

**PATHWAYS**

TELEHEALTH NURSE PROGRAM



# Pathways Telehealth Nurse Service High Level Report

November 2023

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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, Sara, Susan and Kate, delivering direct patient support through the Pathways Telehealth Nurse service on a volunteer basis.

*Information presented represents clinical data as at 15 October 2023*

We also thank all partners:



Australian Sickle Cell Advocacy Inc.



Brainwave Australia



Charge Syndrome Australasia



CMT Australia



Genetic Alliance Australia



Pink Hope



SATB2 Connect



Scleroderma Australia



Syndromes Without a Name Australia



Genetic Support Network Victoria

# 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. In March 2022, the now Minister for Health, the Hon Mark Butler MP, joined the National Patient Organisation Network Australia conference and made an election commitment that the program would be expanded to 18 disease areas from our funding end date of 30 June 2022. It was a great recognition from the Minister who acknowledged that the two evaluations performed demonstrated exceptional value and impact, and that the government would accept all of the recommendations provided in our submission. For a nurse-led program this values our contribution to the health system when the advice and evidence we provide is accepted.

CCDR offered additional cost reductions to Mr Butler, however the commitment was unfortunately not honoured and since then, volunteer nurses have been engaged to ensure patients receive the care they need. Pathways is current a program services completely by volunteers.

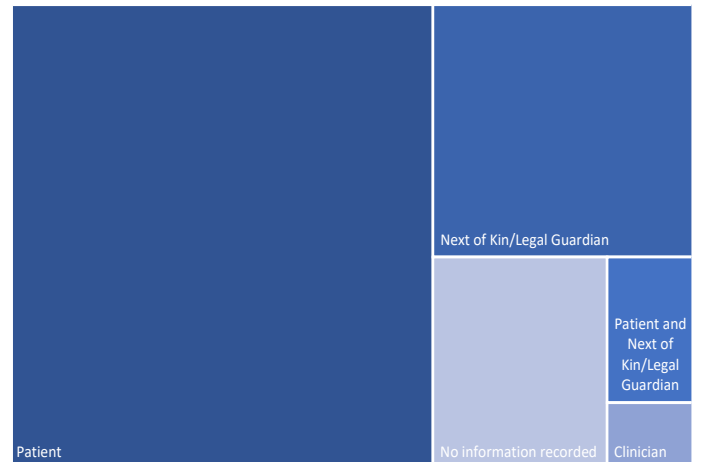
## Impact

- 3,276 people have accessed the Pathways telehealth service from August 2019 to October 2023.
- From 2019 to 2023, Pathways Telehealth Nurses made 23,711 assessments at an average of 7.75 per patient. In this reporting period of 2022 to 2023, there were 2,688 assessments at an average of 14 per patient.
- There was 100% compliance with the Pathways protocol from nurses engaged in the program in the 2022 to 2023 period. This is in contrast to previous years where overall compliance was 70.03%
- The average time per patient for an initial consultation and follow-up was 92.51 minutes.
- Nurses are most commonly speaking with women (68.23%)
- The majority of people who accessed the services were patients (75.52%) followed by next of kin or family members (24.48%)
- 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 (22.92%)
- There was an increase in access to the service from low to medium socioeconomic areas with 56.25% of participants coming from low to medium socioeconomic areas compared to 38.87% across the life of the program
- There was an increase in access to the service from regional and remote areas in the 2022 to 2023 reporting period with 43.75% of participants coming from regional or remote areas compared to 24.57% across the life of the program

## Part 1: Who we've helped

## Consultation with

Since the commencement of the program in 2019, 3,252 people have accessed the Pathways Telehealth Nurse service. The majority of people were patients (n=2040, 62.73%) followed by next of kin/legal guardians (n=681, 20.94%).



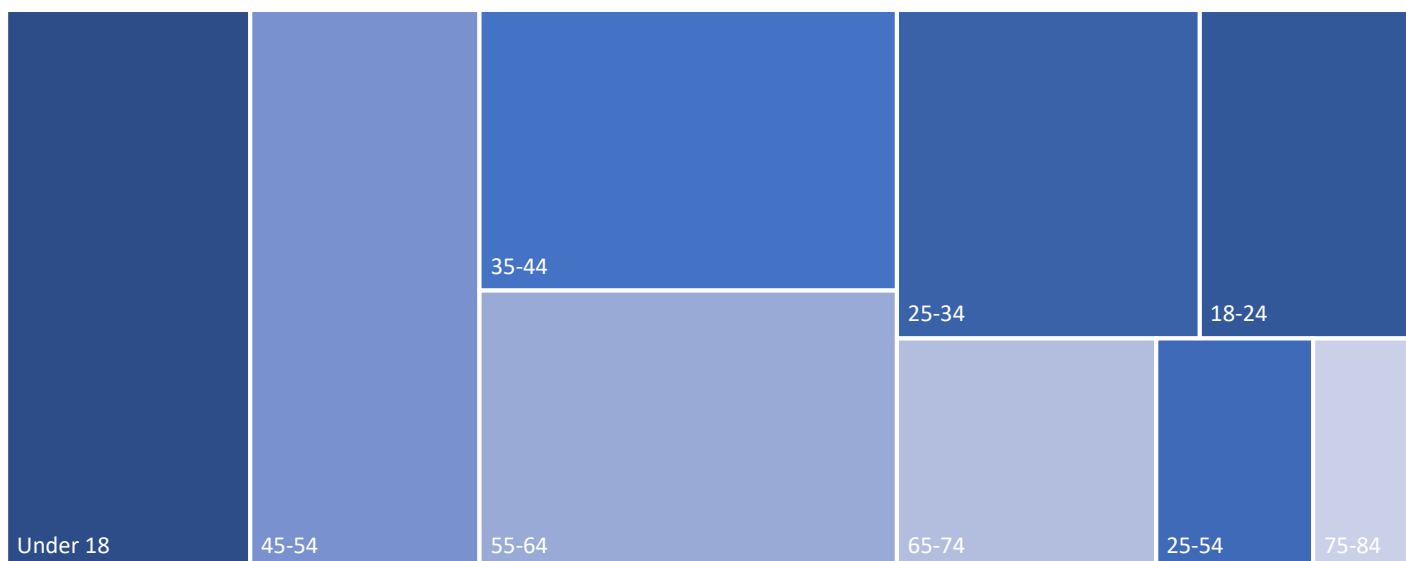
Consult with	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Patient	2040	62.73	145	75.52
Next of Kin/Legal Guardian	681	20.94	47	24.48
Patient and Next of Kin/Legal Guardian	120	3.69	0	0.00
Clinician	55	1.69	0	0.00
No information recorded	356	10.95	0	0.00
<b>Total No. of Patients</b>	<b>3252</b>	<b>N/A</b>	<b>192</b>	<b>N/A</b>

## Age

The service was accessed by 479 patients under the age of 18 (14.73%). 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 25 to 64 represented 51.75% of all patients accessing the service.

Age	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
<b>Under 18</b>	479	14.73	44	22.92
<b>18-24</b>	231	7.10	4	2.08
<b>25-34</b>	347	10.67	31	16.15
<b>25-54</b>	116	3.57	0	0.00
<b>35-44</b>	382	11.75	9	4.69
<b>45-54</b>	433	13.31	24	12.50
<b>55-64</b>	405	12.45	35	18.23
<b>65-74</b>	226	6.95	36	18.75
<b>75-84</b>	85	2.61	9	4.69
<b>85 and older</b>	8	0.25	0	0.00
<b>No information</b>	540	16.61	0	0.00
<b>Total No. of Patients</b>	<b>3252</b>	<b>N/A</b>	<b>192</b>	<b>N/A</b>



### Gender

The majority of people accessing the Pathways Telehealth Nurse service were female (n=2150, 66.11%), with 894 (27.49%) men and a small number of people who identified as intersex, transgender or non-binary.

Gender	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Female	2150	66.11	131	68.23
Male	894	27.49	60	31.25
Non-binary	12	0.37	0	0.00
Not wish to disclose	7	0.22	0	0.00
Transgender	8	0.25	1	0.52
No information	181	5.57	0	0.00
<b>Total No. of Patients</b>	<b>3252</b>	<b>N/A</b>	<b>192</b>	<b>N/A</b>

### Home status

A home status assessment refers to the Pathways Telehealth Nurse asking the patient questions about 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 995 (30.60%) people who lived in a family home without dependents, 929 (28.57%) that lived in a family home with children and 441 (13.56%) people that lived alone.

Home status	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Lives alone	441	13.56	30	15.63
Lives with family (including children who are dependents)	929	28.57	66	34.38
Lives with family (including elderly who are dependents)	29	0.89	3	1.56
Lives with family (no dependents)	995	30.60	81	42.19
Lives with a friend/share house	89	2.74	7	3.65
Other	32	0.98	5	2.60
No response recorded	737	22.66	0	0.00
<b>Total No. of Patients</b>	<b>3252</b>	<b>N/A</b>	<b>192</b>	<b>N/A</b>



### Point that patient joined service

The majority of people joined the Pathways Telehealth Nurse service while undergoing ongoing management for their condition, including active management (n=1735, 53.35%). This was followed by people that were newly diagnosed (n=310, 9.53%) and people seeking a diagnosis (n=253, 7.78%).

Point patient joined service	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Diagnosis	310	9.53	2	1.04
Pre-treatment	21	0.65	0	0.00
Maintenance post primary treatment	0	0.00	0	0.00
Ongoing chronic condition: active management	1735	53.35	120	62.50
Ongoing chronic condition: no management	149	4.58	20	10.42
Recurrence - no treatment	17	0.52	7	3.65
Recurrence - with treatment	20	0.62	10	5.21
Seeking Diagnosis	253	7.78	33	17.19
Surveillance post primary treatment	42	1.29	0	0.00
Palliative	59	1.81	0	0.00
Other	33	1.01	0	0.00
No information recorded	613	18.85	0	0.00
<b>Total No. of Patients</b>	<b>3252</b>	<b>N/A</b>	<b>192</b>	<b>N/A</b>



## Ethnicity

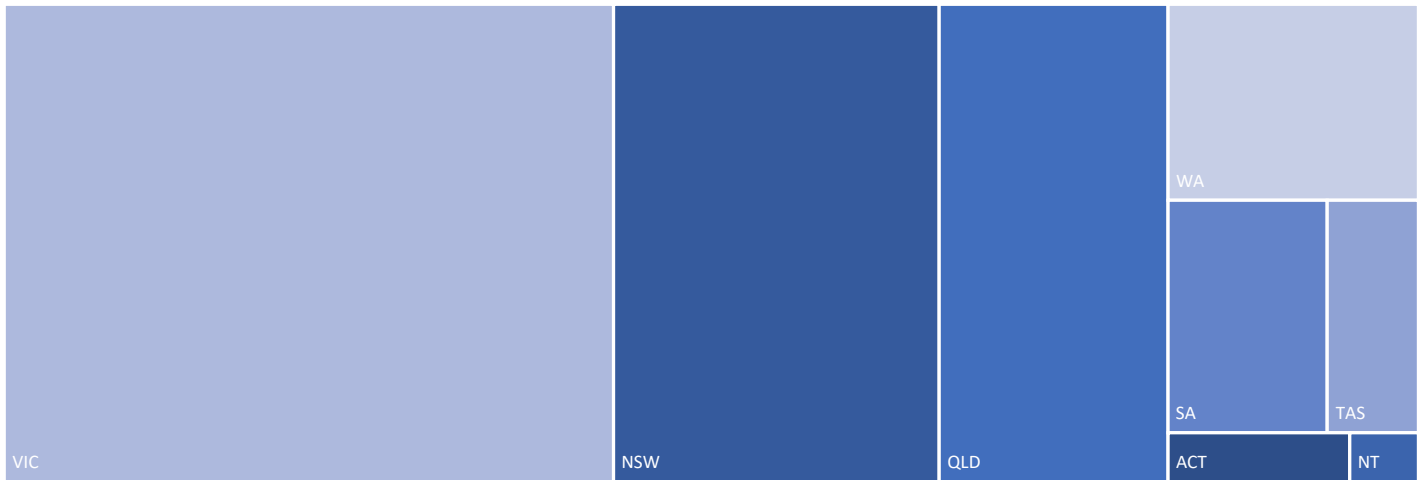
The majority of people accessing the Pathways Telehealth Nurse service were caucasian (n=2924, 89.91%). There were 130 (4.00%) people that did not wish to disclose their ethnicity.

Ethnicity	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Caucasian/White	2924	89.91	169	88.02
Aboriginal/Torres Strait Islander	41	1.26	9	4.69
African	13	0.40	0	0.00
Arab	20	0.62	4	2.08
Asian	97	2.98	2	1.04
Hispanic/Latino	10	0.31	2	1.04
Pacific Islander	14	0.43	0	0.00
Does not wish to disclose	130	4.00	3	1.56
Other	3	0.09	3	1.56
<b>Total No. of Patients</b>	<b>3252</b>	<b>N/A</b>	<b>192</b>	<b>N/A</b>

## State

The majority of people accessing the Patient Pathways telehealth service were from Victoria (n=1243, 38.22%). This is in part due to a number of Victorian-based organisations within the pilot program that didn't have national outreach. There were 693 (21.31%) people from New South Wales, 494 (15.19%) from Queensland and 234 (7.20%) from Western Australia.

State	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
ACT	42	1.29	5	2.60
NSW	693	21.31	50	26.04
NT	15	0.46	1	0.52
QLD	494	15.19	44	22.92
SA	165	5.07	12	6.25
TAS	93	2.86	6	3.13
VIC	1243	38.22	43	22.40
WA	234	7.20	31	16.15
No information recorded	273	8.39	0	0.00
<b>Total No. of Patients</b>	<b>3252</b>	<b>N/A</b>	<b>192</b>	<b>N/A</b>



## Region

The location of patients was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics<sup>1</sup>. The majority of patients came from major cities (n=1925, 59.19%), with 799 (24.57%) coming from regional Australia. In the 2022 to 2023 period, 56.25% of patients came from metropolitan areas and 43.75% came from regional or remote areas.

Region	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
<b>Metropolitan</b>	1925	59.19	108	56.25
<b>Regional or remote</b>	799	24.57	84	43.75
<b>No information recorded</b>	528	16.24	0	0.00
<b>Total No. of Patients</b>	3252	N/A	192	N/A

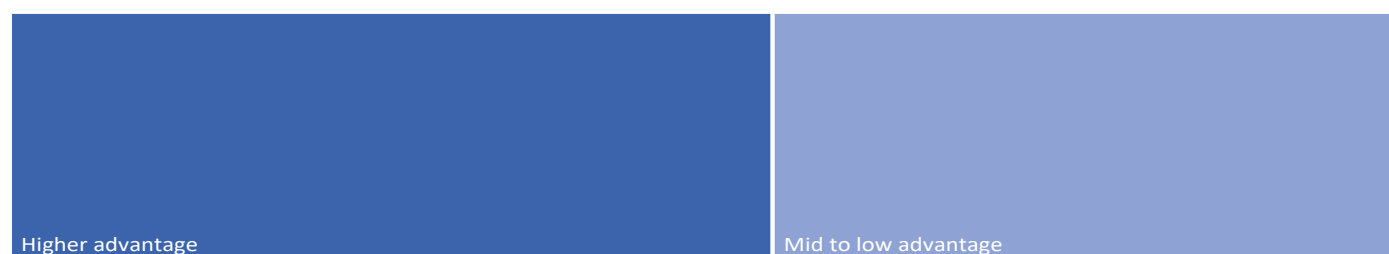


<sup>1</sup> Australian Bureau of Statistics 2016, Australian Statistical Geography Standard (ASGS): Volume 5 - Remoteness Structure, July 2016, 'Correspondence, 2017 Postcode to 2016 Remoteness Area', data cube: Excel spreadsheet, cat. no.1270.0.55.005

## 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. There were 1264 (38.87%) people coming from low to medium socioeconomic areas and 1485 (45.66%) people coming from higher socioeconomic areas<sup>2</sup>. In the 2022 to 2023 period, there were 56.25% of patients representing low to medium socioeconomic areas.

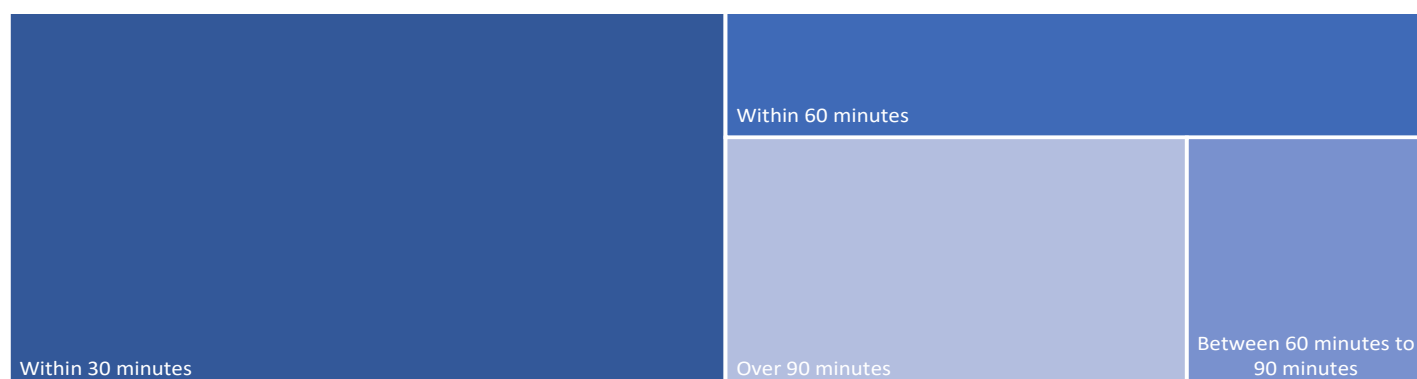
Socioeconomic status	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Higher advantage	1485	45.66	84	43.75
Mid to low advantage	1264	38.87	108	56.25
No information recorded	503	15.47	0	0.00
<b>Total No. of Patients</b>	<b>3252</b>	<b>N/A</b>	<b>192</b>	<b>N/A</b>



## 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=925, 28.44%). There were 598 (18.39%) people needing to travel up to 60 minutes and 305 (9.38%) needing to travel up to 90 minutes or more.

Access to healthcare	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Within 30 minutes	925	28.44	94	48.96
Within 60 minutes	598	18.39	51	26.56
Between 60 minutes to 90 minutes	108	3.32	16	8.33
Over 90 minutes	197	6.06	22	11.46
Not applicable - no regular treatment	628	19.31	9	4.69
No access to treatment recorded	796	24.48	0	0.00
<b>Total No. of Patients</b>	<b>3252</b>	<b>N/A</b>	<b>192</b>	<b>N/A</b>



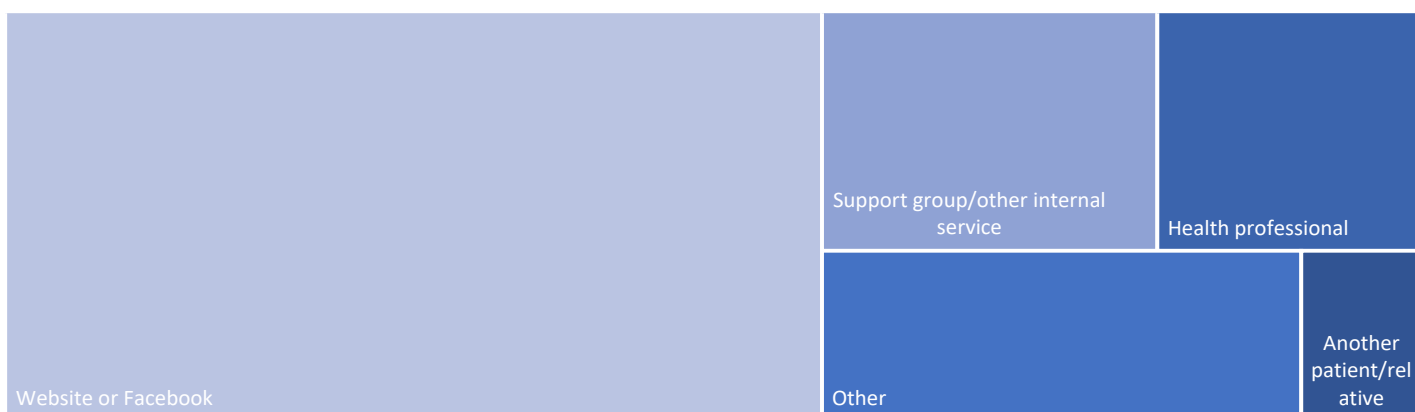
<sup>2</sup> Australian Bureau of Statistics, 2016, Census of Population and Housing: Socio-Economic Indexes for Areas

# Part 2: When we've helped

## Referred from

The majority of patients found the service through their local patient organisation website or Facebook page (n=1541, 47.39%). This was followed by a support group or internal service referral (n=521, 16.02%) and health professional referral (n=382, 11.75%).

Referred from	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Another patient/relative	64	1.97	3	18
Health professional	382	11.75	37	106
Other	241	7.41	0	116
Support group/other internal service	521	16.02	85	144
Website or Facebook	1541	47.39	67	635
No information recorded	503	15.47	0	106
<b>TOTAL NO. PATIENTS</b>	<b>3252</b>	<b>N/A</b>	<b>192</b>	<b>N/A</b>



# PATHWAYS

TELEHEALTH NURSE PROGRAM



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

## What's new in the Pathways Telehealth Nurse service since the pilot

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



### Duration of support

The average time per patient for an initial consultation and follow-up in the 2022 to 2023 reporting period was 92.51 minutes. Across the life of the program the average total time per patient is 95.48.

Duration consult	All patients 2019 to 2023	All patients 2022 to 2023
Average Initial consult	46.66	48.26
Care plan development and follow-up	48.82	44.25
<b>Total time per patient</b>	<b>95.48</b>	<b>92.51</b>

\*Average times not calculated for Pathways nurses in training

## Part 3: How we've helped



## Assessments

There are a series of assessments that constitute the Pathways protocol. Pathways nurse receive training on the protocol and data is reviewed to ensure all assessments are complete.

The tables below compare this year's reporting period compliance with Pathways assessment protocols with the whole of the program. In 2022 to 2023, all nurses maintained 100% compliance with the protocol. This is in contrast to previous years where overall compliance was 70.03%. The main difference in operations accounting for this is that previously, nurses were directly managed by partner organisation employee contracts however in 2022 to 2023, all Pathways nurses were under direct contract and supervision by CCDR.

From 2019 to 2023, Pathways Telehealth Nurses made 23,711 assessments at an average of 7.75 per patient. In this reporting period of 2022 to 2023, there were 2,688 assessments at an average of 14 per patient.

Primary care assessment	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessment complete	2453	74.88	192	100.00
Total No. of Patients	3252	N/A	192	N/A

Home status assessment	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessment complete	2515	76.77	192	100.00
Total No. of Patients	3252	N/A	192	N/A

Diagnosis assessment	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessment complete	192	100.00	192	100.00
Total No. of Patients	192	N/A	192	N/A

Symptoms and comorbidities assessment	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessment complete	2264	69.11	192	100.00
Total No. of Patients	3252	N/A	192	N/A

Information assessment	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessment complete	3252	99.27	192	100.00
Total No. of Patients	3252	N/A	192	N/A

MDT assessment	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessment complete	1861	56.81	192	100.00
Total No. of Patients	3252	N/A	192	N/A

Point of coordination assessment	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessment complete	192	100.00	192	100.00
Total No. of Patients	192	N/A	192	N/A
Clinical trials	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessment complete	2180	66.54	192	100.00
Total No. of Patients	3252	N/A	192	N/A
Emotional and social assessment	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessment complete	2180	66.54	192	100.00
Total No. of Patients	3252	N/A	192	N/A
Palliative care assessment	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessment complete	2108	64.35	192	100.00
Total No. of Patients	3252	N/A	192	N/A
Advance care planning assessment	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessment complete	192	100.00	192	100.00
Total No. of Patients	192	N/A	192	N/A
Pain assessment	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessment complete	2065	63.03	192	100.00
Total No. of Patients	3252	N/A	192	N/A
Referral assessment	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessment complete	2065	63.03	192	100.00
Total No. of Patients	3252	N/A	192	N/A
Assessments and interventions completed	All patients 2019 to 2023		All patients 2022 to 2023	
	ALL (n=)	ALL (%)	ALL (n=)	ALL (%)
Assessments completed	23711	N/A	2688	N/A
Average per person	7.75	N/A	14.00	N/A
Total No. of Patients	3276	N/A	192	N/A