

# **Movement Disorder Nurse Specialist Pilot Program**

## **Evidence Profile**

### **Introduction**

Hunter New England Central Coast Primary Health Network (HNECC) has been funded by the Commonwealth Department of Health to trial a new approach to improve the quality of life of people with movement disorders. The Movement Disorder Nurse Specialist (MDNS) pilot program will initially focus on Parkinson's disease (because of its high prevalence) with plans to expand the program over time to cover other movement disorders.

The pilot is currently funded until June 30 2023.

This project will use a co-design process. This means that people involved in delivering or receiving the new services will have a say in the design of the project. This includes individuals and families that live with Parkinson's disease, GPs, practice nurses and AMS staff who see patients with Parkinson's disease, and people who work in organisations that advocate for and support people with Parkinson's disease and their families and carers.

Project design will have a number of phases. We'll invest in understanding the problems, from a user perspective, that need to be resolved for the project to work. We'll test ideas with stakeholders and build in feedback loops so we can make upgrades to the design and implementation of the project as we go along. This document is one step in the co-design process.

### **Problem Description**

There are many different movement disorder conditions including: Parkinson's disease, multiple sclerosis, motor neurone disease and Huntington's disease.

Parkinson's disease (PD) is a high prevalence movement disorder. It is a complex, neurodegenerative and disabling condition that requires a coordinated approach to managing the health needs of people as their disease progresses. Presenting symptoms include slowness of movement, muscle rigidity, tremor, instability, depression and anxiety. There is no known cure. The primary health sector, including general practices and Aboriginal Medical Services (AMS), has a critical role to play in helping patients live well, with the best quality of life possible.

People diagnosed with Parkinson's disease need access to specialised clinical care and support. And with over 93% of neurologists being located in major cities, this can be challenging if you live in a rural area like Tamworth and surrounding communities. This project aims to improve the care and support provided to people living with movement disorders in Tamworth and surrounding communities by building the capacity of the local primary care sector and improving access to specialised movement disorder clinical care and support.

## Key statistics

Parkinson's NSW states that the number of people living with Parkinson's in Australia may range from 84,000 to 212,000 (0.85%) of the population. A diagnosis can occur at any age with the most common age being 65. 10% of people diagnosed with Parkinson's are under the age of 45. 18% of people living with Parkinson's are of working age, that is under 65 (this includes people diagnosed under 45).<sup>i</sup>

In 2016 an NSW Health Agency for Clinical Innovation (ACI) estimation of the prevalence of movement disorders in NSW was:

Condition	Prevalence	People affected in NSW – estimate (NSW pop. 7,300,000)
<b>Parkinson's disease</b>	283:100,000 <sup>1</sup> 3400:100,000 over 55 years <sup>1</sup>	20,900
<b>Multiple sclerosis</b> <sup>2</sup>	100:100,000	8000
<b>Neurofibromatosis 1</b> <sup>3</sup> <b>Neurofibromatosis 2</b> <sup>3</sup>	33:100,000 3:100,000	3000
<b>Muscular dystrophy</b> <sup>4</sup>	1:1000	7000
<b>Motor neurone disease</b> <sup>5</sup>	7:100,000	500
<b>Huntington's disease</b> <sup>6</sup>	7:100,000	500
<b>Subtotal</b>		<b>39,900 people</b>

In relation to Aboriginal communities the ACI report stated that "little is known about the Aboriginal population with neuromuscular and neurodegenerative conditions. They may be cared for in the community with little access to financial and other resources". The report noted Australian Bureau of Statistics findings that Aboriginal people are more likely than other Australians to need assistance due to a disability, health condition or ageing, and to have problems accessing services.<sup>ii</sup>

HNECC PHN identified New England/Northwestern as a priority area for the pilot. It was estimated that a minimum of 696 people live with Parkinson's disease in the New England/Northwestern region (0.37% of the population). Unsurprisingly the highest number of people living with Parkinson's disease are in Tamworth and Armidale. The following tables displays the estimated prevalence of Parkinson's disease across the New England/Northwestern region.

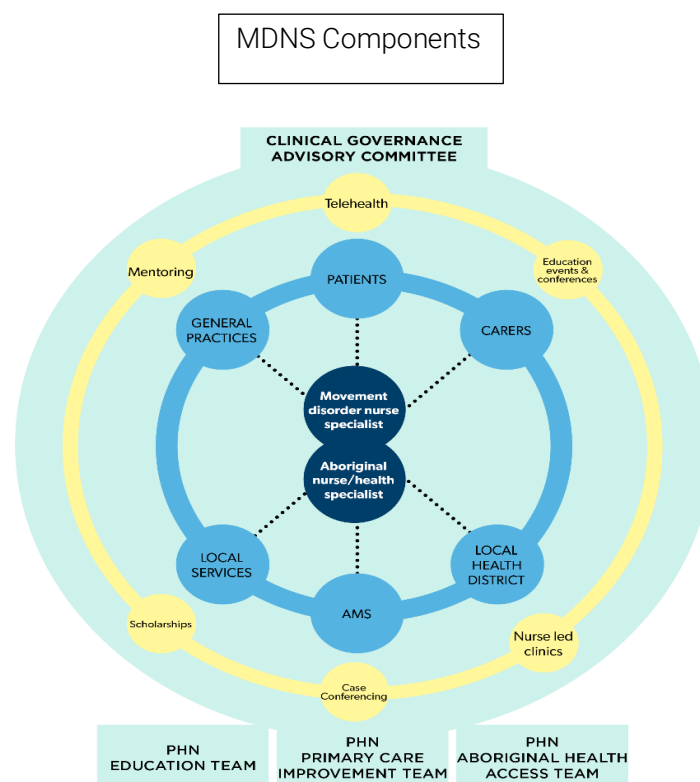
LGA	Estimated number of PD patients	Population	Percentage of population	MM Region Classification	Aboriginal population 2016 as proportion total population 2016	SEIFA Index of Relative Socio-economic Disadvantage 2016 based on Australian score of 1000
<b>Proposed Regions to be services by pilot program</b>						
Tamworth Regional	223	62156	0.36%	MM3-MM5	12%	962
Moree Plains	39	13,350	0.29%	MM4-MM6	27%	920
Inverell	67	16844	0.40%	MM4-MM5	10%	909
Tenterfield	34	6638	0.51%	MM5	7%	910
Narrabri	45	13231	0.34%	MM4-MM6	15%	960
Armidale Regional	102	30707	0.33%	MM3-MM5	9%	980
Glen Innes Severn	43	8908	0.48%	MM4-MM5	7%	915
Gunnedah	45	12661	0.36%	MM4-MM5	15%	950
Liverpool Plains	34	7893	0.43%	MM5	15%	914
Gwydir	25	5349	0.47%	MM5	7%	942
Walcha	15	3132	0.48%	MM5	7%	981
Uralla	24	6062	0.40%	MM3-MM5	8%	992
<b>Totals</b>	<b>696</b>	<b>186931</b>	<b>0.37%</b>		<b>12%</b>	

Estimated number of PD patients and Population based on ABS 2018 Estimated Resident Population

## Project description

The project has 5 components:

1. A central hub (Tamworth) and spoke outreach service for people living with Parkinson's disease.
2. A new Nurse Specialist role, responsible for program management and clinical governance, who will run weekly nurse-led clinics from a local community organisation and monthly/quarterly clinics on an outreach basis. They will also establish a general practice visiting schedule to support local GPs and practice nurses.
3. A new part-time Aboriginal Nurse/Health Worker co-located with the Nurse Specialist, who will assist in providing culturally appropriate care, linking with Aboriginal communities and Aboriginal Medical Services.
4. In-practice case conferencing (including telehealth) to build local capacity
5. A range of professional development strategies including mentoring, education, scholarships, and a local community of practice.
6. Project guidance and support from an expert advisory group



## Lived experience of Parkinson's disease

There is no one standard journey for people living with Parkinson's disease. There are many different paths and lots of ups and downs. The journey varies according to a range of factors including a person's symptomology, their personal support networks, local community services and the availability of effective clinical and therapeutic services.

The Parkinson's disease literature and recent stakeholder interviews about this pilot project identify some of the recurring themes that this project can potentially address and work with.

### Getting a timely diagnosis

*I had a delay in diagnosis – my GP thought it might be symptoms of ageing or side effects of medication I was taking.*

*My GP ordered a battery of tests because of my symptoms but they all came back negative. Finally I was referred to a neurologist but it took 6 months to get an appointment. As soon as I saw the neurologist they diagnosed Parkinson's disease.*

*I have seen Parkinson's disease in older family members. When I developed symptoms I went to my GP and demanded a referral to a neurologist.*

*If you get an early diagnosis – there are things that you can do to slow down the disease.*

### After the diagnosis

*I was in shock devastated – all I could think about was the wheelchair.*

*I had no idea of where to go for help and what was available. I didn't know what the symptoms were and what to look out for.*

*I was given practical advice about exercise but no one told me anything about the psychosocial impacts. You need support people to talk to.*

## **Dealing with symptoms**

*Parkinson's disease is terrible. Awful symptoms. It's a shit disease.*

*I started going downhill again after I lost one of my major support people.*

*I have trouble walking. I get pain and stiffness. Often when I first wake up its difficult to get going.*

*I wake up in the middle of the night and I just can't get back to sleep – even though I still feel tired.*

*People treat me differently because I have a wooden expression or appear to be just staring at them – it the Parkinson's.*

*I have had depression and anxiety – I know what brings it on but I still get overwhelmed by the panic attack.*

## **Medication management**

*Medicine really helps. Over time I am taking stronger medications. Some make me sick and require lots of adjustment.*

*The drugs are very complicated. Every time I ask my GP for help they say "I'll ask the neurologist". Sometimes it can take weeks for the response to get from the neurologist to my GP and then to me.*

*Sometimes I'm having a poor response to my meds and I need someone to help me figure out why.*

## **Getting the right support really helps**

*My GP really helps me with a lot of my symptoms like anxiety and depression and dealing with the pain.*

*Since I joined Movers and Shakers and began exercising I've been going from strength to strength.*

*It was important to me to have people to talk, to share experiences and start having a laugh. Once I started getting that support I began to see a positive future again.*

## **Carers need support too**

*Carers feel like they have to do everything. And sometimes it seems that they do but there are other services and supports out there that we can access.*

*Carers need lots of support. They look after us but who looks after them?*

## **Navigating the system**

*If I have to go the hospital I need to plan and prepare in advance and make sure the hospital knows what to expect. If the timing of my medication is late I am unable to move or speak and I don't want them to misinterpret the symptoms.*

*I know I am eligible for an aged care nursing package but trying to communicate my needs and get a timely assessment and assignment of the package has been very difficult. I had to wait for months and I needed the care immediately.*

*It may take twenty years but you know how this disease ends. It's important to prepare for that so that you have a plan for how you want to be cared for.*

## **Every day is a gift**

*Sure, the future is more uncertain but I get inspired by the people I've met with Parkinson's disease who have lived active lives for many years.*

*I've done amazing things because of Parkinson's disease – things that I never would have dreamt that I'd do.*

*We've had the most incredible adventures and been able to give back to others at the same time!*

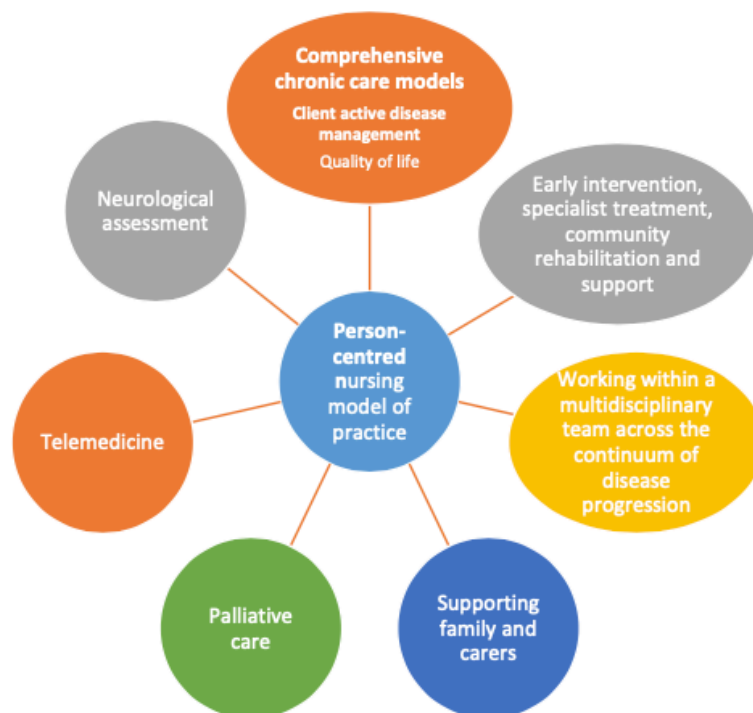
*Once I met other people with Parkinson's disease it made all the difference. I can still go to my workroom and be creative and make things. Now every day is a gift.*

## Evidence

An integrative literature review examined fifteen evidence-based models of primary care from five countries (the UK, the Netherlands, the US, Canada and Australia) as frameworks to advocate for developing the specialist Parkinson's disease nursing role in rural and remote areas.

The review found that specialist Parkinson's disease nursing models of practice focuses on improving quality of life and outcomes for people living with PD in seven areas:

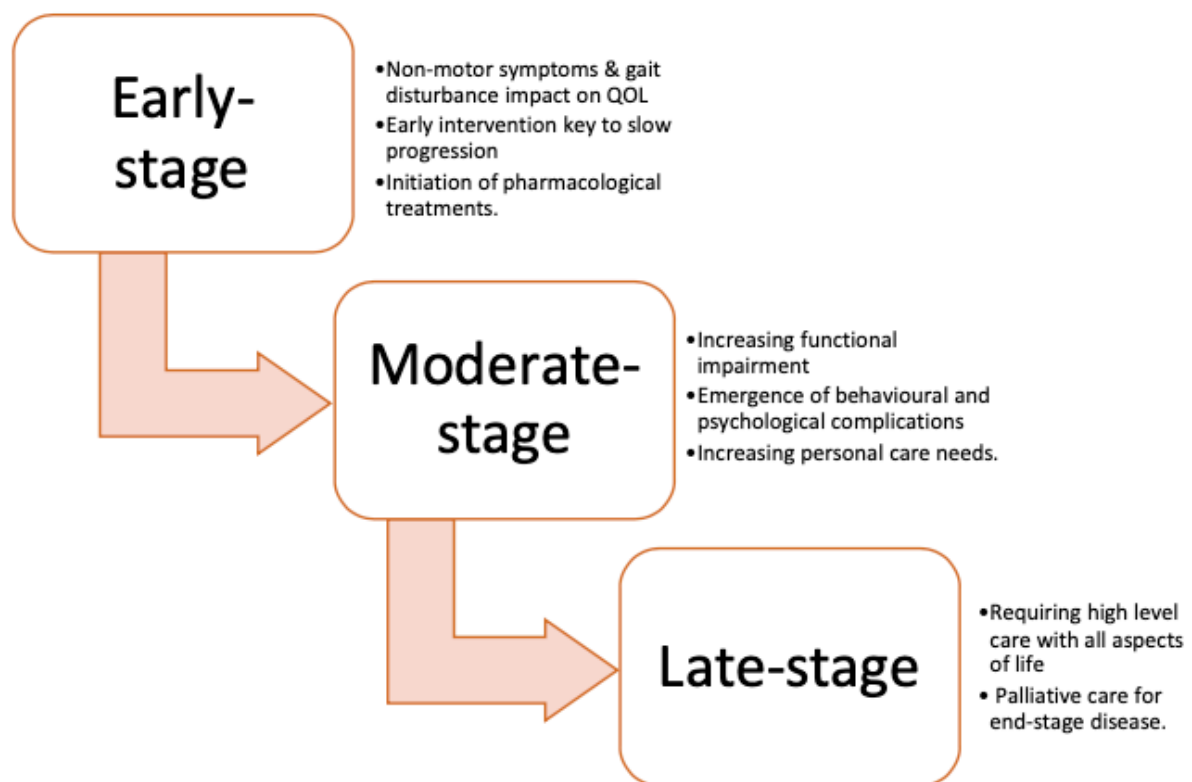
1. A comprehensive chronic care model of person-centred care
2. Early intervention, specialist treatment, community rehabilitation and support.
3. Working within multidisciplinary teams across the continuum of disease progression
4. Supporting family and carers
5. Palliative care
6. Telemedicine and
7. Neurological assessment.



The review also found that specialist PD nurses also 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.<sup>iii</sup>



The implementation of a specialist nursing model of practice needs to operate across the different stages of care needs. The Institute of Medicine describes three stages of care needs across the progression of chronic illnesses.<sup>iv</sup>



## Emerging design themes

Over the next 6 weeks we will be progressively developing a design for the Movement Disorder Nurse Specialist Program. Even after an initial design is finalised for implementation, we will continue to reflect on the model and refine it. We will be drawing on observations and lessons that we learn as we implement the model.

The following are some of the emerging themes and questions that we will explore as we develop the initial model for implementation.

### Working across settings in a multi-disciplinary team (MDT)

How can the Nurse Specialist and Aboriginal Nurse/Health Worker work across the continuum of settings: acute, specialist, community and primary care?

For example how could the Nurse Specialist and Aboriginal Nurse/Health Worker

- Know about ED admissions and respond?
- Access patients in acute settings?
- Co-attend specialist appointments?

How could the Nurse Specialist and Aboriginal Nurse/Health Worker work in a multi-disciplinary team across the continuum of settings?

- Is there a team? How formally is it constituted?
- Who are the team members?
- How do they function as a team?
- Is it the same team at all stages of the patient experience?
- How do we ensure that the service networks effectively with related services and teams (LHD, primary health and specialist)

What interrelationships could we establish across teams/service settings?

- How could they be constituted and documented?
- What clinical and corporate governance could authorise and supports these interrelationships?
- How could information be communicated between members of a MDT?
- What intersectoral relationships could be developed and formalised?

How will referrals be made to the MDNS?

## **Access to data and clinical information**

How could the Nurse Specialist and Aboriginal Nurse/Health Worker access relevant patient information to support: medication management, translation/education about treatment and problem solving with patients and carers?

What data should the MDNS project ideally access to evaluate the success of the project?

How can the right data be accessed by the project?

How will the project capture, record and share information and data about the service?

- How is this information and data managed and governed?
- How is patient confidentiality maintained?

How will the pilot minimum data set required by the Nous Group be collected, recorded and provided to the evaluators?

## **Working with Aboriginal communities**

What could the MDNS project need to do to ensure that it delivers culturally competent and safe services?

How could the project, the Nurse Specialist and the Aboriginal Nurse/Health Worker partner and co-deliver services with local Aboriginal Health Services?

How do we establish, support and govern the project to ensure that the Movement Disorder Aboriginal Nurse/Health Worker can work in a culturally safe environment?

There is anecdotal evidence that Parkinson's disease and other movement disorders are underdiagnosed in Aboriginal populations. How could the project promote early diagnosis in Aboriginal communities?

## Supporting Advanced Nursing Practice

How can the Movement Disorder Nurse Specialist and Aboriginal Nurse/Health Worker be supported to develop their advanced specialised practice?

- Mentoring
- Professional development opportunities
- Networking and supports
- Professional/clinical supervision

What clinical and corporate governance (including professional indemnity) will be established to support and protect the Nurse Specialist and Aboriginal Nurse/Health Worker as they work across settings?

What scope of practice should be developed for the two positions? What measures can we put in place to ensure the clinician's role is framed within NMBA requirements?

<https://www.nursingmidwiferyboard.gov.au/codes-guidelines-statements/professional-standards.aspx>

- Code of conduct for nurses
- Registered nurse standards for practice
- International Council of Nurses Code of Ethics for nurses

## Utilising available tools and technologies

How can telehealth and virtual care be explored and utilised to maximise the reach of the project and to support effective networks and partnerships?

How can Health Pathways be utilised or developed to support GPs to make effective referrals for people living with Parkinson's disease and other movement disorders?

How can existing GP Guidelines be promoted to assist GPs to partner in the management and treatment of Parkinson's disease?

## Working with Residential Aged Care Facilities

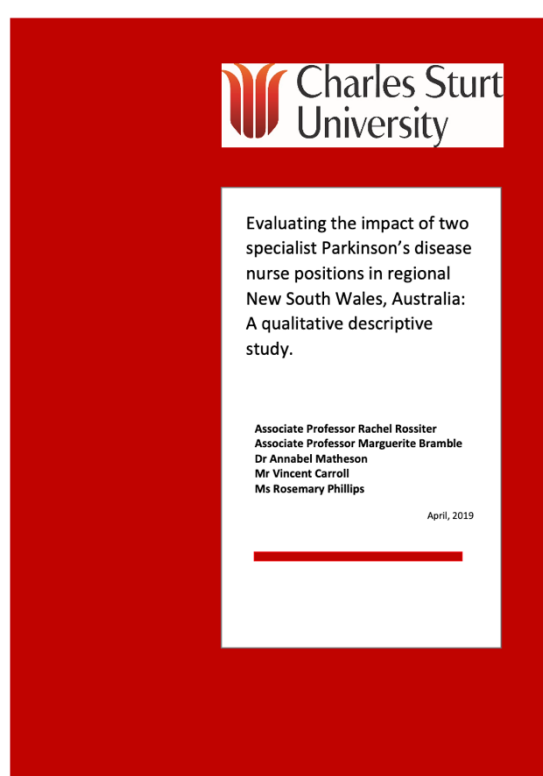
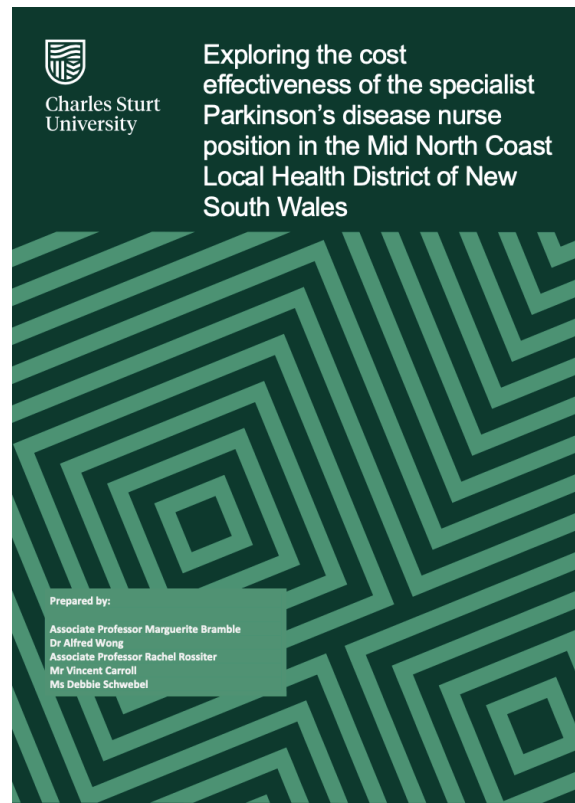
Many people with Parkinson's Disease live in Residential Aged Care Facilities (RACFs). How can the project partner with and support RACFs to deliver effective care for people living with Parkinson's disease and other movement disorders?

## **Next steps**

This evidence profile will be used to support co-design activities being held in Tamworth on Tuesday 2 March 2021. Participants will include people with lived experience, carers, GPs, neurologists, PHN staff, LHD staff and community health providers.

Following these activities we will continue to consult with our partners and stakeholders. We will explore the emerging design ideas and start solving any critical issues we identify. We will host more co-design activities in March to further refine the design for the MDNS Pilot Program with our partners.

## Additional reading



REPORT

**Care pathways for people with  
neurodegenerative and  
neuromuscular conditions**  
Action areas for consideration  
by ACI Networks

ACI Neurodegenerative and Neuromuscular Conditions Working Group



Collaboration. Innovation. Better Healthcare.

<sup>i</sup> <https://www.parkinsonsnsw.org.au/about-parkinsons-disease/parkinsons-disease/>

<sup>ii</sup> [https://aci.health.nsw.gov.au/\\_\\_data/assets/pdf\\_file/0020/332282/Neuro-diagnostic-report.pdf](https://aci.health.nsw.gov.au/__data/assets/pdf_file/0020/332282/Neuro-diagnostic-report.pdf)

<sup>iii</sup> Bramble, M., Carroll, V., & Rossiter, R. (May, 2018) *Evidence based models that support best practice nursing services for people with Parkinson's disease in Regional NSW: An integrative literature review*, Charles Sturt University.

<sup>iv</sup> IOM (Institute of Medicine). (2012). *Living well with chronic illness: A call for public health action*. Washington DC: The National Academies Press, Cited in Rossiter, R., Bramble, M., Matheson, A., Carroll, V., & Phillips, R. (April, 2019) *Evaluating the impact of two specialist Parkinson's disease nurse positions*, Charles Sturt University.