Creating a supportive nurse-led model for improved outcomes for people living with Parkinson’s and their families and carers.
Overview

- Introduction
- Why this research?
- Three stage project:
  - Stage 1
  - Stage 2
  - Stage 3
Research commissioned by Parkinson’s NSW and conducted in partnership with our Research Team from CSU

To 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.
Six pillars supporting the Parkinson’s NSW community 2017/18 and into the future
Why is this research needed?
Parkinson’s disease
Described as a neurological disease

• Re-classified as a neurodegenerative condition with both motor and non-motor symptoms*

• In Australia
  • More common than prostate cancer, bowel cancer and many other cancers considered National Health Priority areas
  • Neurological disease is now second to cardiovascular disease as a major cause of disease burden in older Australians (65 years +).
  • 20% of those affected are of working age and the remaining 80% are over 65.

World Health Organisation policy framework

- Parkinson’s disease places a heavy burden on the person with the disease, their caregiver, family and society.

- WHO emphasises the need for positive and proactive government policies with clearly identified links to healthcare organisations and the community.

In Australia

- Currently, **no national policy framework** in this country addressing the needs of people living with Parkinson’s disease.

- The lack of policies and 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 Parkinson’s Disease when compared with those living in urban areas.
Stage 1 (completed)

Research title

Building evidence to support Parkinson's NSW advocacy for neurological nurses in rural and remote New South Wales
Stage 1

A comprehensive review of the existing research evidence to identify:

- **Best practice nursing services for people living with Parkinson’s disease**, and
- **Measures of sustainability for recruitment and retention for rural and remote area nurses.**

Reviewed Australian & international literature published in English

Included models that:

• Have been trialled or implemented as evidence-based model/s of primary care for people living with PD;
• Are 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;
• Provide 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.
### 15 models
Primary and specialist nursing care for Parkinson’s disease

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<th>Canada</th>
<th>Netherlands</th>
<th>United Kingdom</th>
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United Kingdom

Cost-effective primary health services are available for people with Parkinson’s disease.

**PARKINSON'S NURSES**

Parkinson's nurses have specialist experience, knowledge and skills in Parkinson's, and play a vital role in giving expert care to people with Parkinson's.

[https://www.parkinsons.org.uk/information-and-support/parkinsons-nurses](https://www.parkinsons.org.uk/information-and-support/parkinsons-nurses)
Well-developed policies formed jointly by government and nursing bodies have increased the scope of the Parkinson’s Disease nurse specialist.
Since 2004, implemented the ParkinsonNet program, a low cost, evidence-based model of integrated care.

- Aims to enable connectedness, training, transparency and a team-based approach using a web-based system
- 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

International collaboration across Europe and Canada to improve community care for people living with Parkinson’s disease.
ParkinsonNet model

http://www.parkinsonnet.info/about-parkinsonnet
Developing specialist PD nursing models of practice

- Early intervention, specialist treatment, community rehabilitation and support
- Working within multidisciplinary teams across the continuum of disease progression
- Comprehensive chronic care model of person-centred care
- Supporting family and carers
- Palliative care
- Neurological assessment
- Telemedicine

Integrated care delivered across services

- General Practice
- Acute/Subacute
- Community
- Residential Care
- Palliative Care
Addressing needs of regional communities

- Effective use of technological advances for people living with PD and their families
- Assessment, ongoing management, health education, tele-monitoring
- Funding options available for reimbursement
In summary

Specialist services that:

• Maximise the scope of the nursing role
• Incorporate access to a multidisciplinary team
• Use the latest technological advances

Are more likely to be sustainable and cost effective for service providers and people living with Parkinson’s disease in regional communities.
Stage 2 (now underway)

Research title

Evaluating the impact of two specialist neurological nurse positions in regional NSW

Additional team member for Stage 2A:
Dr Annabel Matheson - SNMIH
Charles Sturt University
Stage 2

- Designed to collect NSW focused information from two regional specialist PD nurse positions.

- Will provide current NSW located research evidence to extend the findings from Stage 1.

- We are using the information from Stage 1 to inform the interpretation of the Stage 2 data.
Listening to:

- People living with Parkinson’s
- Carers/Family
- Health Professionals
- PD nurse specialists

Data analysis in progress

Cost impact of the Parkinson’s nurse specialist position:
- A pilot retrospective study

Ethics approval obtained
Research Questions:

• How does the specialist neurological nurse describe each aspect of the model of care that they employ to deliver care to people with Parkinson’s disease and associated conditions?

• How do people accessing these specialist nursing services describe their experience of the service?

• How do carers of people accessing these specialist nursing services describe their experience of the service?

• What is the perspective of health care professionals (neurologists, allied health professionals) of the value and impact of the specialist nursing role?
Research Question:

Does service usage data for the past five years demonstrate the cost impact of the Mid North Coast LHD Parkinson’s nurse specialist position?
Successful grant application

- Mid North Coast Local Health District have contributed $20,000 to 2B, providing project officer to collect data.
Community engagement

Stage 3 (underway)

Research Masters student
- Vince Carroll - Parkinson’s Nurse Consultant

Academic Supervisors
- Associate Professor Rachel Rossiter
- Associate Professor Marguerite Bramble
Community engagement

Stage 3 (underway)

Research (DRAFT) aims

• Identify the factors that affect the functioning of community support groups in rural areas.

• Recommend support group model/s for people living with Parkinson’s disease that have the potential to be sustainable.
Research addresses **Four** of the Six pillars supporting the Parkinson’s NSW community 2017/18 and into the future.
For further information:

Rachel Rossiter
rrossiter@csu.edu.au
02 6365 7245
CSU – Orange

Marguerite Bramble
mbramble@csu.edu.au
02 6338 4596
CSU - Bathurst

Vincent Carroll
vincent.carroll@health.nsw.gov.au
02 6659 2333
MNCLHD – Coffs Harbour