continuum model that incorporates culturally competent care and an increased emphasis on a holistic approach to the delivery of client-centred care (see Figure 4) (Hermanns, 2011).

**FIGURE 4: CLINICALLY RELEVANT CONTINUUM MODEL**



## Early Intervention, Specialist Treatment, Community Rehabilitation and Support

Reports suggest that without high-accuracy early detection of PD, a person may have PD for 5–10 years before receiving a formal diagnosis. Consequently, at the time of diagnosis, up to 70% of the neurons in the affected part of the brain (substantia nigra) have already been lost (Adams, 2017). Early assessment and detection through methods such as observing changes in hand and finger movement while typing, which can be used in the home setting, have potential to improve management of PD through early intervention and specialist treatment

(Adams, 2017). Other assessment tools that are important in managing disease progression are condition-specific instruments, such as the UPDRS (Fundament et al., 2016).

Recent research supports the evidence that non-motor symptoms that occur in the early stages of PD, such as constipation, sleep disorders, pain, neuropsychiatric problems (e.g. depression, apathy, cognitive deficits) and sexual dysfunction can be more debilitating than motor symptoms (Carroll, 2017). These non-motor symptoms strongly impact on a person's QoL. Specialist PD nurses play an important role in providing clinical input, education and support for the person, caregiver and community agencies (Carroll, 2015). Findley et al. (2002) demonstrated that early intervention and support can markedly impact on depression, as measured by the Beck Depression Inventory, and disease severity evaluated with a global severity measurement (Hoehn and Yahr Scale) (Goetz et al., 2004; Hoehn & Yahr, 1967). That study found that depression and disease severity can be ameliorated by a sense of optimism and understanding of the condition, with a significant improvement in HRQoL evaluated with the Parkinson's Disease Questionnaire 39 (PDQ-39) (Findley et al., 2002).

Some studies have focused on revising and improving current nursing assessment tools used for people living with PD so that the influence of non-motor symptoms (e.g. apathy, depression) and motor symptoms on QoL trajectories can be better identified (C. Jones, Pohar, & Patten, 2009). These studies also suggested that a reduced level of self-reported QoL among patients with PD is primarily related to depression. This supports the discussion in previous sections of this review highlighting the importance of education in self-care and management focused on improving psychological adjustment to life with PD and implementing treatment for depression (C. Jones et al., 2009). Martinez-Martin and Chaudhuri (2018) highlighted the growing body of evidence linking the impact of non-motor symptoms to decreased QoL for people living with PD. They emphasised that from the perspective of people living with PD, non-motor symptoms are consistently described as the

most troubling and difficult aspect of living with PD. Those authors also asserted that ‘exclusion of validated non-motor symptoms tools in regular assessment of PD is no longer acceptable’ (Martinez-Martin & Chaudhuri, 2018, p. 46).

Recent research acknowledges the importance of recognising that apathy<sup>3</sup> is another major psychological sign found in people living with PD who are cared for at home (Morita & Kannari, 2016). Available validated assessment tools for measuring apathy include the Lille Apathy Rating Scale, item 4 of the UPDRS (as described by Leetjens and Startstein [2012] cited by Sampaio, Goetz and Schrag [2012]), the Starkstein Apathy Scale and the Apathy Evaluation Scale (Morita & Kannari, 2016; Myerson, 2012; Sampaio, Goetz, & Schrag, 2012).

Impairment in executive function is another commonly reported cognitive deficit in PD, and can be observed in the early stages of the disease. Recommended assessment tools to measure cognition include the Montreal Cognitive Assessment and Cambridge Cognitive Assessment-revised. These tools are well explained by Stebbins in Sampaio, Goetz and Schrag (2012).

Executive function impairment has been shown to impact on QoL, health status and caregiver burden (Kudlicka, Clare, & Hindle, 2014). Living with PD has also been shown to impact on sexual function, as described in a UK study that reported around 25% of people with PD experience sexual dysfunction (Hand, Gray, Chandler, & Walker, 2010).

Sleep disturbances are among the most frequently reported and poorly managed non-motor symptoms experienced by people with PD. A 3-day sleep management course developed in Scotland for PD nurse specialists found improvement in the anxiety of people with PD about their sleep problems, and an improved ability to manage their sleep (Gregory, Morgan, &

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<sup>3</sup> See Apathy and Parkinson’s disease (Shake It Up <https://shakeitup.org.au/apathy-and-parkinsons-disease/>) for a plain English description of apathy as a non-motor symptom of PD and the impact on disease progression, risk for falls and increased distress and caregiver burden.

Lynall, 2012). Sleep disturbances are also influenced by motor impairment, resulting in sleep fragmentation, nocturnal pain and cramps (Happe & Berger, 2002). Excessive daytime sleepiness is a frequent and highly persistent feature of PD, related to various aspects of physiological changes associated with PD. Both age and disease-related disturbances of sleep-wake regulation contribute to hypersomnia in PD. Medication treatment, in particular those with dopamine agonists, was reported to contribute to excessive daytime sleepiness (Gjerstad, Alves, Wentzel-Larsen, Aarsland, & Larsen, 2006).

The number of falls a person with PD is likely to experience increases significantly as the disease progresses (Hiorth, Larsen, Lode, & Pedersen, 2014). Multiple factors contribute to a person falling, including: reduced ability to control gait and balance due to a reduction in dopamine levels and disease progression; lack of physical activity; visual impairment; medication use; and environmental hazards (Hiorth et al., 2014; Pikel, Costa, Nogueira, Okamoto, & Piemonte, 2015). However, a proactive approach to fall reduction that includes multifactorial fall risk assessment and implementation of exercise and wellbeing programs (incorporating interventions such as dancing, Tai Chi, hydrotherapy, and boxing) can help reduce the rate of falls in older adults by 24%–37% (Hiorth et al., 2014; Pikel et al., 2015). A ‘three-step’ clinical tool assessing falls in the past year, freezing of gait in the past month and gait speed has been demonstrated to have a high-level of accuracy in predicting fall risk in the next 6 months (Canning, Paul, & Nieuwboer, 2014; Duncan et al., 2015). For more comprehensive assessment, a recent publication provided a practical algorithm to diagnose and manage falls in PD, which emphasised that ‘fall prevention is an urgent priority’ and highlighted the challenges inherent in this aspect of PD research (Fasano, Canning, Hausdorff, Lord, & Rochester, 2017, pp. 1532-1533).

Person-centred care for people living with PD to improve the specific combination of motor and non-motor symptoms experienced by each individual should also include specific drug

therapies, physiotherapy, complimentary therapies and strategies to assist the person to cope with symptoms that cannot be changed, educational support and measures to reduce/avoid hospital admission (Carroll, 2017).

## Multidisciplinary Team Care across the PD Continuum

As knowledge and understanding of PD advance, there is increasing evidence that effective care for people living with PD should involve a multidisciplinary team of health professionals, including a neurologist or geriatrician, PD nurse specialist, physiotherapist, occupational therapist, speech therapist (Australian term), dietician, clinical psychologist and social worker (Skelly, Lindop, & Johnson, 2012; Vaughan et al., 2017). In Australia, as multidisciplinary teams collaborate further, there is the opportunity for an increased focus on self-management strategies designed specifically for people with PD, including those provided by occupational therapists such as the Canadian Practice Process Framework (Jansa & Aragon, 2015).

In some countries such as Israel, where a biomedical model is more closely followed, the multidisciplinary team is led by a neurologist with expertise in PD care and includes a nurse, a psychologist, a speech and language therapist, a psychiatrist, a physiotherapist, an occupational therapist, a sexologist, a dietician and (when indicated) an expert in sleep disturbances, an orthopaedic surgeon and a physiologist with special expertise in respiration (Giladi, Manor, Hilel, & Gurevich, 2014). In the US, latest innovations include the Emory Parkinson's Disease Comprehensive Care Clinic, a novel model enabling interdisciplinary team-based care of persons with PD (see Table 2) (Vaughan et al., 2016; Vaughan et al., 2017). This model aims to provide higher quality and more cost effective care through increased communication between multidisciplinary team members (Vaughan et al., 2017).

Another US study found that a multidisciplinary home visit program led to improved QoL for homebound people with advanced PD whose level of disability had resulted in them being estranged from care (Brooks, 2016).

## Supporting Family and Carers

Worldwide, many carers of people living with PD suffer multiple physical, psychological, social and financial burdens through providing care for a person with a progressive, degenerative disease such as PD. There is evidence that caregivers experience increased levels of depression and associated mood disorders and an inferior QoL compared with that reported by the general population (Martinez-Martin, Arroyo, et al., 2008; Martinez-Martin et al., 2005). This is reflected in studies using measures of caregiver burden and HRQoL (Martinez-Martin, Rodriguez-Blazquez, & Frades-Payo, 2008). Reports also suggest that those living in rural regions may not be seen by specialists, or any medical doctor (D. Hobson et al., 2012). The limited contact with medical services experienced by people living in rural regions is reported to increase caregiver burden and increase the rate of hospitalisation compared with those living in urban areas (D. Hobson et al., 2012).

Research evidence has identified a number of non-motor symptoms of PD that significantly impact the wellbeing and QoL of caregivers. When sleep disturbances from motor symptoms are severe, partners are also affected, with 27% of spouses reporting poor night-time sleep and an increase in overall caregiver burden (Happe & Berger, 2002). Behavioural disturbances, such as apathy and impulse control disorders, have significant negative implications for burden of care, as do a combination of cognitive, psychiatric and medication factors (i.e. impaired attention, higher levels of depression and levodopa equivalent daily dose) (Leroi et al., 2012). As a single symptom, apathy is particularly troublesome for carers and family, and there is evidence that caregiver reports of apathetic symptoms are a predictor

of future dementia in people with PD (Fitts et al., 2015). There is also increasing evidence that neuropsychiatric symptoms in PD (e.g. dementia) are particularly burdensome for caregivers, and detailed assessment and specific interventions aimed at these symptoms could alleviate caregiver burden (Martinez-Martin et al., 2015).

The role of the PD nurse specialist is vital in easing caregiver burden. Knowledge of ‘what is to come’ for an individual client and how to handle potential problems may reduce caregiver stress levels. It is imperative that nurses include education and support for people living with PD to use self-management techniques such as exercise and energy conservation. As well as benefiting people with PD, these techniques may also relieve caregiver burden. This may enhance the QoL of both caregiver and care recipient (Edwards & Ruettiger, 2002). High levels of care relationship mutuality (care relationship quality) are also reported to ameliorate caregiving burden and motivate carers, particularly those showing signs of depression, to continue care (Edwards & Ruettiger, 2002; Martinez-Martin et al., 2015).

Relationship-focused skill training strategies may improve psychological outcomes for family and other informal carers (Shim, Landerman, & Davis, 2011). Knowledge of individual caregiver characteristics and factors contributing to increased burden of care may assist in alleviating challenges by enabling situation-specific interventions, resulting in benefits for patients, caregivers and society (Martinez-Martin et al., 2005). A study measuring the risk for strain in caregivers of persons with PD using the Caregiver Strain Risk Screen-10 highlighted the importance of preventive care and the need for referrals to suitable services (Abendroth, 2016). It is important to recognise that even with education and support, many carers experience the informal caregiving role as daunting, requiring constant vigilance and major changes in lifestyle.

## Palliative Care

Integrated service provision based on individual needs is a compelling palliative care model, including understanding the ‘red flags’ (in PD, red flags refer to depression, anxiety, sleep disturbances, hallucinations) that can alert health professionals to unmet need and aid in developing efficient assessment methods (Richfield, Jones, & Alty, 2013). Although PD is described as a chronic deteriorating condition, a ‘palliative phase’ of the disease has been suggested. This stage is described as lasting 2.2 years on average, and is defined by waning response to dopaminergic treatments and cognitive decline (Bunting-Perry, 2006; Richfield et al., 2013). Clinical features heralding the need for end-of-life care in long-term neurological conditions are swallowing problems, recurrent infections, marked decline in physical function, first episode of aspiration pneumonia, cognitive difficulties, weight loss and significant complex symptoms (Bunting-Perry & Vernon, 2007; Richfield et al., 2013).

A recent study found that patients were accepting of outpatient team-based palliative care services to address psychosocial issues, adjustment to illness (particularly at diagnosis and with progression), non-motor symptom control and advance care planning as an adjunct to usual care (Boersma et al., 2016). In an Irish study, key implications for clinical practice and policy included the need for an evidence-based, integrated model of care, and education for all healthcare workers, patients, carers and the public on the nature of advanced PD and the potential for palliative care services to support patients and family members (Fox et al., 2016).

## Telemedicine

In general healthcare, telecommunication, telehealth (telemedicine) and biotechnology are expanding at exponential rates, particularly in Australia, Canada and the US. Telehealth is described as the transmission of diagnostic images, video and/or information between two

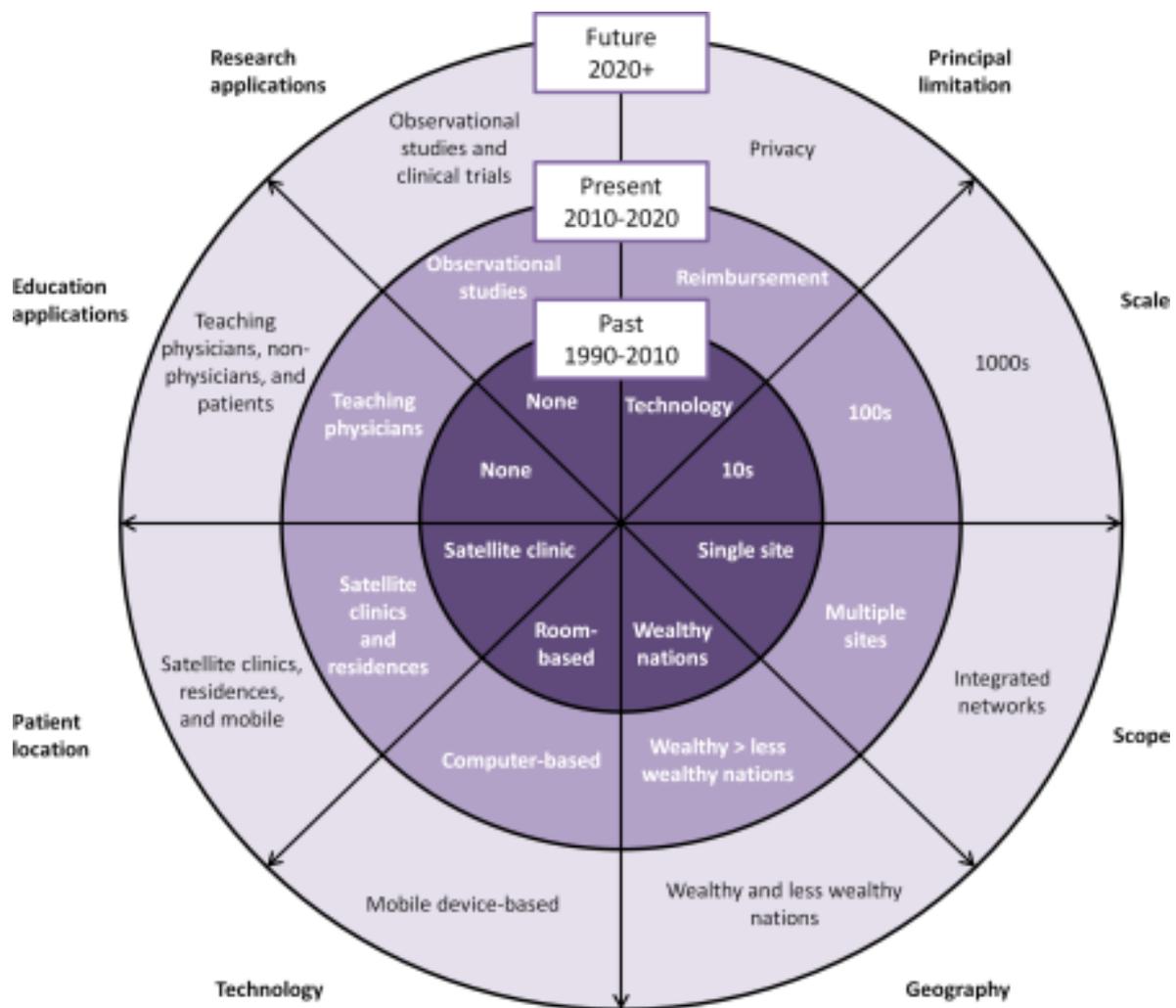
sites that are not physically in the same place (Dorsey et al., 2016; Schneider & Biglan, 2017). Technology of various types is being used for medical consultations, diagnostic purposes and health education between two entities (client/caregiver) separated by some distance (Bloem et al., 2017; Keus et al., 2012; Lakshminarayana et al., 2016). Certain specialties dominate telehealth use, specifically, mental health, cardiology, orthopaedics, radiology and dermatology. International collaborative efforts are critical to refine the theoretical foundations for rural nursing to guide education, research, practice and policy development in technology for people living with PD and their families (Bloem et al., 2017; Bushy, 2002; Dorsey et al., 2016).

Movement disorders such as PD are well suited to telemedicine because they can be primarily visually assessed, generally limit mobility and require ongoing multidisciplinary care (Achey, Aldred, Aljehani, Bloem, & Biglan, 2014; Achey, Beck, et al., 2014). As discussed in previous sections, some mature telemedicine programs are found in the Netherlands and parts of the US, and are developing in Canada and Australia. Evidence suggests that where virtual visits are reimbursed they flourish; however, it has been found in the Netherlands and most of the US that limited or absent government support and reimbursement hinders broader adoption (Achey, Aldred, et al., 2014; Dorsey et al., 2015).

A study protocol for a virtual house call program, Connect.Parkinson, evaluated the feasibility and effectiveness of using technology to deliver care into the homes of individuals with PD (further discussed in section VI). That trial may serve as a model for increasing access and delivering patient-centred care at home for individuals with chronic conditions (Achey, Beck, et al., 2014; Dorsey et al., 2016).

Figure 5 provides an overview of the development of telemedicine, its past, present and future, and the major implications to be addressed for successful development.

**FIGURE 5: THE PAST, PRESENT AND FUTURE OF TELEMEDICINE FOR PARKINSON’S DISEASE**



(Achey, Aldred et al., 2014)

## Neurological Assessment

A well-developed capacity to undertake a neurological assessment is a core competency for specialist nurses across a range of specialty areas, such as orthopaedic nursing, emergency department nursing and critical care nursing (Duignan & O'Connor, 2016; Maher, 2016).

The Australasian Neuroscience Nurses' Association outlines Professional Standards for Neuroscience Nurses (Australasian Neuroscience Nurses' Association (ANNA), 2013). Standard 4.1 is a performance standard, whereby the specialist neuroscience nurse 'initiates and integrates ongoing patient assessment and utilises interpretive and critical thinking skills to achieve optimal patient outcomes' (Australasian Neuroscience Nurses' Association (ANNA), 2013, p. 12). The 2016 UK competency framework for nurses working in PD management emphasises assessment as a core focus area for PD nurse specialists. Nurses are expected to be aware of clinical rating scales, be competent in undertaking physical examinations (Parkinson's Disease Nurse Specialist Association, 2016, p. 21) and assessing and managing complications related to psychological problems, motor and non-motor fluctuation, independence level, mobility, falls and concurrent illness across the trajectory of a person's illness (Parkinson's Disease Nurse Specialist Association, 2016, pp. 33-40). Guidelines such as these provide evidence of the skill development and competence needed for specialist PD nurses.

Consistent with evidence cited earlier, an individualised person-centred approach to care is essential. For specialist PD nurses, neurological assessment requires the ability to undertake neurological assessments that seek objective evidence of physiological impairment, and comprehensive assessment that includes the impact of PD on a person's QoL.

## Summary and Conclusions

In summary, the research evidence and findings supporting the development of specialist PD nursing models of practice focuses on improving QoL and outcomes for people living with PD within a comprehensive chronic care model. Studies highlight the importance of early intervention and self-management strategies as key means of reducing the burden of disease and caregiver burden. The detrimental impacts of PD non-motor symptoms on QoL, such as depression, apathy, sleep disturbances and impaired executive function are also highlighted. The evidence presented in this section supports the critical role of specialist PD nurses in regular monitoring and consistent assessment of people living with PD, using validated instruments that measure symptom changes, QoL and caregiver burden. Assessment tools are presented in detail in Appendix 3.

## **VI. Achieving Sustainability for Specialist PD Nurses in Rural and Remote Contexts**

### **Introduction**

When building a case for investment in specialist PD nurses and nurse-led PD models of primary healthcare, it is imperative to consider how governments consider measures of effectiveness in health system performance and the importance of equity in resource management across public-private partnerships (Deloitte Access Economics, 2011; Willis, Reynolds, & Keleher, 2016). For people with PD in rural and remote areas, measures of equity and effectiveness are even more critical, particularly in relation to timely diagnosis, support for informal carers to reduce caregiver burden, equitable access to medications and therapies, avoidance of hospital admissions and delayed admission to residential care (Deloitte Access Economics, 2011; Parkinson's Australia, 2014). In 2011, Australian federal and state governments bore around 73% of health systems costs for PD, individuals (people with PD and carers) bore another 17% and private health insurance and other parties bore the remaining 11% (Deloitte Access Economics, 2011).

Although funding for the education of specialist nurses was identified as a key positive step (in both economic and productivity terms) by Deloitte Economics in 2011, no nurses were funded by the Australian Government as a result of the report (Deloitte Access Economics, 2011; Parkinson's Australia, 2014). This was despite evidence from the UK that a single specialist PD nurse can save approximately AUD 60 000 in consultation appointments, AUD 105 000 in avoided hospital admissions and AUD 194 00 in hospital bed days per annum (Parkinson's UK, 2011). The following sections discuss nursing models of care, commencing with the nurse-led clinic model, whose outcomes are measurable with the framework used by Deloitte Access Economics (2011). These models have been shown to lead to reductions in

costs at individual and society levels, particularly as a result of reduced burden through improved wellbeing (or QoL) for people with PD and carers, as well as reduced avoidable hospital admissions.

## Effective Models of Nursing Care for People with PD in Regional and Remote Contexts

Worldwide, it is well documented that the nurse-led clinic model has a positive effect on patient care, provides a more flexible and holistic service to clients and is often preferred to more traditional physician-led models (Carroll, 2017; Dodd, 2014; Gow et al., 2014; Martin & Mills, 2013). Studies show that nurse-led services are associated with significant reductions in health costs, and comparative evaluations between medical and nurse-led diagnosis and treatment have proven to be at least equitable (Bauer, 2010; Chenoweth, Martin, Pankowski, & Raymond, 2008; Gow et al., 2014; McNally, 2015). As noted, an evaluation undertaken in the UK found a single PD nurse can save significant expenditure, for both government and individuals. The potential benefits are obvious in the context of growing numbers of people with PD, and significant and growing health system and other financial costs in Australia going forward (Deloitte Access Economics, 2011). Extending this to a nurse-led PD nurse specialist model in rural areas gives people with PD and their carers equitable access to education and self-management, multidisciplinary teams and telehealth options, leading to better outcomes such as improved QoL and reduced time in hospital (Parkinson's Australia, 2014).

As discussed in Section VI., there is growing evidence to support the benefits of improved access and quality of clinical care to rural Australians through telemedicine and telehealth (Achey, Beck, et al., 2014; Bloem et al., 2017). Telemedicine is defined here as the use of real-time, synchronous videoconferencing to deliver medical care (Schneider & Biglan, 2017). Making these technological advances available in rural areas could improve urban-

rural disparities, provide professional development opportunities and support from specialists through the use of telehealth for rural PD nurse specialists and multidisciplinary teams, and improve recruitment and retention of healthcare professionals (Keus et al., 2012; Moffatt & Eley, 2010). However, many barriers to widespread implementation of telemedicine services remain to be addressed, including reimbursement, legal considerations and technological issues (Schneider & Biglan, 2017).

There is evidence to suggest that patient management aided by telehealth diagnostics provides outcomes comparable with current standards of care. These technologies have potential to improve care for disparate populations of people living with PD or those unable to travel (Heldman et al., 2016). Some pilot models, such as the US Connect.Parkinson program have demonstrated the feasibility and effectiveness of using technology to deliver in-home care to people with PD (see Table 2). Remote enrolment in this care model is feasible, but is likely to be affected by variable Internet access (Achey, Beck, et al., 2014; Dorsey et al., 2016). Another US pilot study examining the success of online professionally-led support groups found that people with PD with similar characteristics, such as age or experience of depressive symptoms, were willing to participate (Lieberman et al., 2005). That study showed ‘patient similarity’ enhanced positive outcomes measured by changes in QoL (PDQ-39) and a self-report depression scale (Center for Epidemiologic Studies Depression Scale); however, there are no further published reports that this program has continued or expanded (Lieberman et al., 2005).

A randomised controlled trial conducted in England and Scotland examining the impact of a smartphone-based Parkinson’s Tracker App concluded that the application may be an effective way of enhancing medication adherence and quality of clinical consultation by supporting self-management of PD (Lakshminarayana et al., 2016) (see Table 2). In Canada, a randomised controlled trial aimed to improve access to services using an individually

tailored multidisciplinary/specialist team intervention. The team included a movement disorders specialist, PD nurses and social workers. The findings revealed improved primary (PDQ-39) and secondary (UPDRS-III) outcome measures, as compared with management by a general neurologist alone. Several tertiary outcomes (UPDRS total score, Scales for Outcomes in Parkinson's disease-PsychoSocial questionnaire, and the Montgomery-Asberg Depression Scale) also improved during the 8-month intervention period. As such, this is one of the first randomised controlled trials to give credence to a multidisciplinary/specialist team approach in Canada (Van der Marck et al., 2013) (see Table 2).

Deep brain stimulation (DBS) is becoming an established and substantiated strategy to reduce motor complications in patients with PD. Moreover, motor improvement following DBS has been reported to be sustained for up to 10 years (Castrìoto et al., 2011). Work has commenced on establishing an in-depth evaluation of real-world clinical outcomes and measures of effectiveness following DBS, which will add to existing knowledge and serve as a useful tool for health services providers (Vesper et al., 2017).

## Effective Models of Care for People with Other Neurological Conditions

A study by Thyrian et al. (2017) showed dementia care management, which is a model of collaborative care provided at home by specifically trained nurses, was effective in improving patient and caregiver outcomes. This collaborative care model is defined as a complex intervention aiming to provide optimal treatment and care for patients with dementia and support caregivers using computer-assisted assessment determining a personalised array of intervention modules and subsequent success monitoring. Main outcome measures were QoL, caregiver burden, behavioural and psychological symptoms of dementia, pharmacotherapy

with anti-dementia drugs and use of potentially inappropriate medication (Thyrian et al., 2017).

A nurse-led telehealth program has been delivered to individuals with multiple sclerosis (MS) with the aim to improve their emotional health while keeping costs low (Tietjen & Breitenstein, 2017). This feasibility project was a trial implementation of an existing nurse-led telehealth promotion program in a community neurology clinic with a single MS provider. Within the limits of a feasibility pilot, the program showed positive patient outcomes, was well received by participants and was not a burden for clinic staff (Tietjen & Breitenstein, 2017).

In summary, in Australia, major outcome measures using the prevalence rate model are direct health system costs, loss of productivity, informal care costs, other financial costs (e.g. medications and health aids) and burden of disease (see Appendix 1 & 2). The largest costs are acute care and nursing home costs and indirect costs from lost productivity. Major drivers of cost increments are disease progression and severity along with motor and cognitive dysfunctions. Nurse-led models of care enable timely diagnosis, provide support for informal carers to reduce caregiver burden, ensure equitable access to medications and therapies, support avoidance of hospital admissions and assist in delaying residential care admission.

## Outcome Measures to Evaluate Quality of Service Provision for People with PD

### Background

Internationally, estimates of the societal costs associated with PD vary from country to country. However, the largest direct financial cost component is consistently identified as

acute inpatient and nursing home costs, while the greater component of indirect financial costs arises from lost productivity for people with PD and their carers (see definitions, Appendix 1 & 2) (Findley et al., 2002). A number of different approaches for measuring the financial and non-financial costs associated with a particular condition exist. Deloitte Access Economics (2011, p. 28) identified a prevalence (annual costs) approach<sup>4</sup> as more applicable for chronic conditions such as PD. Specific areas measured in the 2011 report were direct health system costs, loss of productivity, informal care costs, other financial costs (e.g. medications, health aids) and burden of disease (Deloitte Access Economics, 2011; Willis et al., 2016). Based on this approach, the total cost per annum in Australia (as calculated in 2011) was AUD 8.3 billion, which is set to rise as the number of people with PD increases. (Deloitte Access Economics, 2011; Findley, 2007). In seeking to ascertain areas of potential cost-saving and means by which the quality of service provision for people living with PD and their carers can be improved, it is important to identify accurate and comparable outcome measures by which interventions can be measured and evaluated.

A Singaporean study estimating the cost to society (measured as lifetime economic burden) reported the cost as substantial. Priority areas for research and policy development were identified, with recommended focus areas of reducing productivity losses, reducing the cost of medication, implementing measures to decrease hospitalisation and reducing home care costs (Zhao et al., 2013).

Major contributors to increasing costs are disease progression and the increasing severity of symptoms associated with this progression, in combination with motor and cognitive dysfunction. It could therefore be anticipated that disease/symptom management strategies

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<sup>4</sup> ‘Measures the number of people with a given condition in a base period and the costs associated with treating them as well as other financial and non-financial costs (productivity losses, loss of quality of life) in that year, due to the condition’ (Deloitte Access Economics, 2011, p. 28).

and therapeutic measures that minimise the impact of disease progression and maximise QoL should result in optimal resource use and contain disease expenses (Findley, 2007; Martínez-Martin et al., 2015). As discussed in Section V, p.36, studies support evidence that poor self-care in PD is reflected by worsening UPDRS-III scores and is strongly correlated with low generic HRQoL (Kleiner-Fisman, Stern, & Fisman, 2010). There is also strong evidence that reducing disease progression rates could produce significant economic benefit by improving QoL and thus quality adjusted life years (QALYs) (S. Johnson, Diener, Kaltenboeck, Birnbaum, & Siderowf, 2013). As discussed in Section III, relative to other chronic diseases, the burden of disease and caregiver burden tend to be high in PD (see definitions in Appendix 2). It is therefore important to link quality and effectiveness of service provision to consistent measures of QoL, both for people with PD and their caregivers (Findley, 2007).

The US National Institute of Neurological Disorders and Stroke Quality of Life instruments (Neuro-QoL) provide a ‘common currency’ of represented constructs across patient groups in different PD studies. In strong contrast to historically disparate measures frequently used in neurological research, the Neuro-QoL provides a standard measurement tool that incorporates assessment of physical, emotional, cognitive and social patient function, heightening researcher insight into patient wellbeing and the potential to directly inform clinical treatment (Gershon et al., 2012). A number of other assessment tools are available related to the symptoms, functional status, psychological wellbeing, HRQoL, preferences and health-related aspects for people with PD (see Appendix 3) (Martinez-Martin et al., 2015).

The following sections discuss several models of care in terms of associated cost savings.

### Evaluations of Studies with Cost Effective Outcomes

Feasibility studies conducted in the Netherlands in relation to the ParkinsonNet program showed modest but important cost savings (at least US \$439 per patient annually), and that these cost savings outweighed the costs of building and maintaining the network (Bloem et al., 2017). There is also evidence that ParkinsonNet can be replicated in other settings; as a result of the program's success, it has been implemented in several other countries and serves as a model of a successful and scalable innovation, with comparable if not better outcomes than the Netherlands version (Bloem et al., 2017).

The results of evaluations examining the use of DBS in PD with early motor complications indicated that DBS is a cost-effective intervention for people with PD when compared with existing interventions. Currently the UPDRS is the key tool used to evaluate the impact of DBS (Fundament et al., 2016). DBS may also be effective in advanced stages for younger people with PD (Dams et al., 2016). In recognition of the need to measure changes in QoL, other tools for measuring the effectiveness of DBS used in both early and advanced stages are the PDQoL and HRQoL (Dams et al., 2016; Pietzsch, Garner, & Marks, 2016).

In Australia, the nurse-led PD and Movement Disorder Service at Canberra Hospital was evaluated using Stufflebeam's context, input, process and product evaluation model<sup>5</sup> (B. Jones et al., 2016; Stufflebeam & Shinkfield, 2007) (see Table 2). That evaluation revealed a positive impact of the service, particularly in relation to improving patient support and

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<sup>5</sup> 'Context' evaluates the current situation, key stakeholders, identifies areas of need and gaps in service and provides the background to the problem.

'Input' evaluates the resources and strategies that will be needed and used in developing the program.

'Process' evaluates the implementation of the program and any issues that arose in development and execution of the program.

'Product' evaluates the program outcome, whether the objective was achieved, its impact and any other outcomes that have arisen as a result of the program implementation. (Jones, 2016, p. 266).

education (B. Jones et al., 2016). In the US state of Florida, researchers undertook a 5-year project to measure hospitalisation and re-admission rates for 7,507 people with PD and identify factors contributing to risk for admission (Shahgholi et al., 2017). As reported in other studies, hospital admission and re-hospitalisation occurred frequently. Those researchers recommended a range of areas to be addressed that would potentially reduce hospitalisation rates and thus costs. These include implementing measures to ease caregiver burden; review and simplification of medication regimes; and careful attention to providing primary/multidisciplinary care for associated comorbid conditions (Shahgholi et al., 2017).

A UK randomised controlled trial, entitled 'spiritt', aimed to investigate the components of recent national policy recommendations for people with PD; in particular, the cost effectiveness of a multidisciplinary approach to rehabilitation in primary healthcare. Findings from that study are not yet available; however, those researchers believed that studies are needed that investigate cost-effective community-based service delivery models to reduce disability and dependency and admission to long-term care, and improve QoL (Gage et al., 2012; Gage et al., 2011).

A UK study identified potential cost savings that could result from a move from hospital- to community-based treatment (Lebcir, Demir, Ahmad, Vasilakis, & Southern, 2017). This study used a 'discrete event model' to propose that shifting more patients with PD from hospital treatment to community services will reduce the number of visits of patients with PD to hospitals by about 25%, and the number of doctors and nurses required to treat these patients by around 32% (Lebcir et al., 2017). Overall, hospital-based treatment costs should decrease by 26%, leading to overall savings of 10% in the total cost of treating patients with PD. The conclusions were that community services need to be formalised and better integrated into PD care, particularly with people with PD and carers to improve informed choices and care plans (Lebcir et al., 2017). A second study examining the effectiveness of

PD specialist nurses compared with neurologists found that complementing rather than substitution was seen as the way of the future, particularly for patients with complex needs (Reynolds, Wilson-Barnett, & Richardson, 2000).

### Pilot Study Evaluations

Pilot study evaluations are often an essential, cost effective means to establish the feasibility of conducting a larger study, and test methods and procedures that may improve a study's design before larger scale research (see Appendix 1). For example, an early UK study using the PDQ-39 and Euroqol-5D (EQ-5D) reported that PD nurse specialists had little effect on clinical measures of disease state (Jarman et al., 2002). However, patients reported an improved sense of wellbeing as measured by the global health questionnaire, and importantly the PD nurse specialist role did not result in an overall increase in patients' healthcare costs (Jarman et al., 2002). Another pilot randomised controlled trial used adherence therapy to improve medication non-adherence and found that PDQ-39 and MDS-UPDRS measures improved in 76 patients (Daley et al., 2014). That study showed that adherence therapy provided cost savings and improved QoL; however, those authors concluded that a larger trial with multiple therapists was required to determine cost effectiveness (Daley et al., 2014).

In the physiotherapy field, an economic evaluation of a pilot fall prevention study aimed to compare the effects of a targeted exercise program with usual care. Health and social care use and HRQoL (EQ-5D) were measured for 93 participants, and incremental cost per QALY was estimated. However those researchers identified that although the cost utility analysis was conducted within UK health economics guidelines and the framework was sound, there were difficulties collecting data from community-based clients and services, resulting in inconclusive outcomes (Fletcher, Goodwin, Richards, Campbell, & Taylor, 2012).

Pilot evaluations are also being conducted for occupational therapy, where rigorous studies measuring the effectiveness of improving daily functioning of community-dwelling people with PD are lacking. The study by Sturkenboom et al. (2013) developed a protocol to conduct a randomised controlled trial, looking at both functional improvements using the Canadian Occupational Performance Measure as a primary measure and cost effectiveness using the health utilities measure (EQ-5D), as well as a number of secondary measures. The results demonstrated positive cost-effectiveness from the occupational therapy intervention for caregivers but not for people with PD; those researchers recommended further studies to establish benefits for clients (Sturkenboom et al., 2013; Sturkenboom et al., 2015).

In summary, national and international evaluations of evidence-based models (such as ParkinsonNet, nurse-led clinics, DBS clinics and the nurse-led PD and Movement Disorder Service at Canberra Hospital) have shown cost savings and feasibility. Developmental work that builds evidence of cost effectiveness continues through pilot evaluations, feasibility studies, protocols and randomised controlled trials. As this work continues, the level of consistency in measures of cost-effectiveness (e.g. QoL, caregiver burden, QALYs and cost utility) provides a sound base for more effective strategies to advocate for improved nurse-led primary health services for people living with PD.

## **VII. Recruitment and Retention Issues in Rural and Remote Areas**

This section discusses the research evidence available in Australia and internationally about recruitment and retention issues in relation to specialist nurses in rural and remote contexts. Across regional and rural areas worldwide there are fewer healthcare providers as a proportion of the population compared with urban settings (Hegney, McCarthy, Rogers-Clark, & Gorman, 2002b; I. Johnson, 2017; Kulig, Kilpatrick, Moffitt, & Zimmer, 2015). Therefore, attracting and retaining nurses in these areas is imperative for both private and public health providers. To address the complex issues associated with retention of rural nurses and the high costs of staff replacement, research on incentives such as educational rural preparedness opportunities, financial incentive programs, enhanced infrastructure for the workplace and support for families is discussed (Kulig et al., 2015; Molanari, Jaiswal, & Hollinger-Forrest, 2011; Molinari & Monserud, 2008; D. Russell, Wakerman, & Humphreys, 2013). In NSW, the NSW Health Professionals Workforce Plan: 2012–2022 supports capacity building within the nursing workforce across local health districts (NSW Health, 2015). However, the majority of nurses are still employed in acute care settings in major hospitals (Australian Institute of Health and Welfare (AIHW), 2016b).

In recognition of the need for new ways of thinking about the work of rural nurse policy, education, recruitment, retention and clinical governance, the Australian Government formulated several measures of rurality and remoteness to provide a framework for clarifying the context of nursing in rural or remote areas. Of these, the Remoteness Area Structure within the Australian Standard Geographical Classification (ASGC), produced by the Australian Bureau of Statistics is currently used to produce the Australian Institute of Health and Welfare nursing and midwifery labour force statistics (Australian Institute of Health and

Welfare (AIHW), 2016b). This structure comprises five categories based on an accessibility/remoteness index score, which measures the remoteness of a point based on physical road distance to the nearest service facility in an urban centre (Australian Bureau of Statistics, 2003). Statistical research using the ASGC as a framework for analysis informs policy and funding decisions affecting rural and remote nurses. Therefore, to compare like with like, it can be argued that the ASGC is the most appropriate classification system by which a rural nurse can be designated.

An additional measure, the modified Monash model (MMM) is a recently developed geographical classification system that enables categorisation of health professionals, medical services and nurses in primary healthcare in Australia's metropolitan, regional, rural and remote areas according to geographical remoteness and town size. The MMM uses two key indicators to classify 'rurality': the Australian Bureau of Statistics measure of remoteness as described above, and the Australian Statistical Geography Standard, which is based on 2011 population census data and local town size (Australian Government Department of Health, 2016). Therefore, in primary health settings, the definition of rural nursing has recently been widened to include nurses working outside major metropolitan areas where patients have reduced access to health services (Australian Government Department of Health, 2016).

These nurses may practice within teams that have resident or non-resident members, such as medical practitioners, allied health practitioners and specialist nurses.

An Australian study examining the sustainability of retention strategies for health workers in rural and remote areas found that a flexible, multifaceted response to the problem is required because of lack of demonstrated effectiveness of any specific strategy (Buykx, Humphreys, Wakerman, & Pashen, 2010). One such response to developing rural career pathways in Australia is the 'rural pipeline' model, which includes four stages: 1) making career choices; 2) being attached to a place; 3) taking up rural practice; and 4) remaining in rural practice.

This model has been extended to include nursing, midwifery and allied health (Fisher & Fraser, 2010). The rural pipeline template may strengthen current approaches to recruitment and retention in rural areas and provide a consolidated evidence base for policy development, with a focus on multidisciplinary approaches (Fisher & Fraser, 2010).

In Australia, challenges to recruiting nurses and other health professionals to rural areas include socioeconomic difficulties, inequitable access to services including education and health, lower employment levels, harsher environments, occupational hazards, and geographic and social isolation (Francis, 2005). Rural nurses have less consistent exposure to acute areas of practice and less educational opportunities to consolidate any specialist roles they undertake. They are also less likely to be specifically prepared for their role as advanced generalists in rural areas, a role involving the maintenance of a variety of skills for the care of patients who may be seen infrequently (Hegney et al., 2002b). Another major challenge is the difference between rural doctors (who mostly practice under a private business model) and nursing and allied health professionals, who practice in mixed public, private or combined practice settings (Keane, Lincoln, Rolfe, & Smith, 2013). Issues related to management for those who work in the public sector suggests that more involvement at the federal and jurisdictional levels would improve the effectiveness of rural retention policies (Keane et al., 2013).

There is some evidence that undergraduate rural clinical placements and experience can have a positive influence on the recruitment of health professionals in rural areas in Australia (Courtney, Edwards, Smith, & Finlayson, 2002). Rural nurses place particular emphasis on the satisfaction they derive from interdisciplinary and community interaction and respect. These interactions are facilitated by the absence of complex organisational structures within smaller rural health services. Rural nurses consistently discuss job satisfaction in terms of

knowing their community well, which means they are in a position to offer excellent holistic care, particularly in primary health settings (Hegney & McCarthy, 2000; Mills, Birks, & Hegney, 2010).

The results of a study using the Nursing Community Apgar Questionnaire (NCAQ) in rural Australia support the evidence that lifestyle, patient safety, high quality care and availability of necessary materials and equipment are the most important factors in recruitment and retention (Prengaman, Terry, Schmitz, & Baker, 2017). Findings from the NCAQ provide health services with greater evidence as they seek to address site-specific factors to improve staff recruitment and retention (Prengaman et al., 2017). An integrative review concluded that issues associated with professional isolation in rural areas, which may be geographic, social or ideological, may be addressed through electronic communication and information technology.

Other factors that could be used in marketing strategies to improve recruitment of the nursing workforce include previous exposure to rural life, closeness to family and friends and professional job satisfaction (Hegney, McCarthy, Rogers-Clark, & Gorman, 2002a; Kulig et al., 2009). Despite the inherent altruistic motivation of rural nurses, previous reports strongly suggest that nurses leave rural and remote areas because their voice is largely unheard by government health facilities (Hegney et al., 2002b; New South Wales Health Department, 1996, 2001). Strategies that aim to retain staff should therefore consider personal needs, local support from managers and career aspirations (Perkins, Larsen, Lyle, & Burns, 2007).

In a comparable geographic area in Northeast Ohio in the US, an innovative approach to addressing nursing shortages was creating a regional initiative including a regional nursing resource centre (Anderson, Girod, & Brzytwa, 2003). The resource centre aimed to focus on five areas: career attraction and education (job shadowing), public image and communication

(web page), data and reports (workforce benchmarking), a conference on best practices in nursing recruitment and retention and legislative advocacy (Anderson et al., 2003). Funding for the project was provided by a mix of local and state bodies, and the initiative's longer term vision was to create a culture of collaboration, create innovative programming and support nursing leadership (Anderson et al., 2003).

Another US pilot study conducted in Arizona found that evidence-based practice in conjunction with empowering work structures enhanced rural nurses' ability to implement reliable, quality healthcare services in an environment conducive to learning, autonomy, productivity and innovation (Belden, Leafman, Nehrenz, & Miller, 2012). An innovative rural 'grow your own' strategy in Colorado aimed to increase the rural provider workforce pipeline by recruiting registered nurses from within rural communities to return to school (with financial support from local communities) and become primary service providers (I. Johnson, 2017).

Finally, a systematic review examining international financial incentive programs for 'return of service' (a health worker enters into a contract to work for a number of years in exchange for a financial pay-off) in areas of reduced access to services found a significant variation in success across countries such as the US, Japan, Canada, South Africa and New Zealand (Barnighausen & Bloom, 2009). That review suggested that outcome measures for recruitment and retention financial incentive programs are developed with a regional focus, and consider specific characteristics at the local level (Barnighausen & Bloom, 2009).

## Summary and Conclusions

Measures of sustainability are an important consideration for rural and remote nurse recruitment and retention strategies, such as education, financial-incentive programs and workplace infrastructure. Sustainable strategy development should be underpinned by statistical research and evidence to support advocacy for PD nurse specialists in rural and remote areas such as that available from the Australian Bureau of Statistics obtained by the application of nationally applied geographical classification systems such as the ASGC and MMM. Strategies then require a combined public and private sector response, and should be developed with a regional focus that considers specific characteristics at the local level.

## VIII. Appendices

### Appendix 1: Outcome Measures to Evaluate Quality of Service Provision

Outcome	Description of measure
Burden of disease	Years of healthy life lost, both quantitatively and qualitatively (see below for non-financial costs). The total significance of disease for society beyond the immediate cost of treatment, measured in years of life lost to ill health as the difference between total life expectancy (as measured by disability-adjusted life years) and disability-adjusted life expectancy.
Caregiver burden	The extent to which family caregivers perceive their emotional or physical health, social life and financial status has suffered as a result of caring for their relative.
Cost effectiveness	An assessment or determination of the most efficient and least expensive approaches to health provision and prevention. Referring to an intervention that is considered financially optimal if there is no other available intervention that offers a clinically appropriate benefit at a lower cost.
Disability-adjusted life years	Number of healthy years of life lost due to premature death and disability.
Feasibility study	An analysis and evaluation of a proposed project to determine if it: 1) is technically feasible, 2) is feasible within the estimated cost and 3) will be profitable. Feasibility studies are almost always conducted where large sums are at stake.

Outcome	Description of measure
Pilot study	Assessing the feasibility of conducting a larger study by testing methods and procedures to be used on a larger scale. A pilot study evaluation may then identify how to improve the study design before larger scale research.
Productivity costs (losses)	Includes productivity losses of people with PD (long-term employment impacts), premature mortality and the value of informal care (including lost income of carer).
Quality of life	An output measure for comparing the effectiveness of alternative health interventions and allocating scarce resources.
Quality adjusted life years (QALY) Monetised QALY	QALY allows evaluation of the health impact on both life years and quality of life. The QALY approach weights life years (saved or lost) by the quality of life experienced in those years. Provides a single currency for measuring any health impact.
Prevalence (annual costs) Approach	Measures the number of people with a given condition in a base period and the costs associated with treating them, as well as other financial and non-financial costs (productivity losses, loss of quality of life) in that year, due to that condition.
Sustainability	The use of various strategies for employing existing resources optimally so that that a responsible and beneficial balance can be achieved over the longer term.

## Appendix 2: Cost Classifications (Definitions)

Administrative costs and other financial costs	Includes government and non-government programs such as respite, community palliative care, out-of-pocket expenses (e.g. formal care, aids, equipment and modifications that are required to help cope with illness, transport and accommodation costs associated with receiving treatment) and funeral costs.
Direct financial costs	Costs of running hospitals and nursing homes (buildings, care, consumables), GP and specialist services reimbursed through Medicare and private funds, the cost of pharmaceuticals (Pharmaceutical Benefits Scheme and private) and over-the-counter medications, allied health services, research and 'other' direct costs.
Informal care costs	The cost of loss of productivity from providing informal care to people with PD, predominantly provided by family and friends.
Transfer costs	The deadweight losses associated with government transfers such as taxation revenue foregone, welfare and disability payments.
Non-financial costs	The pain, suffering and premature death that result from PD. Although more difficult to measure, these can be analysed in terms of the years of healthy life lost, both quantitatively and qualitatively, known as the 'burden of disease' (see above).

### Appendix 3: Summary of Assessment and Monitoring Tools

Scale/tool	Tested/validated	Brief description	Availability
<i>Tools specific to PD</i>			
Hoehn and Yahr Scale (Goetz et al., 2004; Hoehn & Yahr, 1967; Martinez-Martin, Rodriguez-Blazquez, Forjaz, & Chaudhuri, 2014)	Original tested clinimetrically  Modified version not recommended for research as not tested clinimetrically	First developed in 1967 Global severity assessment Widely used clinical rating scale that describes broad categories of motor dysfunction in PD. Simple to use but limited, and therefore not comprehensive. Largely replaced by the Unified Parkinson's Disease rating Scale (UDPRS) as a primary outcome measure of treatment efficacy (Goetz et al., 2004)	Public domain
Parkinson's Disease Questionnaire (PDQ-39 and PDQ-8)	Validated tool  Available in a range of languages	PDQ-39: largely used in clinical trials, covers eight scales (mobility, ADLs, emotional wellbeing, stigma, social support, cognitions, communication and bodily discomfort). PDQ-8: short form comprising one question from each of the eight scales.	License required Health outcomes <a href="https://innovation.ox.ac.uk/outcome-measures/parkinsons-disease-questionnaire-pdq-39-pdq-8/">https://innovation.ox.ac.uk/outcome-measures/parkinsons-disease-questionnaire-pdq-39-pdq-8/</a> References outlining validation process at this site

Scale/tool	Tested/validated	Brief description	Availability
<p>Movement Disorder Society-Sponsored Revision of the Unified Parkinson's Disease Rating Scale (MDS-UPDRS) (Martinez-Martin et al., 2014) pp. 13–21)</p>	<p>Validated tool</p> <p>Available in many different languages</p>	<p>The MDS-UPDRS has sections to be completed independently by people affected with PD and their carers, and sections to be completed by the clinician:</p> <ul style="list-style-type: none"> <li>• Part 1: non-motor experiences of daily living</li> <li>• Part 2: motor experiences of daily living</li> <li>• Part 3: motor examination</li> <li>• Part 4: motor complications.</li> </ul>	<p>Movement Disorder Society-owned scales</p> <p>Permission required to use this tool (fees may be applicable)</p> <p><a href="https://www.parkinsons.org.uk/professionals/resources/unified-parkinsons-disease-rating-scale">https://www.parkinsons.org.uk/professionals/resources/unified-parkinsons-disease-rating-scale</a></p> <p>May be reported as single section or a UPDRS total score.</p>
<p>Scales for Outcomes in Parkinson's disease- PsychoSocial Questionnaire (Marinus, Visser, Martinez-Martin, van Hilten, &amp; Stiggelbout, 2003)</p>	<p>Validated tool</p>	<p>Short psychosocial instrument for patients with PD. The scale has demonstrated good reliability and validity.</p> <p>11 items with a possible score range of 0–33.</p>	<p>Leids Universitair Medisch Centrum</p> <p>Accessible free of charge, with permission from the authors.</p> <p>Use in studies must be communicated to the developers.</p> <p><a href="https://www.lumc.nl/org/neurologie/research/propark-research/Scales/Psychosocialfunctioning/">https://www.lumc.nl/org/neurologie/research/propark-research/Scales/Psychosocialfunctioning/</a></p>
<p>Parkinson's Disease Quality of Life (de Boer, Wijker, Speelman, &amp; de Haes, 1996)</p>	<p>Validated tool</p>	<p>37-item self-administered questionnaire. Four subscales: parkinsonian symptoms, systemic symptoms, social functioning and emotional functioning</p>	<p>eProvide</p> <p><a href="https://eprovide.mapi-trust.org/instruments/parkinson-s-disease-quality-of-life-questionnaire">https://eprovide.mapi-trust.org/instruments/parkinson-s-disease-quality-of-life-questionnaire</a></p>

Scale/tool	Tested/validated	Brief description	Availability
<p>Non-Motor Symptoms Scale &amp; Questionnaire (NMSS &amp; NRS-Quest) (Chaudhuri et al., 2007; Martinez-Martin et al., 2014)</p>	<p>Validated tool</p>	<p>NMS-Quest: 30 item self-administered questionnaire.            NMSS: 30-item clinician administered questionnaire.</p> <p>Developed by the International Parkinson’s Disease Non-Motor Group.</p>	<p>Copyright, The Movement Disorder Society  <a href="https://www.movementdisorders.org/MDS-Files1/PDFs/MDS-UPDRS-Rating-Scales/NMSS30itemsrevised.pdf">https://www.movementdisorders.org/MDS-Files1/PDFs/MDS-UPDRS-Rating-Scales/NMSS30itemsrevised.pdf</a></p>
<p>Three-step clinical prediction tool to assess the probability of falling in the next 6 months in people with PD. (Canning et al., 2014)</p>	<p>Validated            (Duncan et al., 2015)</p>	<p>Scored against:            Fallen in the past 12 months            Freezing of gait in the past month            Time to walk over the middle 4 m of a 6 m walkway at a comfortable pace</p>	
<p>Multifactorial falls assessment (Hiorth et al., 2014; Pikel et al., 2015)</p>		<p>Canning et al. (2014) describe additional factors for falls assessment in addition to the use of the three-step clinical prediction tool above. Also provides strategies to manage high or low risk of falls.</p>	

Scale/tool	Tested/validated	Brief description	Availability
<p>The Caregiver Strain Risk Screen-10</p> <p>Developed for caregivers of people with PD (Abendroth, 2015, 2016)</p>	<p>Tested in the US. Nonprobability sampling: primarily wives as caregivers.</p>	<p>First version: 28-item scale evaluated briefly in a 2017 paper (Philip, Rebecca, &amp; Nadeeka, 2017, p. 241).</p> <p>10-item single factor model: efficient theory-based instrument to assess caregiver strain risk throughout the care recipient's illness progress.</p> <p>Measures risk for strain in caregivers of persons with PD. Highlights the importance of preventive care and the need for referrals to suitable services.</p>	<p>See the below reference for a review of other tools measuring Caregiver Burden in PD.</p> <p>Philip, E. M., Rebecca, M., &amp; Nadeeka, D. (2017). Caregiver Burden in Parkinson Disease: A critical review of recent literature. <i>Journal of Geriatric Psychiatry and Neurology</i>, 30(5), 235–252. doi:10.1177/0891988717720302</p>
<p><b><i>The following text is available to download in full and provides a useful guide to a number of assessment scales:</i></b></p> <p>Martinez-Martin, P., Rodriguez-Blazquez, C., Forjaz, M. J., &amp; Chaudhuri, K. R. (2014). <i>Guide to Assessment Scales in Parkinson's Disease</i>. Tarpoley: Springer Healthcare Ltd.</p>			
<p><b><i>This text is recommended by Vince Carroll (note, must be purchased as it is not available online):</i></b></p> <p>Sampaio, C., Goetz, C. G., &amp; Schrag, A. (Eds.). (2012). <i>Rating Scales in Parkinson's Disease: Clinical Practice and Research</i>: Oxford University Press.</p>			

Scale/tool	Tested/validated	Brief description	Availability
<i>Generic Tools</i>			
Apathy Evaluation Scale (AES) (Marin, Biedrzycki, & Firinciogullari, 1991)	Validated tool: not specifically for PD	18-item scale: available as self, informant, and clinician versions. The AES addresses characteristics of goal directed behaviour that reflect apathy, including behavioural, cognitive and emotional indicators. Developed for measuring apathy resulting from brain-related pathology (Glenn, 2005).	<a href="https://www.sralab.org/rehabilitation-measures/apathy-evaluation-scale-includes-three-forms-self-informant-and-clinician">https://www.sralab.org/rehabilitation-measures/apathy-evaluation-scale-includes-three-forms-self-informant-and-clinician</a>
Quality of Life in Neurological Disorders	Validated tool	Self-report and proxy measures: evaluate and monitor the physical, mental and social effects experienced by people with neurological conditions.	Health Measures website <a href="http://www.healthmeasures.net/explore-measurement-systems/neuro-qol/obtain-and-administer-measures">http://www.healthmeasures.net/explore-measurement-systems/neuro-qol/obtain-and-administer-measures</a>
Starkstein Apathy Scale (S. Starkstein et al., 1992)	Validated tool	Developed from the AES. Originally tested in PD. Also validated for use in stroke and Alzheimer's disease (S. E. Starkstein, Jorge, & Mizrahi, 2006).	eProvide Accessed via <a href="https://eprovide.mapi-trust.org/instruments/starkstein-apathy-scale#member_access_content">https://eprovide.mapi-trust.org/instruments/starkstein-apathy-scale#member_access_content</a>
Health related quality of life			Available on Centers for Disease Control and Prevention (CDC) website <a href="https://www.cdc.gov/hrqol/methods.htm">https://www.cdc.gov/hrqol/methods.htm</a>

Scale/tool	Tested/validated	Brief description	Availability
Beck Depression Inventory	Validated tool: available in many languages	21-item scale, usually self-completed.  Generic scale but applicable for use in PD.	Owned by Psychcorp.
Montgomery-Asberg Depression Scale (Davidson, Turnbull, Strickland, Miller, & Graves, 1986; Fantino & Moore, 2009)	Validated tool: some validation studies in PD	10-item diagnostic questionnaire used to measure the severity of depressive episodes. Designed to be sensitive to change resulting from antidepressant therapy.	Copyright by Stuart Montgomery MD.

## Appendix 4: Abbreviations

ASGC	Australian Standard Geographical Classification
CNC	Clinical nurse consultant
DBS	Deep brain stimulation
HRQoL	Health related quality of life
PD	Parkinson's disease
MDN	Movement disorder nurse
MMM	Modified Monash Model (geographical classification system measuring rurality and remoteness)
NICE	National Institute for Health and Care Excellence
QALY	Quality adjusted life years
QoL	Quality of Life

## **IX. Contributors**

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As an advanced practice Registered Nurse Marguerite's extensive clinical, education and research expertise is in chronic care nursing with a focus on neurological conditions affecting the older population, such as dementia and Parkinson's disease. Marguerite has a strong scholarly track record in linking nursing theory and evidence based models of care to curriculum development in undergraduate, postgraduate nursing and inter-professional programs. She has national recognition for her expertise in managing and implementing innovative, evidence based models and clinical trial interventions, working collaboratively on projects with industry stakeholders, managers, health professionals, clients and families. This expertise is supported by her previous experience in the corporate sector, both as a consultant, an educator and a manager.

In her current position with CSU, part of Marguerite's role is as Clinical Chair with aged care provider Catholic Healthcare Limited. This role is focused on providing leadership in aged care practice innovation and includes working collaboratively with health professionals across disciplines, developing best practice nursing models and clinical guidelines to improve care quality, with the aim to achieve excellence in this crucial area of health care.

### **Vincent Carroll**

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Vincent's extensive nursing experience includes 20 years in hospital and health administration roles in New South Wales and 16 years clinical nursing experience in the United Kingdom and in Australia.

Vincent's work as a Clinical Nurse Consultant has resulted in significant service delivery improvements for people with Parkinson's disease living in the MNCLHD. His strong commitment to clinically-based research informs his practice and his engagement with Parkinson's NSW.

### **Associate Professor Rachel Rossiter**

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Rachel's clinical nursing experience over 30 years in primary health care, public health, general practice and mental health settings both in urban and rural areas of NSW and in countries such as Madagascar and the Solomon Islands has given her a deep understanding of the key role that nurses play in the provision of health care around the world. This clinical experience, twelve years of which were spent working at an advanced practice level with people living with chronic and disabling autoimmune conditions and a further ten years in specialist mental health practice, informs and enhances her work as an academic and researcher.

Rachel's passion and commitment to expanding the scope and capacity for advanced nursing practice has enabled her to develop and implement advanced practice nursing programs at the University of Newcastle, University of Sharjah (United Arab Emirates) and at Charles Sturt University. Her expertise in curriculum development and ability to work trans-culturally has led to international consultancy engagements with the Aga Khan Development Network and University in Egypt and East Africa and ongoing research activities in the United Arab Emirates. As a researcher, her activities continue to focus on the role of nurses in the provision of specialist care, and the translation of evidence-based practice into effective health care delivery.

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