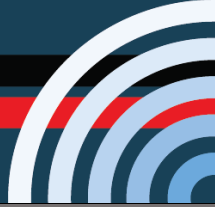


patient organisation network

AUSTRALIA

THE PROFESSIONAL BODY FOR PATIENT ORGANISATIONS



JOINT PRE-BUDGET SUBMISSION 2022-2023

Organisation
Contact

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COLLABORATING PATIENT GROUPS



Executive summary

The Centre for Community-Driven Research (CCDR) is a non-profit organisation established in Australia in 2012. It was developed to take a systematic approach to engaging patients in decisions about health and to develop community-based health services. CCDR host the National Patient Organisation Network, Australia (NPON) which, with 135 patient groups, is the largest network of its kind in Australia.

Initial funding for the Patient Pathways telehealth nurse program provided through the Department of Health in 2019. Funding was provided to CCDR and distributed amongst NPON members to cover a minimum of 10 disease areas. Funding for this program ends in June 2022.

Since the commencement of the program in August 2019, 2,336 people with complex care needs have accessed the service. Patient Pathways telehealth nurses conduct a range of nurse-led interventions and referrals. Overall, there have been 19,867 referrals or interventions made at an average of 8.50 per patient. Nurses spent an average of 1.61 hours per patient at an average cost of \$67.37 per patient.

This submission is in relation to the continuation and expansion of this program that has proven to be cost effective and provides a model for telehealth nurse services to be implemented in a community setting, within patient organisations.

Collaborating organisations call on the federal government to use the 2022/23 federal budget to commit funding for the continuation and expansion of Patient Pathways over the next three years to cover 18 disease areas at a cost of **\$825,739 per annum (\$2,477,217 requested over three years)**.

Disease and condition areas included in the program

The conditions below represent a patient population of approximately 6.2 million people. The Patient Pathways telehealth nurse program services those that have particularly complex needs, including those in rural and regional locations.

Arthritis	Liver cancer
BRCA-related cancers	Mitochondrial disease
Cerebral palsy	Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)
Crohn's disease	Neuromyelitis optica spectrum disorder
Ehlers-Danlos syndrome	Sickle cell disease
Eosinophilic gastrointestinal disorders	Stroke
Epilepsy: Complex, rare and genetic	Tuberous sclerosis
Fabry's disease	Ulcerative colitis
Genetic and rare disease	Usher syndrome

Collaborating organisations

Arthritis NSW, AusEE inc, Australian Sickle Cell Advocacy Inc, Centre for Community-Driven Research, Crohns & Colitis Australia, Cerebral Palsy Support Network, Ehlers-Danlos Syndrome Australia, Emerge Australia, Epilepsy Foundation Australia, Fabry's Australia, Syndrome Without a Name, Genetic Alliance, Genetic Support Network Victoria, Liver Cancer Support Australia, Mito Foundation, Tuberous Sclerosis Australia, Pink Hope, NMOSD Australia, Usher Kids Australia, Stroke Foundation.

Patient Pathways Telehealth Nurse Program

Background

The Centre for Community-Driven Research (CCDR) is a non-profit organisation established in Australia in 2012. It was developed to take a systematic approach to engaging patients in decisions about health and to develop community-based health services.

Initial funding for the Patient Pathways telehealth nurse program provided through the Department of Health in 2019. Funding was provided to CCDR and distributed amongst patient organisations. Funding for this program ends in June 2022.

The initiative places specialist telehealth nurses in community organisations. Patient pathways provides a remote clinic that can be inclusive of families, carers, and patients. All of the Patient Pathways telehealth nurses are able to consult with patients living in all areas, including regional or remote areas, without any of these patients having to leave their home, or paying any costs associated with travel and accommodation to access health services. Most importantly, Patient Pathways telehealth nurses help patients make the most of existing services within the Australian health system, including access to clinical trials.

The National Patient Organisation Network Australia sits within this funding, and through this initiative a network of 135 patient groups has formed which is the largest network of patient groups in Australia. A program of work is available at www.cc-dr.org/au/pon/ As part of this initiative, CCDR have a central research and project support program to assist small organisations to develop evidence-based projects and programs.

Challenges being addressed and opportunities

Australia has an excellent health system and patients are offered exceptional treatment, care, support and opportunities to participate in medical research. However, with so much to offer comes complexity, difficulty in navigating the health system, and challenges knowing about and accessing existing services, which can result in a decreased level of satisfaction with the health system. In addition, with an ever-evolving clinical trial environment and new technologies emerging, we need to create systems that can adapt and keep up to date with these opportunities, while supporting patients and their families. The first point of call for many patients when they are diagnosed with a condition is to go to local non-profit organisations for information and support. The Patient Pathways initiative makes the most of this relationship by establishing a central point of contact within non-profit organisations - a specialist, Patient Pathways nurse – to help patients and their families access existing services and connect them with opportunities to participate in medical research and patient feedback initiatives. Collectively, this is also an opportunity to reduce duplication between patient organisations and forge collaboration across the health sector.

Patient Pathways Pilot results¹

The evaluation report from the Pilot is available at www.pathwaysportal.org

Impact

* There were 2,336 people that accessed the Patient Pathways telehealth service from August 2019 to the end of October 2021. The majority of people were patients (n=1318, 56.42%) followed by next of kin/legal guardians (n=530, 22.69%).

* There was an average of 7.32 concerns or questions per patient at the start of each consultation.

* Patient Pathways telehealth nurses conduct a range of nurse-led interventions and referrals. Overall, there have been 19,867 referrals or interventions made at an average of 8.50 per patient.

* There were 6,705 instances where information was provided or discussed in consultation, 2,812 allied health and supportive care referrals, 1,711 primary care assessments, 1,646 home status assessments, 1,577 clinical trial assessments, and 1,450 pain assessments.

* Dr Kate Holliday who is leading the Patient Pathways program has been recognised by the World Health Organisation, International Council of Nurses, United Nations Population Fund and Women in Global Health by being listed as one of the 100 outstanding nurse and midwife leaders in 2020.

Cost

* The average hourly rate for nurses in the Patient Pathways telehealth service was \$41.67. With an average time per patient of 1.61 hours, this results in an average cost per patient of \$67.37.

Program management

* Having central program support through CCDR has proven to be effective in both cost and program cohesion. There is a constant stream of support needed to maintain a consistent data set and ongoing support and oversight to the nurses working in the program. CCDR also have the responsibility of evaluation across the program, again reducing the need for each organisation to have a separate project officer to conduct evaluation. Another service provided by CCDR was database design and development for each organisation.

* Weekly, group case discussions are held. Case discussions are a professional development and in-service opportunity to share resources and discuss best-practice in telehealth nursing. In addition, there were in-service opportunities held regularly (equalling one hour of CPD per session).

* There were a total of 40 hours of Continuing Professional Development offered to each nurse in the program, as well as 16 hours of clinical supervision available.

* Within the program, CCDR also host the National Patient Organisation Network Australia (previously described)

¹ Pilot project partner organisations: Metabolic Dietary Disorders Association, Mito Foundation (Mitochondrial disease), Maddie Riewoldt's Vision (Bone Marrow Failure Syndromes), Crohn's & Colitis Australia, Eating Disorders Victoria, Emerge Australia (Myalgic encephalomyelitis/Chronic Fatigue Syndrome), Tuberos Sclerosis Australia, Save Our Sons Duchenne Foundation (Duchenne and Becker Muscular Dystrophy), Genetic, Rare and Complex Disease (Five partner organisations including Genetic Alliance Australia, Syndromes Without A Name, Genetic and Rare Disease Network, the Genetic Support Network Victoria and CCDR), Cerebral Palsy Support Network and PanCare Foundation (Pancreatic cancer)

Recommendations

A funding formular has been developed based on the amount of time nurses spent with patients during the program (initial consultation and follow-up), the hourly cost of the nurse at a Registered nurse - level 5, grade 4², and volume of new patients per week. It is recommended that this level of funding be used in future iterations of the Patient Pathways program, plus 30% to account for organisational activities that the nurse needs to engage in and 30% oncosts.

Proposal

CCDR opened an expression of interest through National Patient Organisation Network Australia members for organisations that had an interest in continuing or establishing a Patient Pathways Telehealth Nurse within their organisation. Each request has been reviewed by CCDR in relation to projected patient volume, which as noted is what the future funding model is based on.

Collectively, this program will cover 18 disease areas, and the complex care needs of a patient population of approximately 6.2 million, at an average program cost of \$825,739 per annum (\$2,477,217 requested over three years).

Item (PPTN) ³	Requesting group	No. patients per week	Cost per annum
PPTN Arthritis	Arthritis NSW	8	\$48,643
PPTN: Eosinophilic gastrointestinal disorders	AusEE Australia	5	\$30,402
PPTN: Sickle cell disease	Australian Sickle Cell Advocacy Inc	5	\$30,402
PPTN: Cerebral palsy	Cerebral Palsy Support Network	6	\$36,482
PPTN: Crohn's disease and ulcerative colitis	Crohn's & Colitis Australia	4	\$24,322
PPTN: Ehlers-Danlos syndrome	Ehlers-Danlos Syndrome Australia ⁵	3	\$18,241
PPTN: Myalgic encephalomyelitis	Emerge Australia	13	\$40,000 ⁴
PPTN: Epilepsy	Epilepsy Foundation Australia	6	\$36,482
PPTN: Fabry's disease	Fabry's Australia	2.5	\$15,201
PPTN: Genetic and rare diseases	Syndrome Without a Name, Genetic Alliance, Genetic Support Network Victoria	6	\$36,482
PPTN: Liver cancer	Liver Cancer Support Australia ⁵	3	\$18,241
PPTN: Mitochondrial disease	Mito Foundation	3	\$18,241
PPTN: Neuromyelitis optica spectrum disorder	NMOSD Australia ⁵	3	\$18,241
PPTN: BRCA related cancers and prevention	Pink Hope	5	\$30,402
PPTN: Stroke	Stroke Foundation	12	\$72,965
PPTN: Usher syndrome	Usher Kids Australia	2.5	\$15,201
PPTN: Tuberous sclerosis	Tuberous Sclerosis Australia	3	\$18,241
PPTN/APON: Program management and supervision (Senior nurse)	CCDR	N/A	\$90,000
PPTN/APON: Evaluation, network and research support	CCDR	N/A	\$90,000
PPTN: Database development and management	CCDR	N/A	\$35,000
PPTN: Nurse uniforms (shirts)	CCDR	N/A	\$2,550
Annual external evaluation	External evaluation consultant and panel	N/A	\$100,000
TOTAL PER ANNUM			\$ 825,739
TOTAL OVER THREE YEARS			\$ 2,477,217

² The recommended level of nurse is recommended at a slightly higher level (\$45.39) than the average paid within in the pilot (\$41.67). The higher cost is the national equivalent whereas the pilot was based on NSW award levels.

³ PPTN: Patient Pathways Telehealth Nurse

⁴ Emerge Australia is able to provide co-funding for this position

⁵ These groups are governed by independent clinical and community steering committees, hosted by CCDR

