

PATHWAYS

TELEHEALTH NURSE PROGRAM



Pathways Telehealth Nurse Service High Level Report

August 2022

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We thank all of our partners and colleagues and congratulate everyone on the success of this program. This is a community-based and community-led program that we can all be proud of. We acknowledge in particular the hard-working and dedicated women delivering direct patient support through the Pathways Telehealth Nurse service:

Jo supporting patients through Metabolic Dietary Disorders Association
Michele supporting patients through Mito Foundation
Mei Ling and Sophie supporting patients through Maddie Riewoldt's Vision
Bernadette and Kerrie supporting patients through Crohn's & Colitis Australia
Kelly supporting patients through Eating Disorders Victoria
Laura supporting patients through Emerge Australia
Kim and Katrina supporting patients through Tuberous Sclerosis Australia
Michele supporting patients through Save Our Sons Duchenne Foundation
Kate supporting patients through the Genetic, Rare and Complex Disease service
Kellie and Amy supporting patients through Cerebral Palsy Support Network
Shannon supporting patients through Pancare Foundation
Fay supporting patients through Liver Cancer Support Australia
Chris supporting patients through NMOSD Australia
Ashlee supporting patients through Ehlers-Danlos Syndrome Australia

We also thank all CCDR staff who have contributed to the program: Anne, Vanessa, Vivien, Diana, Becca, Hai Ly, Irene, Klair, Katriona, Melanie and Heema.

We acknowledge the traditional custodians of the land on which Pathways Telehealth Nurses have delivered care and support. We pay our respect to elders past, present and emerging and thank them for sharing their knowledge and connection with water, land, air, plants and animals. CCDR commits to helping improve the health outcomes of all Aboriginal and Torres Strait Islander peoples.

Information presented represents clinical data as at 15 September 2022

Introduction

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 Pathways Telehealth Nurse program was initially developed in 2012 and then first tested in pancreas cancer. It was then funded by the Commonwealth to expand into 10 disease areas by the Hon Greg Hunt MP, Minister for Health in 2019 with funding up to 30 June 2022. From this investment, CCDR has now expanded the program to 18 disease areas and it is being taken up internationally as a model of care.

We are very pleased to present this service report while we prepare more detailed academic papers on our work. The initiative places specialist telehealth nurses in community groups and we thank the Pathways Telehealth Nurses and partners for all the support they have given to CCDR, and to the community.

Partner community groups

MDDA - 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)

Tuberous 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

Pancare Foundation (Pancreatic cancer)

Liver Cancer Support Australia

NMOSD Australia

Ehlers-Danlos Syndrome Australia

“The Pathways Telehealth Nurse service demonstrates what nurses can do and the lengths they will go to so that their patients receive the help they need, when they need it and in an environment that is familiar to them.”

In community-based care and telehealth, you've got the chance to look at what's happening to the patient in front of you in their own environment to address all of the physical, mental and social aspects of care. One of the things I really value about telehealth is the fact that you are a guest in someone's home - you are entering their space and it creates a particularly special environment to work in with patients.

What we are really trying to do is support patients to be the host in their own decision-making process, rather than always being the guest. This is their health system, and it needs to work for them”

Kate Holliday MACN

CCDR Founder & Chief Executive, Creator of the Pathways Telehealth Nurse program

Impact

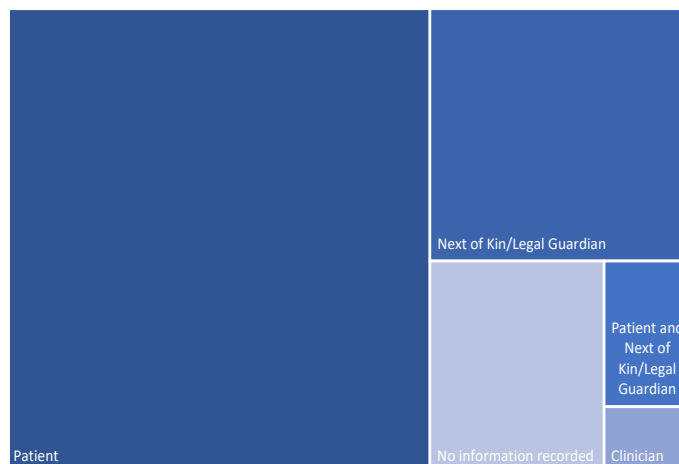
- 3,060 people have accessed the Pathways telehealth service from August 2019 to June 2022.
- Overall, since the start of the program, Pathways Telehealth Nurses have made 26,953 assessments, referrals or interventions at an average of 8.81 per patient. The number of assessments, referrals or interventions made has been consistent across each previous reporting period with an average of 7.43 reported in 2020, and 8.50 reported in 2021.
- 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 as a finalist for the 100 outstanding nurse and midwife leaders in 2020. In 2022 she is one of only three finalists for the 2022 Health Minister's Award for Nursing Trailblazers in recognition of the Pathways Telehealth Nurse program.
- Nurses are most commonly speaking with women (65.98%)
- Across all age groups, the highest number of people accessing the service were under the age of 18 along with a parent or next of kin (n=435, 14.22%).
- The service was designed to take advantage of the close relationship patient groups have with the community. The majority of patients found the service through their local patient organisation website or Facebook page (n=1474, 48.17%).
- The average time per patient for an initial consultation and follow-up was 98.45 minutes.
- Pathways Telehealth Nurses provided services across 9 broad disease areas. The most common conditions were diseases of the nervous system (n=1254, 40.98%). After this, developmental abnormalities (n=377, 12.32%), diseases of the digestive system (n=309, 10.10%), endocrine, nutritional or metabolic diseases (322, 10.52%) and mental, behavioural and neurodevelopmental disorders (n=318, 10.39%), and rare cancers (n=355, 11.60%), all had between 300 and 400 patients accessing the service
- The Pathways Telehealth Nurse model is now being taken up by patient groups in the United Kingdom and Switzerland, with other countries to follow

Part 1: Who we've helped

Consultation with

Since the commencement of the program in 2019, 3,060 people have accessed the Pathways Telehealth Nurse service from August 2019 to 30 June 2022. The majority of people were patients (n=1895, 61.93%) followed by next of kin/legal guardians (n=634, 20.72%).

Consult with	All patients	
	ALL (n=)	ALL (%)
Patient	1895	61.93
Next of Kin/Legal Guardian	634	20.72
Patient and Next of Kin/Legal Guardian	120	3.92
Clinician	55	1.80
No information recorded	356	11.63
Total No. of Patients	3060	N/A



“There’s not really any other, it’s a very unique, for all of the Patient Pathways nurses, in that there isn’t really an equivalent service that people can go to...it’s not going to cost them any money, where they are able to have that consultation and be linked into what they need. I think for many of the clients, it would have been a much lengthy process if they haven’t had access to myself. For parents, I guess, it’s the same. It’s providing access to services that perhaps they wouldn’t have gotten knowledge of quite so quickly” Pathways partner organisation

Tuberous Sclerosis Australia (TSA) is delighted to be a part of this Program and is grateful for the support provided by the Centre for Community-Driven Research (CCDR), particularly in directly supporting its telehealth nurse. As we have no other health professional staff in the organisation it has been invaluable to have the clinical supervision and peer support that CCDR has provided. This has enabled our nurse to feel adequately supported and connected at all times during the Program. Our nurse says she has found it very comforting to know that there is always a qualified and experienced nurse to turn to and a portal on hand to share experiences or ask questions.

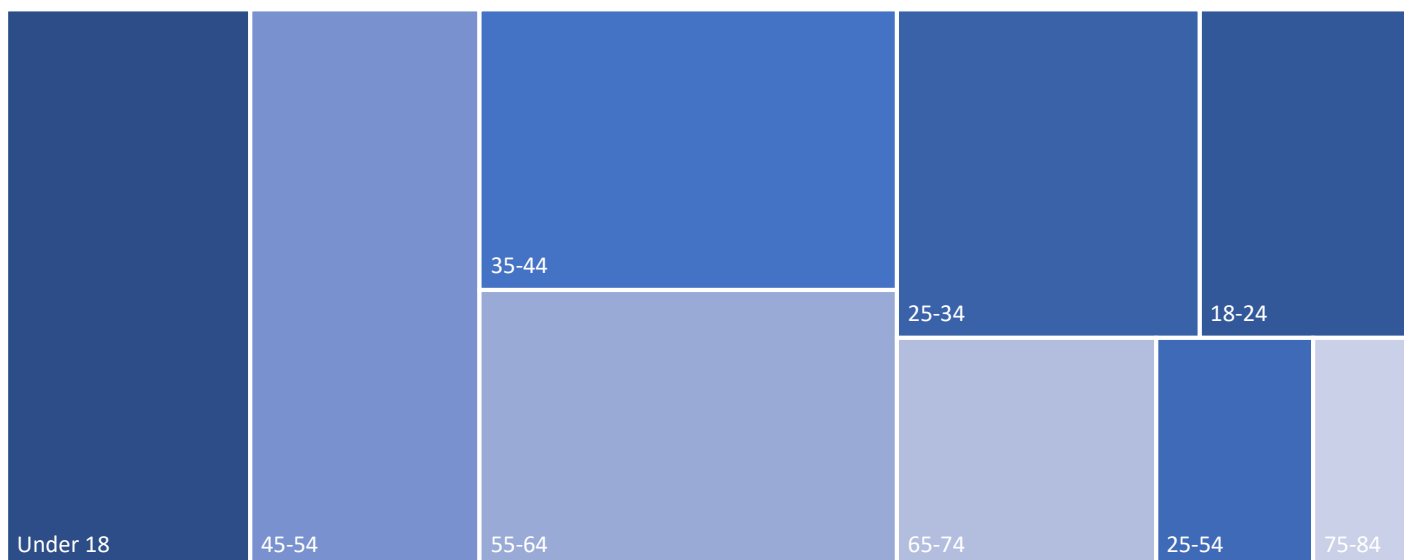
Age

The service has been most commonly accessed by patients under the age of 18 (n=436, 14.25%).

Where a patient is under 18, they are always accompanied or represented by their parent or legal guardian however adults can also be accompanied by a next of kin or family member.

Collectively, the broad age group of 35 to 64 represented 39.02% of all patients accessing the service.

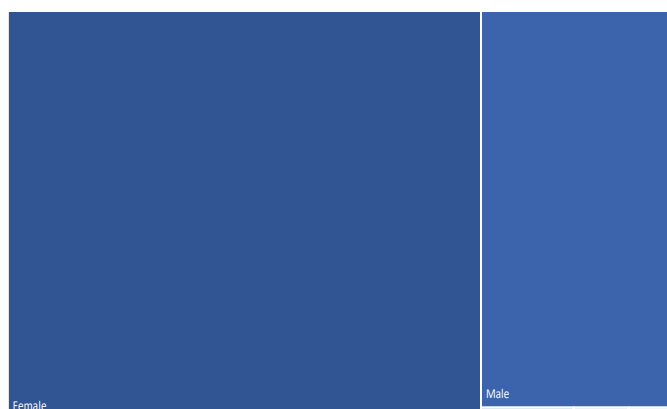
Age	All patients	
	ALL (n=)	ALL (%)
Under 18	436	14.25
18-24	210	6.86
25-34	315	10.29
25-54	114	3.73
35-44	395	12.19
45-54	433	14.15
55-64	388	12.68
65-74	202	6.60
75-84	81	2.65
85 and older	8	0.26
No information	478	15.62
Total No. of Patients	3060	N/A



Gender

Gender	All patients	
	ALL (n=)	ALL (%)
Female	2019	65.98
Male	834	27.25
Non-binary	12	0.39
Not wish to disclose	7	0.23
Transgender	7	0.23
No information	181	5.92
Total No. of Patients	3060	N/A

The majority of people accessing the Pathways Telehealth Nurse service were female (n=2019, 65.98%), with 834 (27.25%) men and a small number of people who were intersex, transgender or non-binary.



Home status

A home status assessment refers to the Pathways Telehealth Nurse asking the patient questions about the their family composition and whether they have dependents in their household. This allows for nurse-led interventions such as providing support for other family members or respite for the primary carer.

There were 914 (29.87%) people who lived in a family home without dependents, 863 (28.20%) that lived in a family home with children and 411 (13.43%) people that lived alone.

Home status	All patients	
	ALL (n=)	ALL (%)
Lives alone	411	13.43
Lives with family (including children who are	863	28.20
Lives with family (including elderly who are	26	0.85
Lives with family (no dependents)	914	29.87
Lives with a friend/share house	82	2.68
Other	27	0.88
No response recorded	737	24.08
Total No. of Patients	3060	N/A



Point that patient joined service

The majority of people joined the Pathways Telehealth Nurse service while undergoing ongoing management for their condition, including active treatment (n=1615, 52.78%). This was followed by people that were newly diagnosed (n=308, 10.07%).

Point joined service	All patients	
	ALL (n=)	ALL (%)
Diagnosis	308	10.07
Pre-treatment	21	0.69
Maintenance post primary treatment	0	0.00
Ongoing chronic condition: active management	1615	52.78
Ongoing chronic condition: no management	129	4.22
Recurrence - no treatment	10	0.33
Recurrence - with treatment	10	0.33
Seeking Diagnosis	220	7.19
Surveillance post primary treatment	42	1.37
Palliative	59	1.93
Other	33	1.08
No information recorded	613	20.03
Total No. of Patients	3060	N/A

Ehlers-Danlos Australia

“The first challenge with EDS is getting an accurate diagnosis and getting one in a timely manner. So many patients with EDS have spent years and a lot of money going around in circles with unnecessary diagnostic tests. The Pathways Telehealth Nurse service has already helped our community streamline the diagnostic process and we are working with CCDR to make sure all patients with EDS continue to have a place to go and find the support they need” Veronica, Rona and Kieran, EDS Australia

Diagnosis

There were a total of 3,060 people accessing the Pathways Telehealth Nurse service across 9 broad disease areas. The most common conditions were diseases of the nervous system (n=1254, 40.98%). After this, developmental abnormalities (n=377, 12.32%), diseases of the digestive system (n=309, 10.10%), endocrine, nutritional or metabolic diseases (322, 10.52%) and mental, behavioural and neurodevelopmental disorders (n=318, 10.39%), and neoplasms (n=355, 11.60%), all had between 300 and 400 patients accessing the service.

Diagnosis	All patients	
	ALL (n=)	ALL (%)
Developmental anomalies	377	12.32
Diseases of the blood or blood-forming organs	78	2.55
Diseases of the circulatory system	14	0.46
Diseases of the digestive system	309	10.10
Diseases of the musculoskeletal system and connectiv	33	1.08
Diseases of the nervous system	1254	40.98
Endocrine, nutritional or metabolic diseases	322	10.52
Mental, behavioural or neurodevelopmental disorder	318	10.39
Neoplasms	355	11.60
Total No. of Patients	3060	N/A



“I’ve lived remotely for over 10 years and it was impossible to have consistent care from a GP or any other medical professional. Only after accessing your services via Telehealth was I able to find out which specialists I needed to see. At 33, I was diagnosed with Ehlers Danlos Syndrome. As a direct result of your services I was able to access Genetic Counselling and genetic testing which I am currently waiting on further results from” Hannah, Western Australia

Ethnicity

The majority of people accessing the Pathways Telehealth Nurse service were caucasian (n=2755, 90.03%). There were 127 (4.15%) people that did not wish to disclose their ethnicity.

Ethnicity	All patients	
	ALL (n=)	ALL (%)
Caucasian/White	2755	90.03
Aboriginal/Torres Strait Islander	32	1.05
African	13	0.42
Arab	16	0.52
Asian	95	3.10
Hispanic/Latino	8	0.26
Pacific Islander	14	0.46
Does not wish to disclose	127	4.15
Total No. of Patients	3060	N/A

Other languages spoken

The majority of people accessing the Pathways Telehealth Nurse service did not speak another language (n=2962, 96.80%). Mandarin was the most common second language spoken (n=14, 0.46%).

Other languages	All patients	
	ALL (n=)	ALL (%)
No other languages noted	2962	96.80
Arabic	7	0.23
Cantonese	2	0.07
French	5	0.16
German	4	0.13
Greek	8	0.26
Hindi	3	0.10
Italian	9	0.29
Mandarin	14	0.46
Spanish	3	0.10
Other	43	1.41
Total No. of Patients	3060	N/A



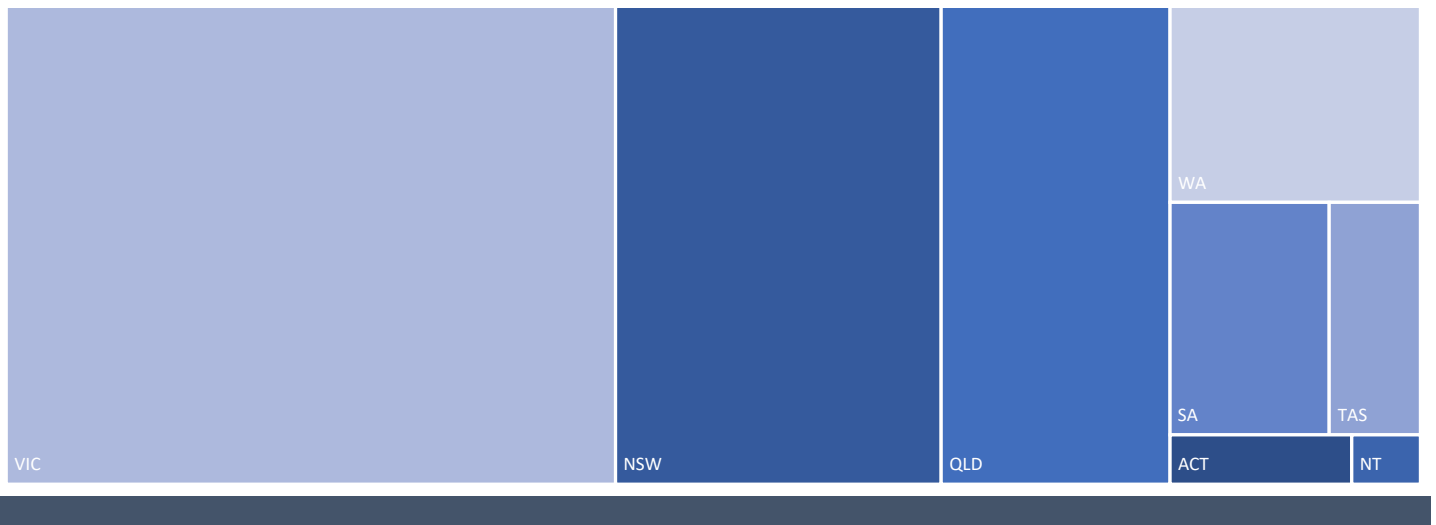
NMOSD AUSTRALIA

“Our patient community has no formal charity that represents us and most of us are busy managing our own health. Not many people know about NMOSD and we get put in the corner. To have CCDR host us and nurture our community has been amazing. No-one has ever gone to such great lengths to help us. We’ve already had an online seminar and later in the year will have a conference just for our community and that’s not happened since 2017 where the NMOSD community without any support, had to put on their own conference. The Pathways Telehealth Nurse service that our community has already had access to is simply a lifesaver” Debbie, NMOSD Australia

State

The majority of people accessing the Patient Pathways telehealth service were from Victoria (n=1032, 33.73%). This is in part due to a number of Victorian-based organisations. There were 702 (22.94%) people from New South Wales, 506 (16.54%) from Queensland and 229 (7.48%) from Western Australia.

State	All patients	
	ALL (n=)	ALL (%)
ACT	39	1.27
NSW	702	22.94
NT	17	0.56
QLD	506	16.54
SA	166	5.42
TAS	99	3.24
VIC	1032	33.73
WA	229	7.48
No information recorded	270	8.82
Total No. of Patients	3060	100.00



Region

The location of patients was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics¹. The majority of patients came from major cities (n=1817, 59.38%), with 715 (23.37%) coming from regional Australia.

Region	All patients	
	ALL (n=)	ALL (%)
Metropolitan	1817	59.38
Regional or remote	715	23.37
No information recorded	528	17.25
Total No. of Patients	3060	N/A



¹ Australian Bureau of Statistics 2016, Australian Statistical Geography Standard (ASGS): Volume 5 - Remoteness Structure, July 2016, 'Correspondence, 2017 Postcode to 2016 Remoteness Area', data cube: Excel spreadsheet, cat. no.1270.0.55.005

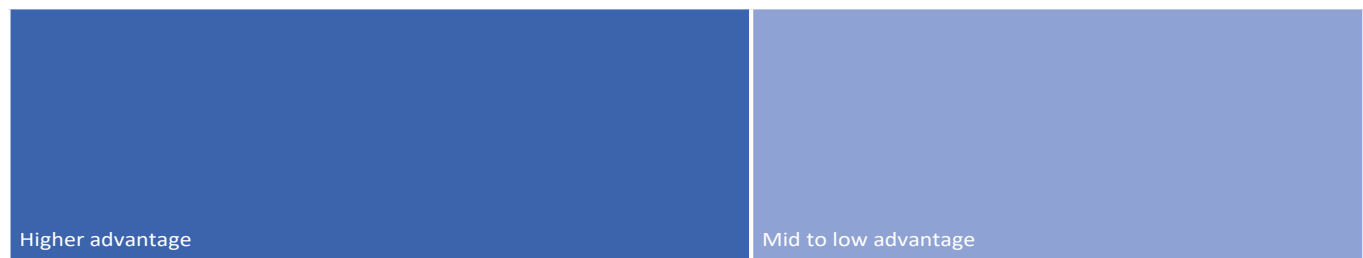
“One of the things that the Telehealth nurse has been able to do is really help those people who have contacted her to make sure that they understand what’s required that she can link them to the services and also do that follow up to say, “Well, how did that go? What did they say you need to do next? How are you going to go about that? Can I help you with that?” Actually, really a proper bit of case management as opposed to just answer a question and move on to the next person.”
Pathways partner organisation

Socioeconomic status

Socio-economic status was evaluated by postcode using the Socio-economic Indexes for Areas (SEIFA) accessed from the Australian Bureau of Statistics. A higher score indicates higher socioeconomic status. Within this evaluation, a score of 1 to 6 is considered low to medium SEIFA and 7 to 10, high SEIFA.

Socioeconomic status	All patients	
	ALL (n=)	ALL (%)
Higher advantage	1401	45.78
Mid to low advantage	1156	37.78
No information recorded	503	16.44
Total No. of Patients	3060	N/A

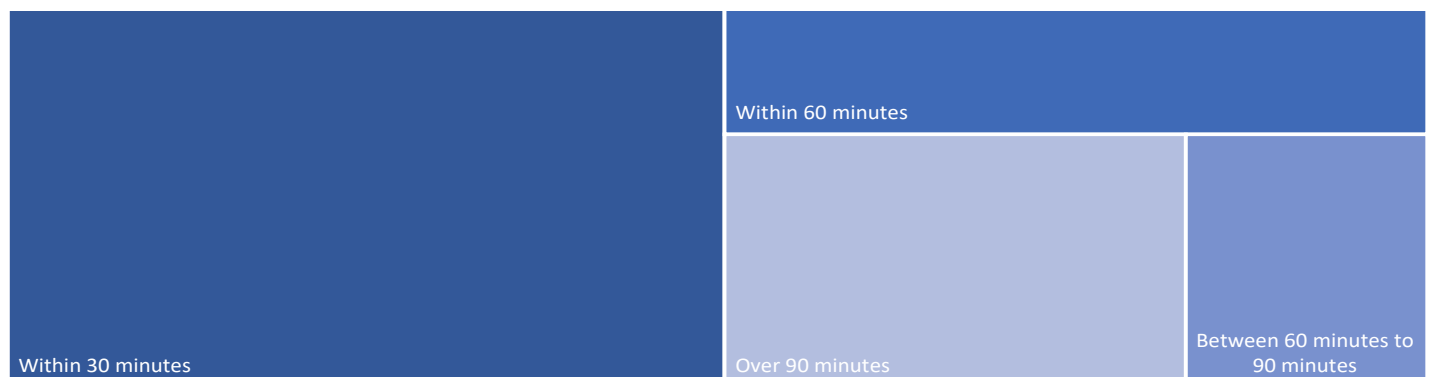
There were 1156 (37.78%) people coming from low to medium socioeconomic areas and 1401 (33.49%) people coming from higher socioeconomic areas².



Access to healthcare

Access to healthcare refers to the length of time it takes patients to access their primary place of treatment or therapy, which may include a general practitioner. The majority of people were able to access care within 30 minutes (n=831, 27.16%). There were 547 (17.88%) people needing to travel up to 60 minutes and 175 (5.72%) needing to travel up to 90 minutes or more.

Access to healthcare	All patients	
	ALL (n=)	ALL (%)
Within 30 minutes	831	27.16
Within 60 minutes	547	17.88
Between 60 minutes to 90 minutes	92	3.01
Over 90 minutes	175	5.72
Not applicable - no regular treatment	619	20.23
No access to treatment recorded	796	26.01
Total No. of Patients	3060	N/A



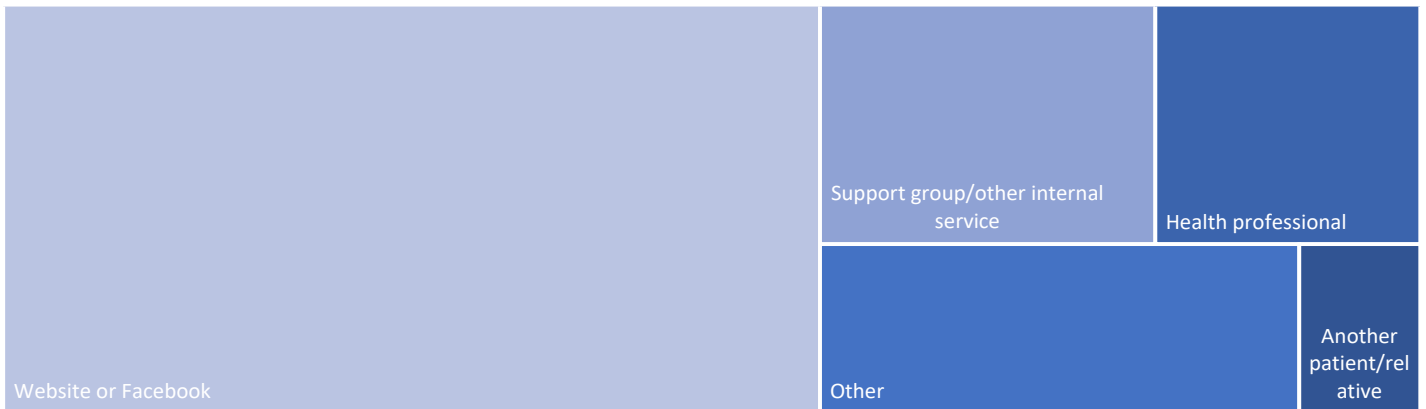
² Australian Bureau of Statistics, 2016, Census of Population and Housing: Socio-Economic Indexes for Areas

Part 2: When we've helped

Referred from

Partner organisations employ a range of strategies to reach out to their communities and promote the Pathways Telehealth Nurse service. The majority of patients found the service through their local patient organisation website or Facebook page (n=1474, 48.17%). This was followed by a support group or internal service referral (n=436, 14.25%) and health professional referral (n=345, 11.27%).

Referred from	All patients	
	ALL (n=)	ALL (%)
Another patient/relative	61	1.99
Health professional	345	11.27
Other	241	7.88
Support group/other internal service	436	14.25
Website or Facebook	1474	48.17
No information recorded	503	16.44
Total No. of Patients	3060	N/A

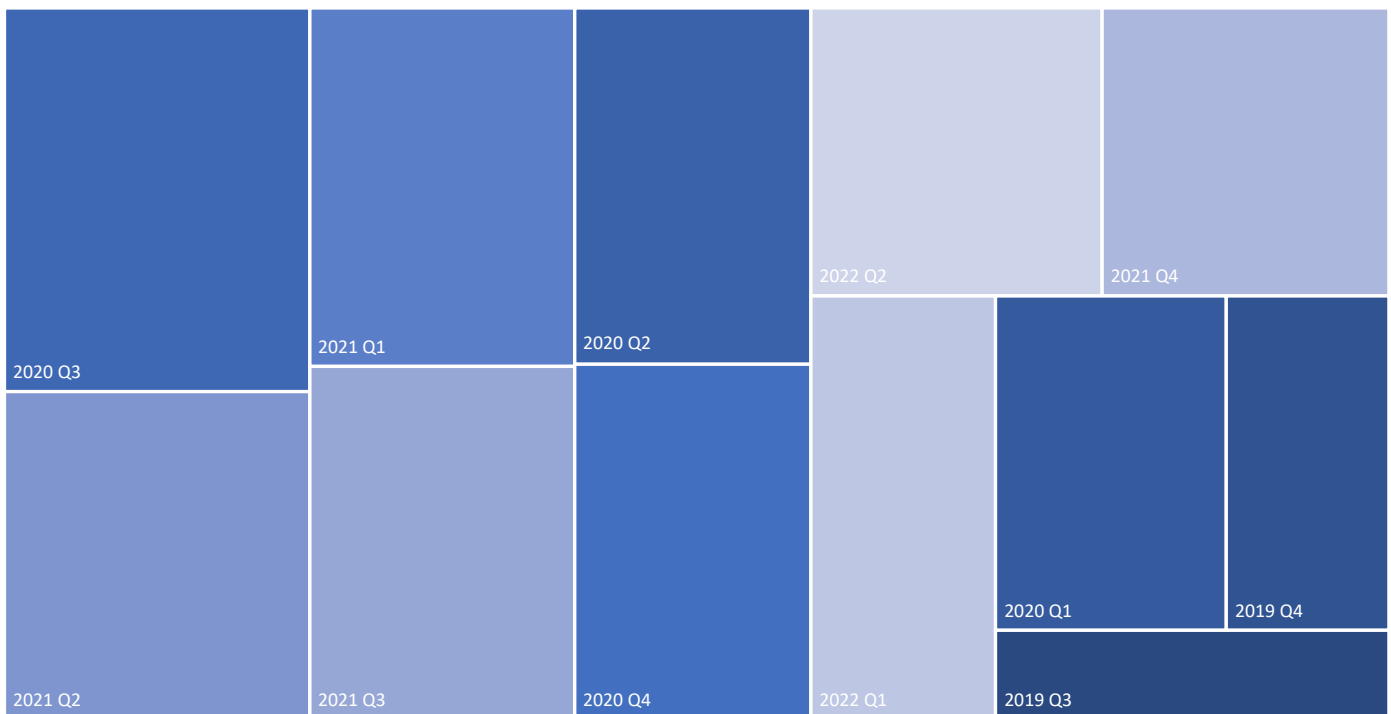


PATHWAYS
TELEHEALTH NURSE PROGRAM

Initial consultations timing by quarter

The Pathways Telehealth Nurse telehealth service commenced in August 2019 following the program announcement in January 2019 and a formal grant round to award funding and selection of partner organisations in April 2019. This was followed by a period of recruitment to select the nurses that would work on the program. Since then, additional groups have joined the program and over the years, it is clear that the number of patients accessing the service is constant over time, with an average of around 250 patients per quarter.

Timing by quarter	All patients	
	ALL (n=)	ALL (%)
2019 Q3	108	3.53
2019 Q4	169	5.52
2020 Q1	240	7.84
2020 Q2	261	8.53
2020 Q3	363	11.86
2020 Q4	261	8.53
2021 Q1	295	9.64
2021 Q2	310	10.13
2021 Q3	290	9.48
2021 Q4	256	8.37
2022 Q1	245	7.94
2022 Q2	262	8.50
Total No. of Patients	3060	N/A

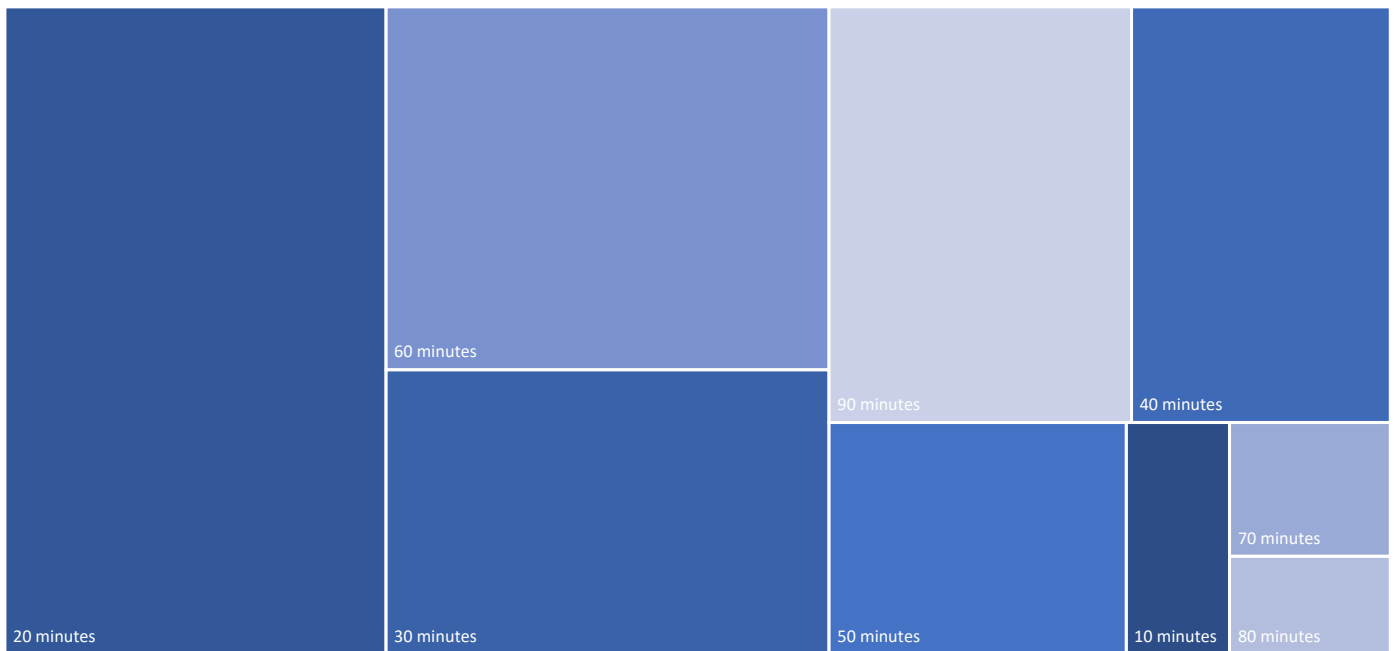


“It was really interesting because a lot of the other nurses were also working in rarer conditions so there was a lot of shared understanding of what that space was like. That’s really powerful, I think. People had such wonderful skill sets that I could draw upon. For example, even though we were working in different clinical areas, we could actually tap into some of the resources that people would have, like managing fatigue and strategies for that which can be a problem in many of the patient groups. There was expertise within the group so we were able to share some of those. I think just the challenges of working in smaller rarer disease groups, I think we had a shared bond in that way, and understanding” Pathways Telehealth Nurse

Duration of initial consultation

The Pathways Telehealth Nurse service delivers health system case management and nurses aim to create - with the patient - a holistic care plan, utilising services available within the health system. The relationship with the patient begins with an initial consultation and there is usually then follow-up activities that the nurse conducts following the initial consultation. There were 749 (24.48%) consultations that took 20 minutes. These would be considered 'short initial consultations'. Outside of these, there were 982 (32.09%) consultations taking 60 minutes or longer.

Duration consult	All patients	
	ALL (n=)	ALL (%)
10 minutes	73	2.39
20 minutes	749	24.48
30 minutes	383	12.52
40 minutes	326	10.65
50 minutes	209	6.83
60 minutes	488	15.95
70 minutes	65	2.12
80 minutes	48	1.57
90 minutes	381	12.45
No information recorded	338	11.05
Total No. of Patients	3060	N/A



The Pathways Telehealth Nurse service model

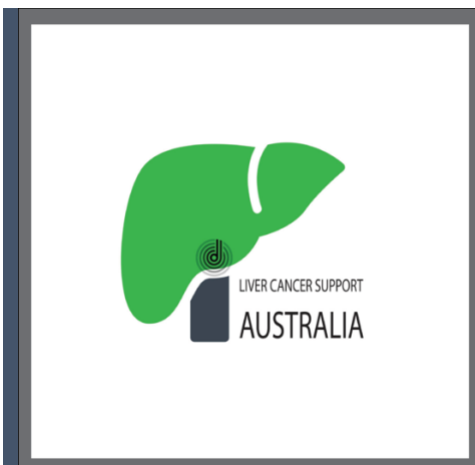
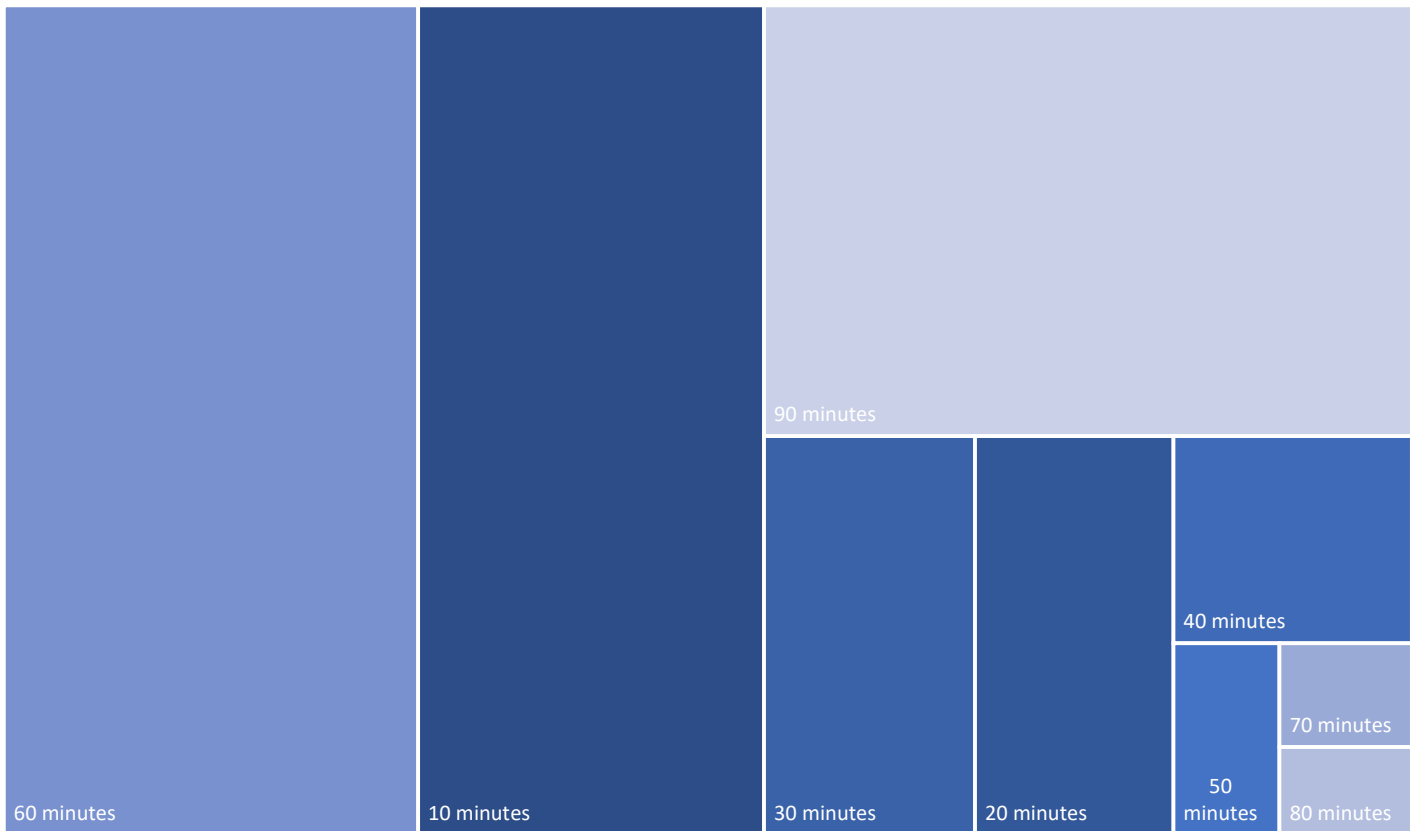
How it is different and the focus on health system navigation

Helpline	Pathways Telehealth Nurse Health System Navigation Case Management	Formal case management
<ul style="list-style-type: none"> Information provision only Relatively short interaction Does not normally include a clinical assessment or follow-up Real time questions answered 	<ul style="list-style-type: none"> Comprehensive primary consultation with care planning Point of coordination with the health system identified Making use of existing services Avoids dependent relationship between nurse and patient Incorporates health literacy models of care Designed with and for nurses working in community-based organisations 	<ul style="list-style-type: none"> Patient numbers are defined (finite number of patients) Ongoing contact and management Long and regular consultations Higher cost per patient e.g. Community mental health services; Disability services NDIS

Follow up at initial consultation duration

Follow-up activities from the initial consultation most commonly took 60 minutes (n=760, 24.84%) or 90 minutes (n=617, 20.16%). Across all patients, the average time per patient in initial consultation and follow-up was 98.45 minutes.

Duration initial follow-up	All patients	
	ALL (n=)	ALL (%)
10 minutes	635	20.75
20 minutes	175	5.72
30 minutes	186	6.08
40 minutes	109	3.56
50 minutes	45	1.47
60 minutes	760	24.84
70 minutes	30	0.98
80 minutes	26	0.85
90 minutes	617	20.16
No information recorded	477	15.59
Total No. of Patients	3060	N/A



“Liver cancer is a neglected cancer and there needs to be a dedicated place for patients to go where they can clearly see the words ‘liver cancer’ and know that they’ll be met with expert knowledge and support. CCDD stepped up to do just that with our community-led group Liver Cancer Support Australia. My patients have already benefited from the Pathways Telehealth Nurse service and we know they will continue to do so in the future” Jacob George, Hepatologist

What's new in the Pathways Telehealth Nurse service for the next iteration and program expansion

We've developed guidelines and a series of nurse-driven interventions, possible in the context of telehealth and the charity sector, that have been confirmed.

- Initial assessment
- Diagnosis assessment
- Symptoms and comorbidities assessment
- Information assessment
- Symptom tracking
- Nurse education session referral
- Record family history
- Primary care assessment
- MDT assessment
- Clinical trial assessment
- Point of coordination assessment
- Emotional and social assessment
- Pain assessment
- Palliative care assessment
- Advance care planning

Nurse support program

The nurse support program will follow the supervision guidelines for nursing and midwifery (AHPRA March 2021)

With the expansion of the program, nurse will be placed into nurse units to have more targeted support

- Rare disease unit
- Chronic disease unit
- Oncology unit

A Director of Nursing will oversee the program and provide clinical support and supervision. This will include:

- Individual CPD planning
- Monthly professional development in-service for nurses
- Regular peer support opportunities
- Support with observing consultations/quality control/clinical trouble shooting
- Possible face-to-face retreat with nurses (Dependent on nurse preference and location of all 20 nurses)

Partners talk about the impact of the Pathways Telehealth Nurse service

“A lot of people who haven't been able to necessarily engage the health care professionals, get some advice and general advice about their illness, haven't been able to access this service and be really flexible. We have some people who are so unwell that they can only connect for 10 to 20 minutes at a time. Then we've got other people who can connect for 30 to 60 minutes at a time. It's quite varied and we can really modify how we are with each individual to make that something that's really important to them.”

“Oh, look, a huge impact. I think one of the things that having the nurse has done is enable us to really not just answer calls and provide information but really do a lot of follow up with people. One of the things about this condition is it's a very complex disease and require ongoing surveillance and visits to many different specialists”

“One of the things that the Telehealth nurse has been able to do is really help those people who have contacted her to make sure that they understand what's required that she can link them to the services and also do that follow up to say, "Well, how did that go? What did they say you need to do next? How are you going to go about that? Can I help you with that?" Actually, really a proper bit of case management as opposed to just answer a question and move on to the next person.”

Small organisation support

Through the pilot, we found that it is difficult for small organisations to recruit, hire and manage nurses. As a result, CCDR will offer a service to small organisations where CCDR becomes the employer of record, however the nurse still provides the service as part of the local patient organisation. The aim is to reduce overhead costs of employment and ensure the nurse has adequate support and supervision. This will be particularly important for organisations that are primarily staffed by volunteers.

Uniform

The newly designed Pathways uniform will be provided to each nurse. There are both casual options and more formal options that can be worn at official functions and formal meetings.



Part 3: How we've helped

GP assessment

Understanding whether the patient has a regular general practitioner is an important assessment. It allows the Pathways Telehealth Nurse to respond with interventions to ensure the patient has access to appropriate primary care. The majority of patients had a regular general practitioner (n=2070, 67.65%) with 108 (3.53%) that did not and 90 (2.94%) that indicated that they would like a referral.

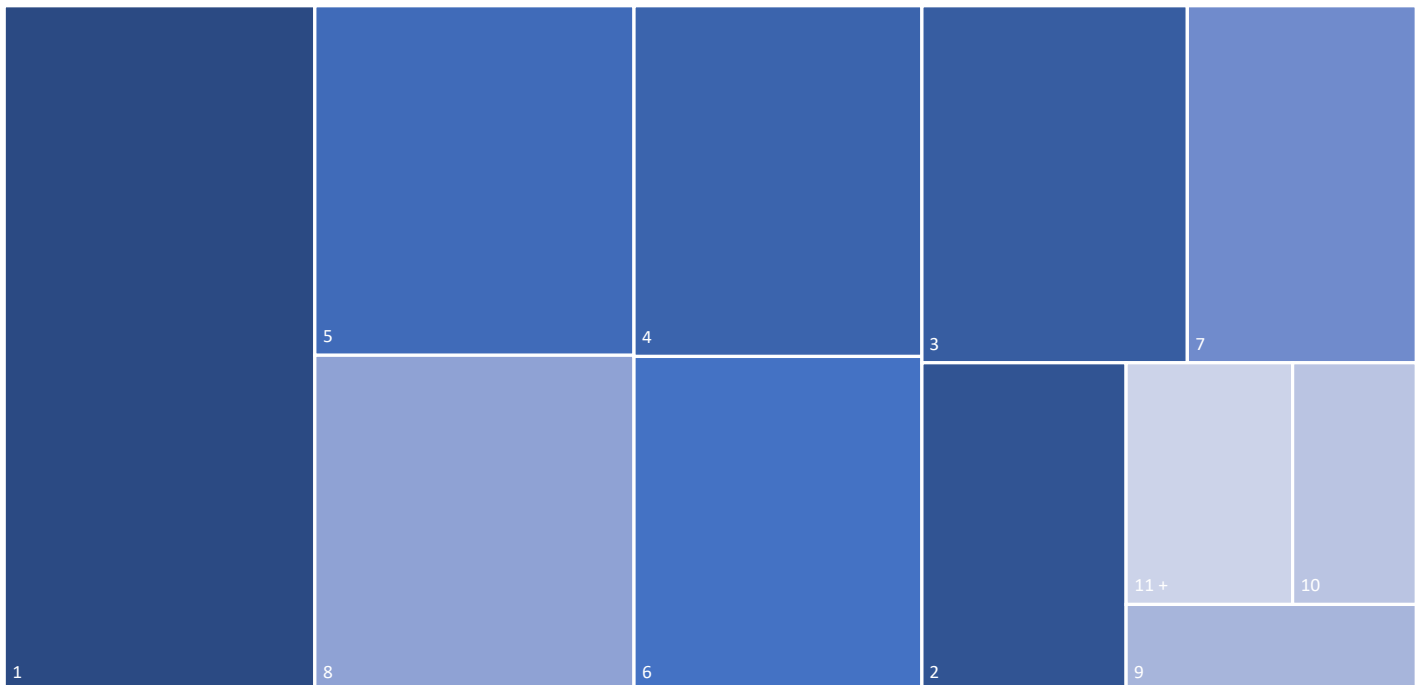
Primary care assessment	All patients	
	ALL (n=)	ALL (%)
Patient has regular GP	2109	68.92
Patient does not have regular GP	108	3.53
Patient reminded of right and importance to choose ¹	425	13.89
Patient would like a new GP referral	98	3.20
No information recorded	799	26.11
Total no. patients	3060	N/A

*More than one option per patient possible

Concerns and questions at consultation time

Within a consultation, patients are asked about the symptoms and concerns they have both now and what they are worried about going forward in the future. There were 456 patients who approached the service with one key question or concern (14.90) and 864 (28.24%) that had between 3 and 6 questions or concerns. The average number of current concerns per patient is 3.20

No of questions at consult	All patients	
	ALL (n=)	ALL (%)
1	456	14.90
2	144	4.71
3	203	6.63
4	216	7.06
5	239	7.81
6	206	6.73
7	175	5.72
8	229	7.48
9	54	1.76
10	64	2.09
11 +	86	2.81
No information	988	32.29
Total no. patients	3060	N/A



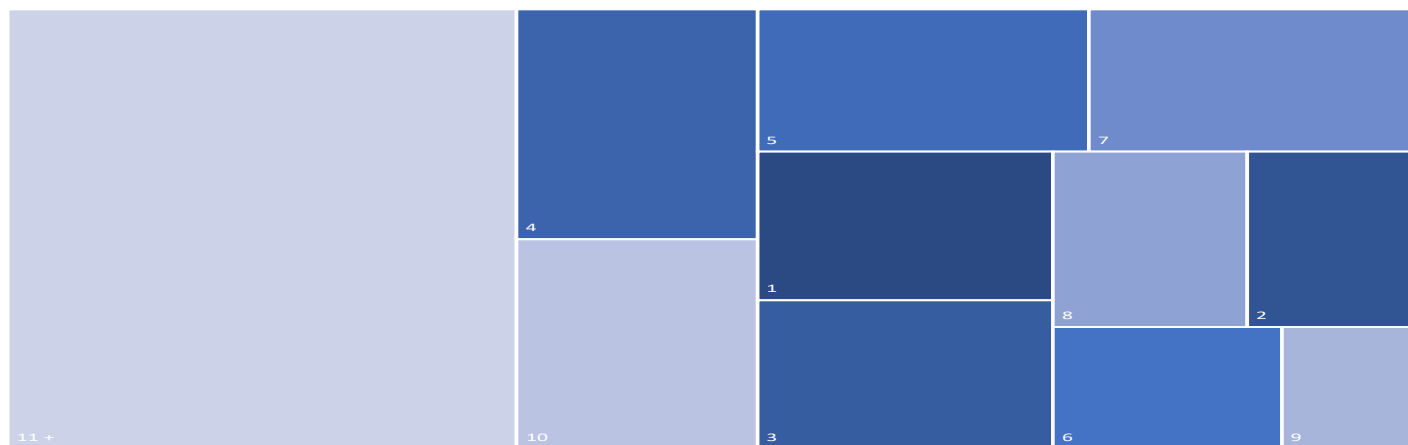
*More than one option possible per patient

Number of concerns in the future

In relation to future concerns, the majority of patients (n=1362, 44.51%) had 11 or more concerns or questions. This is a stark difference to the number of questions and concerns at the time of consultation.

The average number of future concerns per patient is 6.79. The combined average number of concerns (now and in the future) is 4.5 per patient.

No of questions future	All patients	
	ALL (n=)	ALL (%)
1	250	8.17
2	161	5.26
3	155	5.07
4	153	5.00
5	128	4.18
6	77	2.52
7	115	3.76
8	93	3.04
9	65	2.12
10	129	4.22
11 +	1362	44.51
No information	372	12.16
Total no. patients	3060	N/A



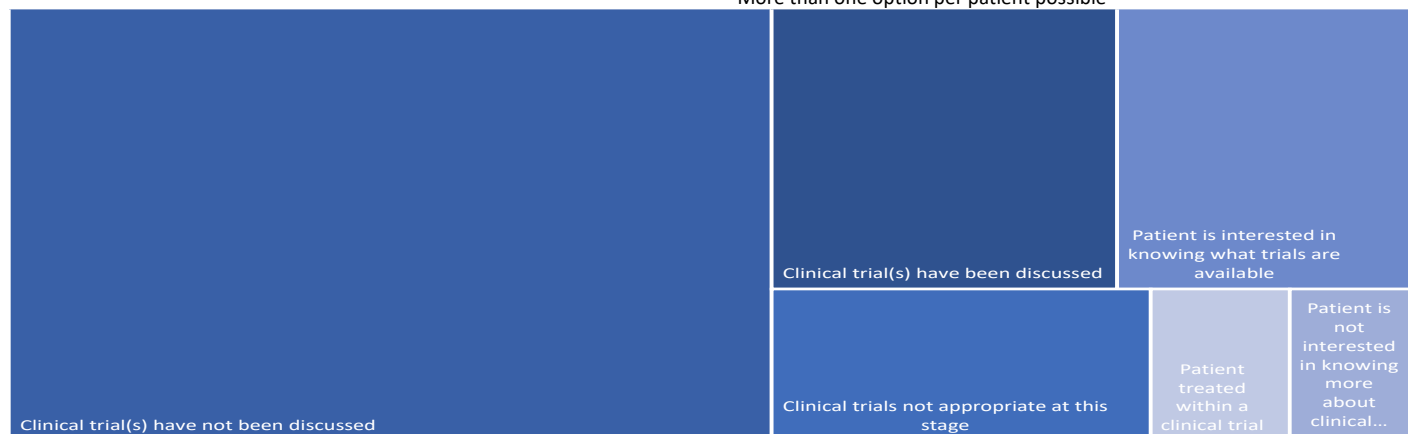
Clinical trial status

Patients are asked about their clinical trial status as a way to open up conversations about clinical trial participation. This is referred to as a clinical trial assessment within the Pathways telehealth service.

There were 1179 (38.53%) patients that had not had any conversation about clinical trials before entering the Pathways service. Only 62 (2.03%) had participated in a clinical trial.

Clinical trials	All patients	
	ALL (n=)	ALL (%)
Clinical trial(s) have been discussed	362	11.83
Clinical trial(s) have not been discussed	1179	38.53
Clinical trials not appropriate at this stage	169	5.52
No response recorded	1072	35.03
Patient is interested in knowing what trials are availal	312	10.20
Patient is not interested in knowing more about clini	56	1.83
Patient treated within a clinical trial	62	2.03
Total No. of Patients	3060	N/A

*More than one option per patient possible



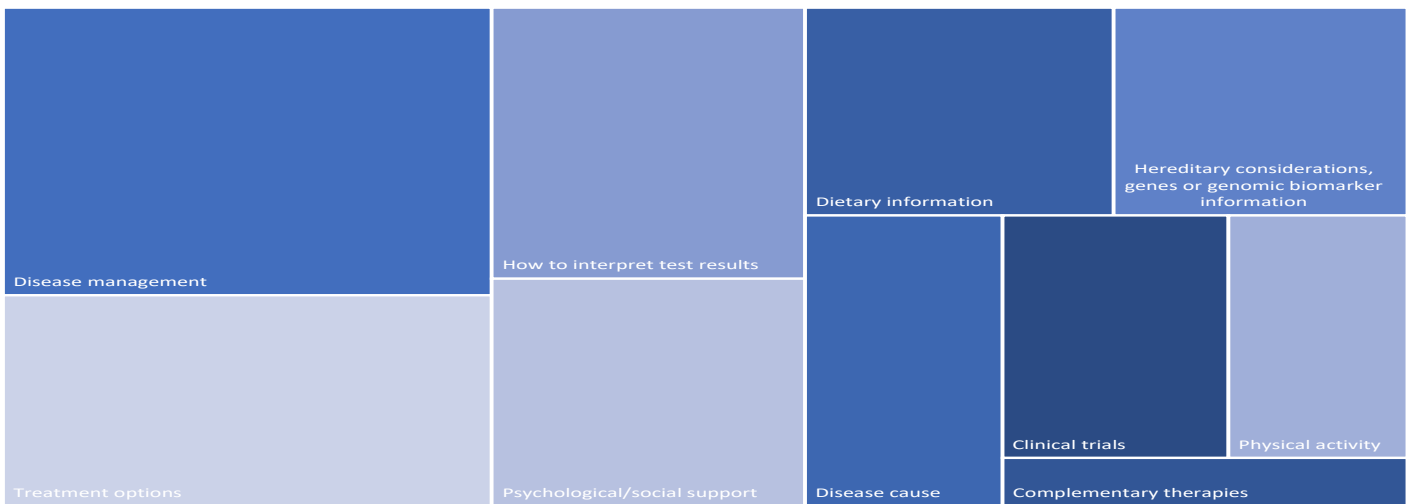
Information requested

Pathways Telehealth nurses provide information through discussion, online materials and written materials. The type of information required also leads to nurse-led interventions such as prompt-list development, symptom management and symptom tracking.

The most common information requested was in relation to disease management (1063, 34.74%), treatment options (n=783, 25.59%) and how to interpret test results (n=638, 20.85%).

Information	All patients	
	ALL (n=)	ALL (%)
Clinical trials	428	13.99
Complementary therapies	148	4.84
Dietary information	481	15.72
Disease cause	432	14.12
Disease management	1063	34.74
Hereditary considerations, genes or genomic biomarl	457	14.93
How to interpret test results	638	20.85
Physical activity	326	10.65
Psychological/social support	538	17.58
Treatment options	783	25.59
No information requested	1423	46.50
Other	2	0.07
Total No. of Patients	3060	N/A

*More than one option per patient possible



*More than one option possible per patient

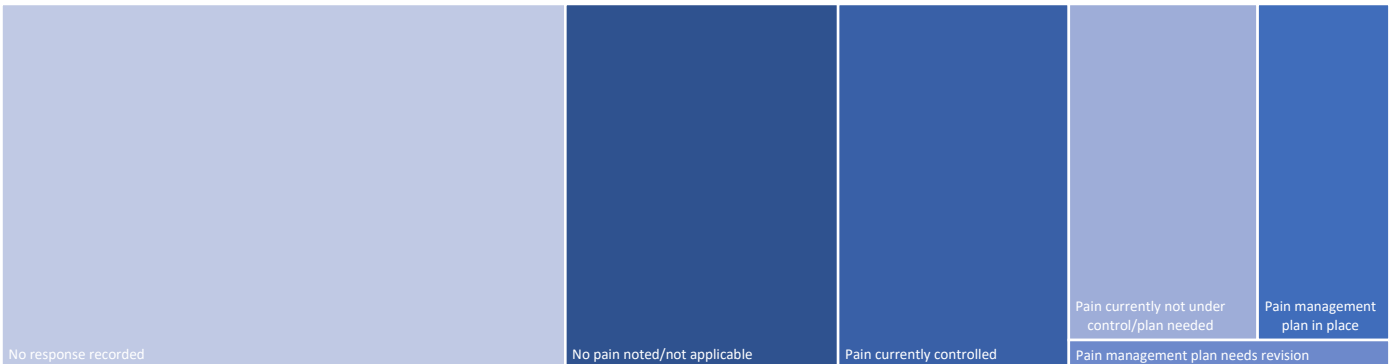
Pain management plan

Timely pain management is an important part of holistic care. A pain management assessment seeks to identify whether the patient is currently having any pain and whether it is being proactively managed.

While pain was a concern for many patients, there were 600 (19.61%) that had no pain needing to be managed. There were also 383 (12.52%) that did not have their pain under control and needing a pain management plan or revision.

Pain	All patients	
	ALL (n=)	ALL (%)
No pain noted/not applicable	600	19.61
Pain currently controlled	506	16.54
Pain management plan in place	266	8.69
Pain management plan needs revision	56	1.83
Pain currently not under control/plan needed	383	12.52
No response recorded	1238	40.46
Total No. of Patients	3060	104.87

*More than one option per patient possible



Palliative care plan

Pathways Telehealth nurses routinely assess the need for palliative care.

There were 1792 (58.56%) patients assessed as palliative care not being applicable. There were 70 (2.29%) patients that needed a referral and 54 (1.76%) that had already been referred to palliative care.

Palliative care	All patients	
	ALL (n=)	ALL (%)
Not applicable	1792	58.56
Patient already referred to palliative care	54	1.76
Patient requires palliative care referral	70	2.29
No response recorded	1104	36.08
Total No. of Patients	3060	100.00



Services in existing care plan

Patient Pathways nurses ask patients about the services that they have in their care team at the time of consultation. This allows the nurse to identify gaps in care and make appropriate referrals. This is known as a multidisciplinary team assessment. 939 (30.69%) patients had one or two services within their care team at the time of consultation, with 537 (17.55%) having 3 to 5 services.

Services at consult	All patients	
	ALL (n=)	ALL (%)
1	596	19.48
2	343	11.21
3	251	8.20
4	181	5.92
5	105	3.43
6	67	2.19
7	40	1.31
8	29	0.95
9	18	0.59
10	24	0.78
11 +	11	0.36
No information	1395	45.59
Total No. of Patients	3060	N/A

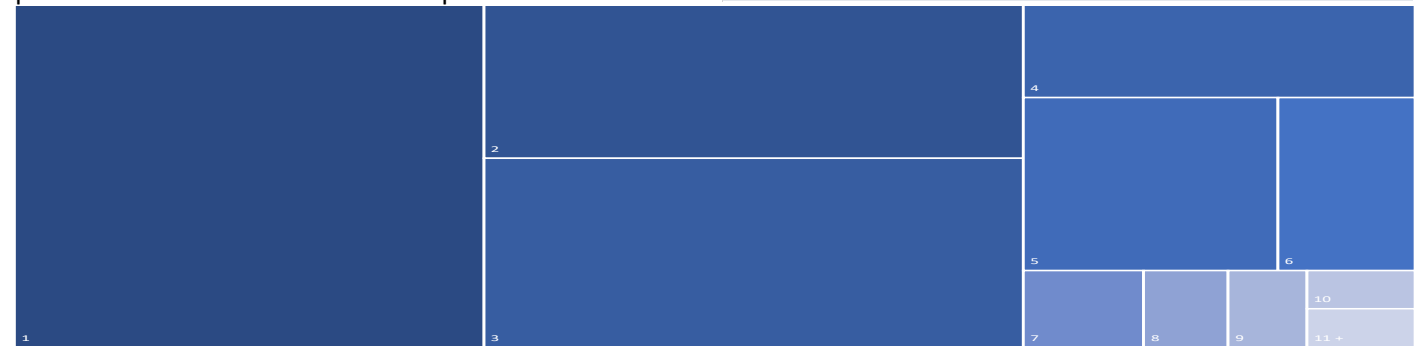


Referrals to specialists, allied health and supportive care

Pathways Telehealth nurses conduct a range of nurse-led interventions and referrals. In relation to referrals made for specific allied health or specialists, there were 412 patients needing one referral (13.46%), 474 patients needing 2 or 3 referrals (15.49%) and 131 patients (4.28%) needing four referrals.

The way referrals are made are either by preparing a prompt list or information for patients to take back to their general practitioner to get a referral through a Chronic Disease Care Plan or Mental Health Treatment Plan (where applicable) and/or providing the patient with the information about an appropriate allied health or specialist that will understand their specific condition.

Services required	All patients	
	ALL (n=)	ALL (%)
1	412	13.46
2	252	8.24
3	222	7.25
4	131	4.28
5	96	3.14
6	52	1.70
7	20	0.65
8	14	0.46
9	13	0.42
10	9	0.29
11 +	9	0.29
No information	1830	59.80
Total No. of Patients	3060	N/A



Assessments, interventions and referrals

Patient Pathways telehealth nurses conduct a range of nurse-led interventions and referrals. Overall, since the start of the program, there has been 26,953 assessments, referrals or interventions made at an average of 8.81 per patient. The number of assessments, referrals or interventions made has been consistent across each previous reporting period with an average of 7.43 reported in 2020, and 8.50 reported in 2021.

Referrals, interventions and assessments	All patients	
	ALL (n=)	ALL (%)
Multidisciplinary team assessment	1669	54.54
Primary care assessment	2261	73.89
Pain assessment	1861	60.82
Palliative care assessment	1916	62.61
Clinical trials assessment	1988	64.97
Home status assessment	2323	75.92
Symptom management assessment	2072	67.71
Information provision, education/discussions	9407	N/A
Allied health and supportive care referrals	3456	N/A
Total no. of referrals, interventions and assessments	26953	N/A
Average no. of interventions per patient	8.81	N/A



PATHWAYS
TELEHEALTH NURSE PROGRAM

Part 4: Finance and governance

History

The Centre for Community-Driven Research (CCDR) established the National Patient Organisation Standing Committee in July 2017 following a call for expressions of interest from patient organisations in Australia. The Standing Committee was developed as a place for patient organisations to convene and talk about the specific challenges that they have in community engagement and supporting their patient communities. The Standing Committee is a collective of organisations that aim to work for the greater good of all patient organisations, rather than for individual gain.

CCDR's role is to bring opportunities to the Standing Committee and use any available resources and existing platforms to support the non-profit sector for the greater good. CCDR does not have a vote in the activities of the Standing Committee.

Meeting with the Hon Greg Hunt MP, Minister for Health, Member for Flinders

The Standing Committee met with the Health Minister in April 2018 where Committee Members spoke about the challenges for patient organisations to fund and provide support programs and that there is an opportunity to leverage the position of patient organisations in the community to help patients navigate the health system and access clinical trials. The Minister then invited a proposal for a pilot program that helped patients navigate the health system.

The Minister indicated that the proposal needed to be a pilot program, not for direct funding of services, and that it would need to be done as a research trial. Minister Hunt used the term Patient Pathways, and this is where the name of the program was initiated.

Patient Pathways proposal

A proposal was developed by CCDR and taken to the Standing Committee based on the health system navigation model already being implemented by CCDR.

A teleconference was held outside our regular meetings in May 2018 to specifically go through the proposal and how funding would be distributed. Following the meeting, Standing Committee were also invited to submit specific comments that they may have before the proposal was submitted to the Minister's office. The Standing Committee decided that funding would be open to any organisation through an application process. Funding was earmarked in the proposal for CCDR to project manage and implement the program across ten disease areas, as well as ongoing support for patient organisations involved in the program and program evaluation, including the development of a database to guide nurses in their work and collect data.

The purpose of the pilot was to demonstrate that telehealth case management (that sits within community-based organisations) works and has economic benefits across various disease areas. To do this, it needed to be demonstrated across a range of disease areas so that we can see if it works in oncology, disabilities, chronic disease, acute care etc. The greater good goal is that if we can do that, we then have the evidence to recommend that a pool of funding be made available for patient organisations to access to run these services. It would mean that the non-profit community would have a place to go to support that side of their work, rather than each organisation lobbying for ad-hoc funding which often leads to inequities in funding. To the credit of the Standing Committee, every patient organisation in Australia has had the same opportunity to access the funding that is available.

Patient Pathways review, transparency and governance

Once funding was approved (in June 2018), Standing Committee members were invited to develop the application form for the Patient Pathways grant process. The Standing Committee agreed that if a member organisation was considering applying for support, they should not be involved in the development of the application form. The majority of members indicated that they may be interested in applying with the exception of MS Australia who were involved in reviewing and contributing to the application process.

Patient Pathways was announced on 12 January 2019 and applications for support opened on this day. The funding period for the program is 2019 to 2021. CCDR had spent a considerable amount of time in the six months leading up to the announcement going through the Australian Charities and Non-Profit Commission website to identify patient organisations in Australia and then searching the internet for contact details. Where contact details were not available, CCDR called the organisation to collect this information. As a result, CCDR had a list of 500+ patient groups and this was used to inform them all of the opportunity to apply for funding. The closing date for applications was 15 February 2019 and the review of applications for support through the Patient Pathways program was held on Friday 22 February.

Standing Committee members were again invited to participate in the Review Committee, however only if they were not intending to submit an application. At this point there were no members that indicated that they were interested in being part of the Review Committee and an independent Review Committee was convened. The Review Committee was convened to assess this and continue to independently monitor and provide technical advice to the program. CCDR's role is an administrator.

CCDR did not have any vote in the funding decisions. At the Review Committee meeting on 15 February 2019, CCDR was present to work the computer slides and take minutes. In addition to the Review Committee members, there was an independent observer to make sure it was a fair and transparent process and that no Review Committee members have any bias.

Eligibility and managing enquiries

All patient organisations in Australia were eligible to submit an application to be part of the Patient Pathways pilot. There were three levels of support.

On the Patient Pathways application page, potential applicants were instructed that all enquiries should be submitted by email only. CCDR took this approach so that there would be a record of any advice provided and so that advice could be provided consistently. CCDR maintained this approach without alteration throughout the application period.

Role of the Review Committee

The Review Committee's role was to make sure that within the Pilot, we can demonstrate efficacy across disease areas as well as addressing need. The Review Committee also needed to assess what was feasible in relation to delivering a program that includes patient organisations with a varying range of capacity and understanding of the role of telehealth.

The Review Committee met on 22 February 2019. In advance of the meeting, each Review Committee member was sent each of the proposals and asked to score them against the published criteria including:

Criteria	Weighting
Need: the review committee will consider the need for a telehealth nurse in the disease or condition being requested. This will include: <ul style="list-style-type: none">- How complex the disease treatment and care needs of the population are- Whether this is a particularly vulnerable population- Whether services already exist for this patient population	25%
Adherence: the review committee will consider the requesting organisation's ability to adhere to the program and protocol. This will include: <ul style="list-style-type: none">- Whether the organisation has existing services that can be adapted to adhere to the Patient Pathways protocol and processes.- Whether the organisation has the capacity to support employing a nurse as part of their team, including a safe and professional work space.- Whether the organisation will be able to manage data privacy- Whether the organisation has the capacity to manage liability for any nurse employed by their organisation	25%
Impact: the review committee will consider the impact that a nurse in the respective disease area will have on the population, including potential cost/benefits.	25%
Overall alignment with the Patient Pathways program: The review committee will take into consideration all of the grant applications and make their final recommendations based on ensuring that there is a balance of disease areas within the Patient Pathways program. As this is a pilot program, this is important so that we are able to demonstrate adaptability across disease areas including chronic, acute and life threatening diseases.	25%

CCDR prepared slides for the Review Committee meeting to rank the organisations overall and against the application criteria.

A spokesperson was assigned to each of the applications and the Review Committee took the time to discuss each of the applications.

Patient Pathways is quite a complex program and it is an enormous responsibility for CCDR to take on to manage the implementation of 11 separate nurse telehealth services. It's not a helpline service, nor is it just a case of providing funding to place a nurse on the phone. There needs to be protocols developed and adapted for the disease areas, developing a data collection system that suits everyone, governance, program evaluation, ethics and support for the nurses in those roles around that etc. All of these components were taken into consideration by the Review Committee in making their final recommendations.

The funding awarded by the Federal Government also covers annual program management for the network, support and for nurses and organisations working in the program, continuing professional development for nurses, database development, data collection and program evaluation (\$80,000). Outside of the Pilot, this program also includes managing a network of Australia patient organisations and conducting an audit of telehealth services/need for services in Australia (\$70,000). The program funding was provided as a way to consolidate resources and to ensure that this is a cost-effective program. For example, the back-end program support that CCDR offers means that each partner organisation does not have to have a research officer to conduct the evaluation of the program and they do not need a project officer to design the program, develop the nurse's clinical protocol or develop a database for data collection. Details of the funding breakdown is available below.

Annual program and financial reporting has been submitted to the Commonwealth Department of Health in 2019, 2020 and 2021. The final report is due 31 July 2022. Each report submitted has been reviewed and accepted as complete by the Commonwealth Department of Health. An additional year of funding was provided to CCDR. Funding commenced in July 2018 however most partners didn't start their service until mid-2019. This was due to the Minister of Health only announcing the program in January of 2019 and CCDR being unable to commence operations until an announcement was made (as per the direction of the Minister's office). There was therefore a hangover funding period into 2022, i.e funding committed in 2021 but the actual funding period of activity extends into 2022. The external review committee also recommended implementing quarterly payments (rather than annual payments) for some organisations so that reviews could be in place to monitor service provision more closely in the final year of the pilot, particularly where services had a low volume of patients.

Additional decision-making and governance throughout the program

The Standing Committee has an oversight role within the program, however as some committee members have been recipients of funding, confidential and independent advisory committees have been convened where necessary to make decisions on the program. Independent advisory committees have also overseen a review of partner organisation's annual reports to confirm continuation of funding. Key decisions have included:

1. Genetic Alliance was initially awarded funding in the grant process. The nurse's engagement ended, and it was difficult to find a nurse with both rare and genetic disease, and community-based care experience. It was also suggested that services could be extended to other rare disease organisations such as Genetic Support Network Victoria and SWAN Australia. It was decided that CCDR would host a nurse to provide a central service to all of these organisations under a Genetic, Rare and Complex conditions service.
2. Eating Disorders Victoria secured external funding and no longer required support. Final payment June 2020. Funding period ending June 2021. The nurse from Save Our Sons Duchenne Foundation (Duchenne and Becker Muscular Dystrophy) resigned in October 2021. The organisation did not feel they could recruit a new nurse if the Government was unable to commit funding and therefore, SOS withdrew from the program. They felt it was unfair to bring a nurse on without being able to offer a secure job. Any unspent funding due to not having a nurse in place was returned. Funding from EDV and SOS re-allocated to the community groups Ehlers-Danlos Syndrome Australia, NMOSD Australia and Liver Cancer Australia. There was no grant process for this as there was not enough time to conduct such a process within the context of the Pilot ending in 2022. Instead, key clinicians and stakeholders in each disease area were consulted on whether there was an existing patient organisation where a nurse could be hosted, however in each disease area, it was agreed CCDR was best positioned to host the service.

Expenditure

Throughout the program, annual budget status and program reporting was provided to the Commonwealth Department of Health with each report approved and accepted. In the final year of the program, the Commonwealth Department of Health provided a template to reconcile all expenditure and an excerpt is presented below.

Grant Income (GST exclusive)	\$1'730'000.00		
Total Expenses Service Provision (GST exclusive)	Total expenditure 2019-2022	Average annual expenditure	No. years of funding
Cerebral Palsy Support Network Grant	\$102'000.00	\$34'000.00	3
Crohn's & Colitis Australia Grant	\$120'000.00	\$40'000.00	3
Eating Disorders Victoria Grant	\$80'000.00	\$40'000.00	2
Emerge Australia Grant	\$60'000.00	\$20'000.00	3
Genetic Alliance Australia Grant	\$119'999.93	\$40'000.00	3
Maddie Riewoldt's Vision Grant	\$120'000.00	\$40'000.00	3
Metabolic Dietary Disorders Association Grant	\$120'000.00	\$40'000.00	3
Mito Foundation Grant	\$90'000.00	\$30'000.00	3
Save Our Sons Duchenne Foundation Grant (1)	\$65'000.00	\$28'888.89	2
Tuberous Sclerosis Australia Grant	\$111'000.00	\$37'000.00	3
Liver Cancer Support Australia Service provision	\$20'000.00	\$20'000.00	1
NMOSD Australia Service provision	\$22'500.00	\$22'500.00	1
Ehlers-Danlos Australia Service provision	\$20'000.00	\$20'000.00	1
Total Expenses Program Management (GST exclusive)	Total expenditure 2018-2022	Average annual expenditure	No. years of funding
Program management (Patient Pathways)*	\$156'184.20	39'046.05	4
Specialist nurse consultancy*	\$75'010.26	18'752.57	4
Evaluation/Database specifications/Governance/Ethics*	\$100'830.80	25'207.70	4
Conference event manager*	\$121'223.27	30'305.82	4
Conference Facilitation	\$30'145.21	7'536.30	4
Conference/Network development and engagement*	\$85'718.70	21'429.68	4
Webinar and workshop facilitation and organisation*	\$43'493.98	10'873.50	4
Database development/Maintenance	\$80'000.42	20'000.11	4
NOTES			
(1) Total expenditure on service delivery was \$1,050,499.93 (\$0.07 under budget). Total expenditure on program delivery was \$692,606.84 (\$12,606.84 over budget)			
(2) No grant funds were used for administration, travel, conference, accounting, office or other non-grant expenses			
(3) Subcontractors paid in advance for services. Implementation of budget expenditure as reported annually			
(4) Funding was received in July 2018 however work could not publically commence until the Health Minister made an announcement. The announcement of the program was made in January 2019. A grant round was then announced with the first nurses commencing service delivery in June 2019.			
(5) All patient groups self-identified the level of funding required and this was reviewed by an independent grant committee.			