



CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Patient Pathways Telehealth Nurse Service

ALL PARTNER ORGANISATIONS

Evaluation, November 2021

Introduction & Evaluation Approach

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.

The Patient Pathways telehealth nurse program was announced by the Hon Greg Hunt MP, Member for Flinders, Minister for Health in 2019. Funding was provided to CCDR to be distributed amongst patient organisations through a transparent and independent grant process.

The initiative places specialist telehealth nurses in community organisations.

“This support will connect patients with specialist care, homecare services or mental health support and open up opportunities to participate in and clinical trials.”

“The aim is to ensure people who are in need of support get fast, expert advice tailored to their particular circumstances in a co-ordinated way. Patient organisations will be identified through a grant round and the result of the pilot will inform future work or expanded roll out.”

Hon Greg Hunt MP, Member for Flinders, Minister for Health. January 2019 program announcement.

Patient pathways provides a remote clinic that can be inclusive of families, carers, and patients wherever they live. For families that live long distances, they are able to provide support for the patient, and become informed without the need and expense of travelling. All of the Patient Pathways nurses are located in metropolitan areas yet were 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.

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 aims to make 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. This is also an opportunity to reduce duplication between patient organisations and forge collaboration across the health sector.

Patient Pathways Program (Telehealth Nurse Pilot)

Many patient organisations have a point of contact, however the way that this is implemented varies from a helpline providing information only, to a structure telehealth system connecting patients with health services, local support and medical research. The pilot project will aim to set standards and a baseline in the way that patient organisations offer support, thereby building capacity within the health sector. CCDR have tested and implemented a Patient Pathways model that can be adapted across disease areas for this pilot project. The aim will be to implement the Patient Pathways model across a minimum of 11 disease types over three years. We will also take this opportunity to not only support patients and their families but also implement a system to encourage community engagement and feedback in health and research.

Patient Pathways Evaluation 2021

Purpose of the Pilot

The aim of the Pilot is to increase the capacity of patient organisations to support patients to navigate the health system and access all that is available to them, including clinical trials. If we are able to demonstrate a significant and positive impact, this increases the potential to make this type of service – through patient organisations – available to all patients in Australia, across all disease areas.

Partner organisations

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

Ehlers-Danlos Syndrome Australia

NMOSD Australia

Through the program:

- Organisations are provided with support from CCDR to establish a telehealth case management service that is relevant to the disease or condition that your organisation focuses on
- Nurses are supported with ongoing education, training and peer support opportunities through a Telehealth Nurse Network
- CCDR collect data throughout the Pilot and produce annual impact reports for all partner organisations

Project 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 11 nurses working in the program. Nurses are offered weekly, group case discussions and in-service opportunities. Case discussions are a professional development opportunity to share resources and discuss best-practice in telehealth nursing. It is also an important part of maintaining mental health as nurses offer each other peer support. There were also two, monthly clinical supervision opportunities between March and October (total of 16 sessions available).

In addition, there were four in-service opportunities in relation to clinical trials, genetic counselling, COVID-19 and access to services, and individual professional reflection interviews with each nurse (equalling one hour of CPD per session).

Some of the benefits of having an organisation like CCDR managing aspects of the service include;

-ongoing support and training of nurses through regular meetings, which include case management presentations, discussing/problem solving difficult cases, sharing success/failures and tips on attracting new patients to the service.

-independent review of each service (like this report), giving each organisation feedback on how their service is going

-Advertising the service using CCDRs relationships with patient organisations and national clinician network

Acknowledgements

Patient Pathways is being funded by the Australian Department of Health

Ethics information

The University of Sydney Human Research Ethics Committee (HREC)

Project No.: 2019/762
Project Title: Quality assurance of a nurse-led telehealth case management service

Evaluation

The areas of evaluation were published and provided to all partner organisations at the commencement of the program. Table A below provides an overview of the evaluation fields and rationale for inclusion.

Additional information

For more information about Patient Pathways contact Kate Holliday holliday@cc-dr.org

Part 1: Demographics

Consultation with

Since the commencement of the program, 2,336 people have 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%).

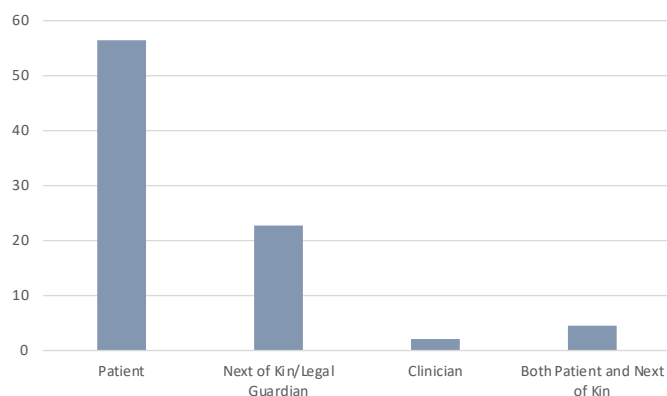


Table 1: Consultation with

Figure 1.1: Consultation with
(% of all people accessing Patient Pathways)

Consultation with	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Patient	705	56.63	613	56.19	1318	56.42
Next of Kin/Legal Guardian	321	25.78	209	19.16	530	22.69
Clinician	38	3.05	10	0.92	48	2.05
Both Patient and Next of Kin	61	4.90	45	4.12	106	4.54
Consultation with not identified	120	9.64	214	19.62	334	14.30

Age

The ages represented in table 1.2 and figure 1.2 are those of the patient (rather than the next of kin/guardian where applicable). The majority of patients accessing the Patient Pathways telehealth service were aged between 25 and 54 years of age (n=962, 41.18%). There were 360 (15.41%) patients under 18 years of age, 252 (10.79%) patients aged 55 to 64 years of age and 199 (8.52%) patients aged 18 to 24 years of age.

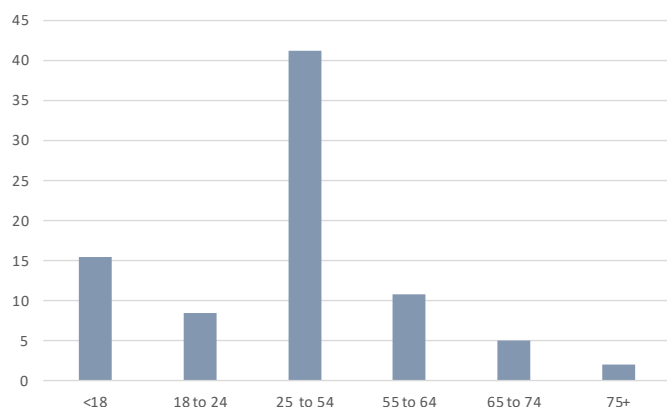


Table 1.2: Age

Figure 1.2: Age
(% of all people accessing Patient Pathways)

Age	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
<18	180	14.46	180	16.50	360	15.41
18 to 24	91	7.31	108	9.90	199	8.52
25 to 54	428	34.38	534	48.95	962	41.18
55 to 64	128	10.28	124	11.37	252	10.79
65 to 74	78	6.27	40	3.67	118	5.05
75+	26	2.09	22	2.02	48	2.05
Age not identified	314	25.22	83	7.61	397	16.99

Gender

The majority of people accessing the Patient Pathways telehealth service were female (n=1568, 67.12%), with 615 (26.33%) men and a small number of people who were intersex, transgender or non-binary.

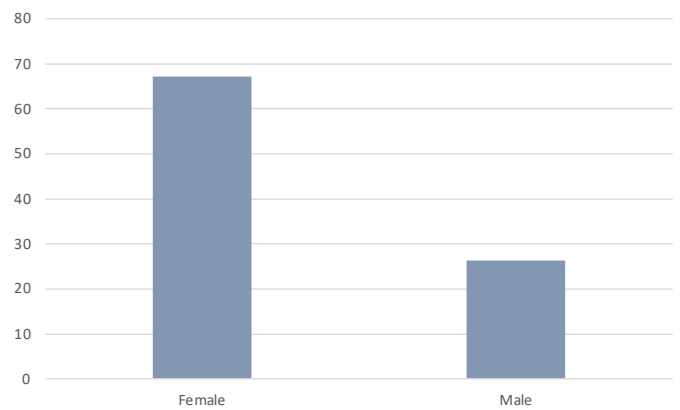


Figure 1.3: Gender
(% of all people accessing Patient Pathways)

Table 1.3: Gender

Gender	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Female	799	64.18	769	70.49	1568	67.12
Male	343	27.55	272	24.93	615	26.33
Non-binary	6	0.48	3	0.27	9	0.39
Does not wish to disclose	1	0.08	6	0.55	7	0.30
Transgender	2	0.16	3	0.27	5	0.21
Gender not identified	94	7.55	38	3.48	132	5.65

Home status

A home status assessment refers to the Patient 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 826 (35.36%) people who lived in a family home without dependents, 545 (23.33%) that lived in a family home with children and 325 (13.91%) people that lived alone.

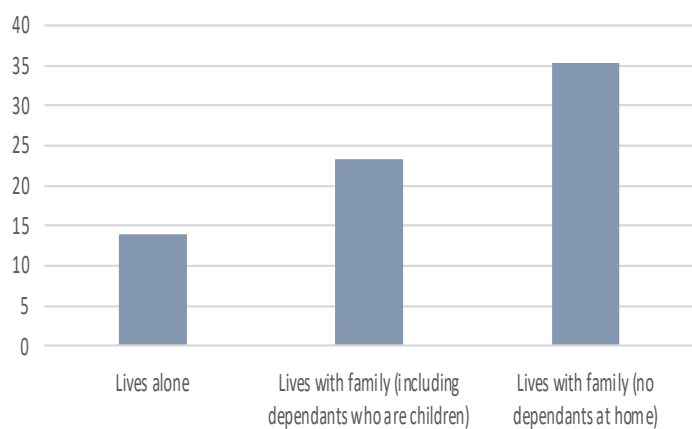


Figure 1.4: Home status
(% of all people accessing Patient Pathways)

Table 1.4: Home status

Home status	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Lives alone	150	12.05	175	16.04	325	13.91
Lives with family (including dependants who are children)	12	0.96	4	0.37	16	0.68
Lives with family (including dependants who are children)	333	26.75	212	19.43	545	23.33
Lives with family (including dependants who are children)	18	1.45	1	0.09	19	0.81
Lives with family (no dependants at home)	336	26.99	490	44.91	826	35.36
Other	102	8.19	22	2.02	124	5.31
Home status not assessed	294	23.61	187	17.14	481	20.59

Point that patient joined service

The majority of people joined the Patient Pathways telehealth nurse service while undergoing ongoing management for their condition, including active treatment (n=1190, 50.94%). This was followed by people that were newly diagnosed (n=339, 14.51%).

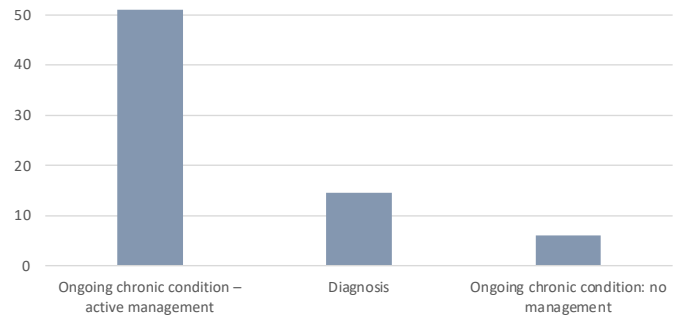


Table 1.5: Point that patient joined service

Figure 1.5: Point that patient joined service (% of all people accessing Patient Pathways)

Point in patient pathways that patient joined service	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Diagnosis	85	6.83	254	23.28	339	14.51
Pre-treatment	30	2.41	5	0.46	35	1.50
Maintenance post primary treatment	32	2.57	23	2.11	55	2.35
Ongoing chronic condition – active	625	50.20	565	51.79	1190	50.94
Ongoing chronic condition: no	83	6.67	58	5.32	141	6.04
Recurrence - with treatment	8	0.64	0	0.00	8	0.34
Recurrence - no treatment	8	0.64	2	0.18	10	0.43
Palliative	22	1.77	2	0.18	24	1.03
Other	19	1.53	11	1.01	30	1.28
Point in pathway not assessed	333	26.75	171	15.67	504	21.58

Diagnosis

There were a total of 2,336 people accessing the Patient Pathways telehealth service across 10 broad disease areas. The most patients accessing the service had myalgic encephalomyelitis (n=766, 32.79%) followed by Complex, rare and genetic conditions (n=374, 16.015) and this includes rare oncology.

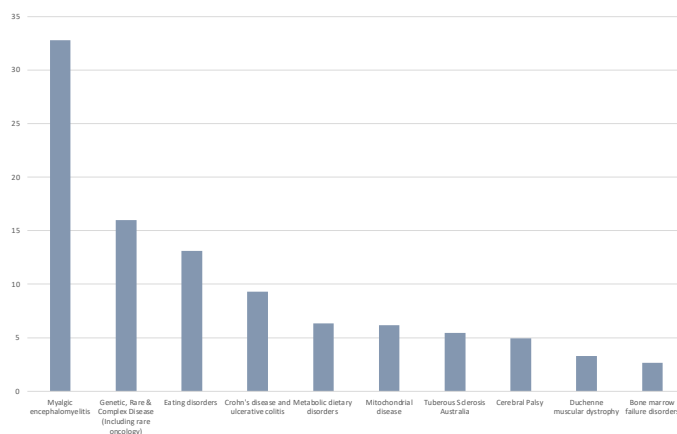


Table 1.6: Diagnosis

Figure 1.6: Diagnosis
(% of all people accessing Patient Pathways)

Diagnosis	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Bone marrow failure disorders	49	3.94	13	1.19	62	2.65
Cerebral Palsy	66	5.30	49	4.49	115	4.92
Crohn's disease and ulcerative colitis	128	10.28	89	8.16	217	9.29
Duchenne muscular dystrophy	60	4.82	17	1.56	77	3.30
Eating disorders	225	18.07	81	7.42	306	13.10
Genetic, Rare & Complex Disease	180	14.46	194	17.78	374	16.01
Metabolic dietary disorders	92	7.39	56	5.13	148	6.34
Mitochondrial disease	90	7.23	54	4.95	144	6.16
Myalgic encephalomyelitis	261	20.96	505	46.29	766	32.79
Tuberous Sclerosis Australia	94	7.55	33	3.02	127	5.44

Ethnicity

The majority of people accessing the Patient Pathways telehealth service were caucasian (n=2068, 88.53%). There were 98 (4.20%) people that did not wish to disclose their ethnicity.

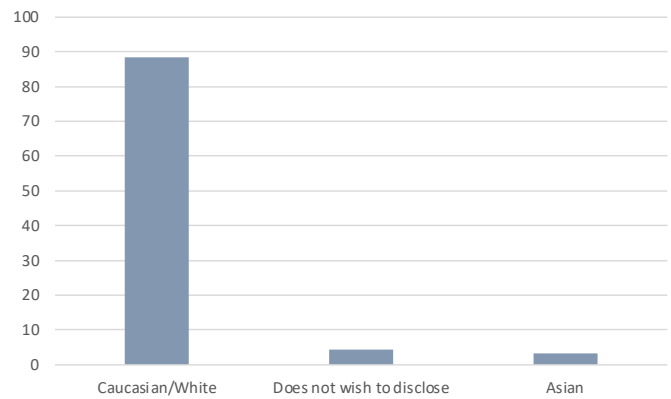


Table 1.7: Ethnicity

Figure 1.7: Ethnicity
(% of all people accessing Patient Pathways)

Ethnicity	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Caucasian/White	1121	58.15	947	86.80	2068	88.53
Does not wish to disclose	34	2.73	64	5.87	98	4.20
Asian	38	3.05	39	3.57	77	3.30
Other	16	1.29	16	1.47	32	1.37
ATSI	14	1.12	8	0.73	22	0.94
Pacific Islander	6	0.48	7	0.64	13	0.56
African	7	0.56	4	0.37	11	0.47
Arab	4	0.32	4	0.37	8	0.34
Hispanic/Latino	5	0.40	2	0.18	7	0.30

Other languages spoken

The majority of people accessing the Patient Pathways telehealth nurse service did not speak another language (n=2252, 96.40%). Mandarin was the most common second language spoken (n=15, 0.96%).

Table 1.8: Other languages spoken

Other languages spoken	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
African dialect	2	0.16	1	0.09	3	0.13
Arabic	6	0.48	0	0.00	6	0.26
Cantonese	2	0.16	1	0.09	3	0.13
Filipino	2	0.16	0	0.00	2	0.09
French	2	0.16	1	0.09	3	0.13
German	3	0.24	2	0.18	5	0.21
Greek	5	0.40	2	0.18	7	0.30
Hebrew	2	0.16	0	0.00	2	0.09
Hindi	2	0.16	1	0.09	3	0.13
Italian	4	0.32	3	0.27	7	0.30
Mandarin	12	0.96	3	0.27	15	0.64
Punjabi	3	0.24	0	0.00	3	0.13
Russian	1	0.08	0	0.00	1	0.04
Serbian	2	0.16	0	0.00	2	0.09
Spanish	1	0.08	2	0.18	3	0.13
Non-verbal/Auslan	6	0.48	0	0.00	6	0.26
No other languages	1190	95.58	1062	97.34	2252	96.40
Other languages spoken			13	1.19	13	0.56

State

The majority of people accessing the Patient Pathways telehealth service were from Victoria (n=962, 41.18%). This is in part due to a number of Victorian-based organisations. There were 457 (19.56%) people from New South Wales, 348 (14.90%) from Queensland and 145 (6.21%) from Western Australia.

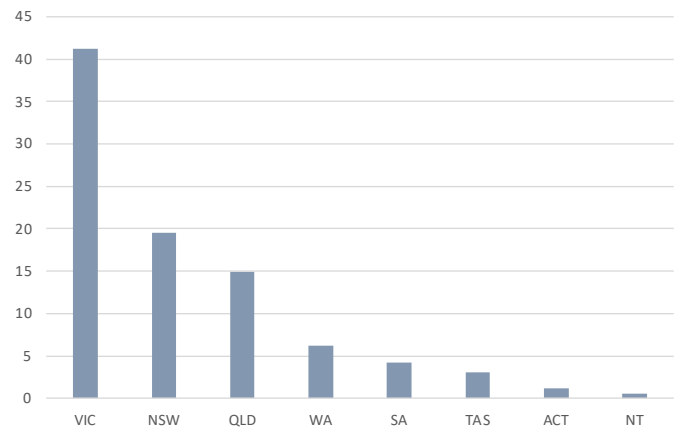


Table 1.9: State

Figure 1.9: State
(% of all people accessing Patient Pathways)

State	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
VIC	548	44.02	414	37.95	962	41.18
NSW	232	18.63	225	20.62	457	19.56
QLD	151	12.13	197	18.06	348	14.90
State not identified	138	11.08	77	7.06	215	9.20
WA	84	6.75	61	5.59	145	6.21
SA	44	3.53	55	5.04	99	4.24
TAS	34	2.73	37	3.39	71	3.04
ACT	13	1.04	14	1.28	27	1.16
NT	1	0.08	11	1.01	12	0.51

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=1272, 54.45%), with 503 (21.53%) coming from regional Australia.

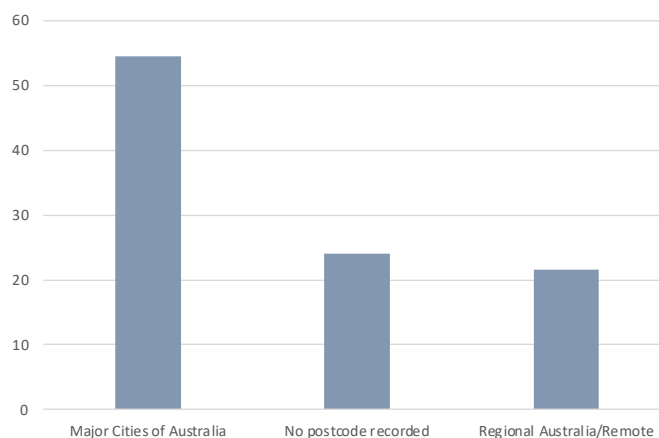


Table 1.10: Region

Figure 1.10: Region
(% of all people accessing Patient Pathways)

Region	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Major Cities of Australia	631	50.68	641	58.75	1272	54.45
No postcode recorded	371	29.80	190	17.42	561	24.02
Regional Australia/Remote	243	19.52	260	23.83	503	21.53

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 831 (35.57%) people coming from low to medium socioeconomic areas and 944 (40.41%) people coming from higher socioeconomic areas.²

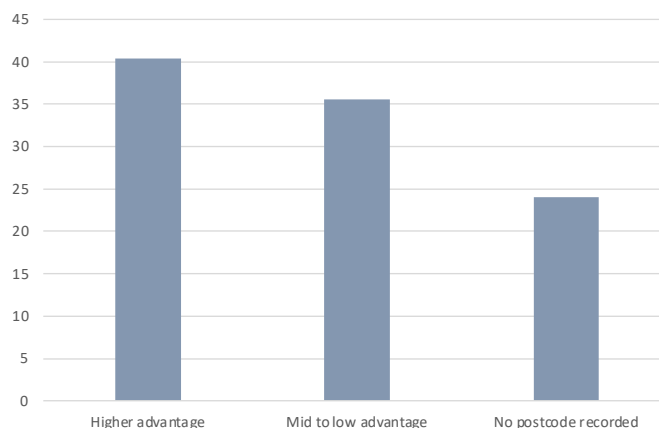


Table 1.11: Socioeconomic status

Figure 1.11: Socioeconomic status
(% of all people accessing Patient Pathways)

Socioeconomic status	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Higher advantage	457	36.71	487	44.64	944	40.41
Mid to low advantage	417	33.49	414	37.95	831	35.57
No postcode recorded	371	29.80	190	17.42	561	24.02

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

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

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. There were 572 (24.49%) people who were able to access care within 30 minutes. There were 457 (19.56%) people needing to travel up to 60 minutes and 135 (5.78%) needing to travel more than 90 minutes or more.

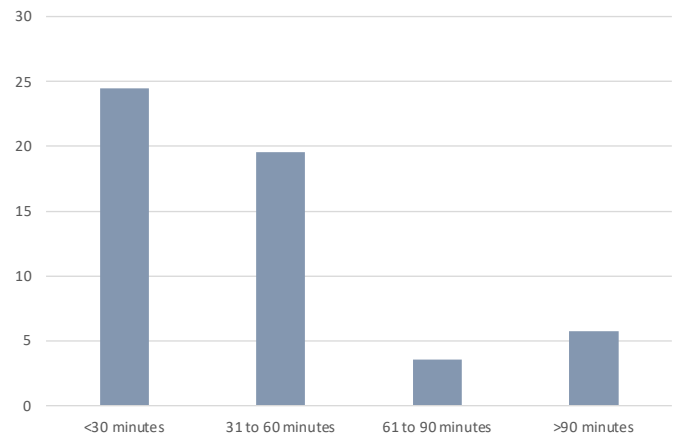


Table 1.12: Access to healthcare

Figure 1.12: Access to healthcare
(% of all people accessing Patient Pathways)

Access to treatment (Time to travel)	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
<30 minutes	283	22.73	289	26.49	572	24.49
31 to 60 minutes	261	20.96	196	17.97	457	19.56
61 to 90 minutes	51	4.10	32	2.93	83	3.55
>90 minutes	80	6.43	55	5.04	135	5.78
N/A (No treatment)	155	12.45	291	26.67	446	19.09
Access to treatment not assessed	415	33.33	228	20.90	643	27.53

Part 2: Consultation information

Referred from

Partner organisations employ a range of strategies to reach out to their communities and promote the Patient Pathways telehealth service. The majority of patients found the service through their local patient organisation website (n=1024, 43.84%). This was followed by a referrals from internal programs or support groups (n=509, 21.79%) and health professional referrals (n=273, 11.69%).

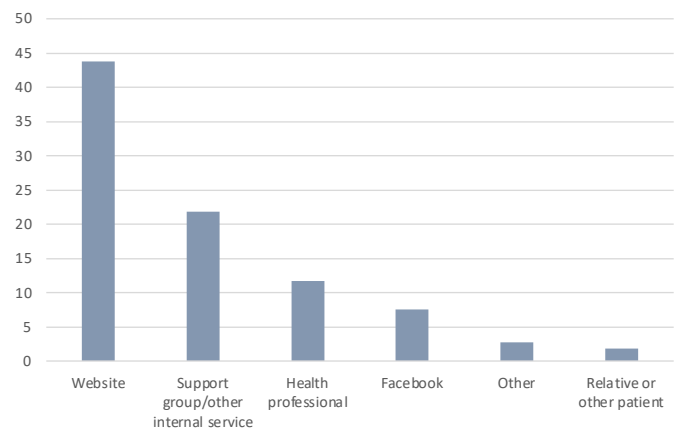


Table 2.1: Referred from

Figure 2.1: Referred from
(% of all people accessing Patient Pathways)

Referral source	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Website	512	41.12	512	46.93	1024	43.84
Support group/other internal service	233	18.71	276	25.30	509	21.79
Health professional	149	11.97	124	11.37	273	11.69
Facebook	122	9.80	56	5.13	178	7.62
Other	14	1.12	51	4.67	65	2.78
Relative or other patient	7	0.56	35	3.21	42	1.80
Referral source not identified	208	16.71	37	3.39	245	10.49

Initial consultations timing by quarter

The Patient Pathways telehealth service commenced in August 2019 following the program announcement in January 2019, a formal grant round to award funding and selection of partner organisation in April 2019. This was followed by a period of recruitment to select the nurses that would work on the program.

As a new program and new service, it was anticipated that it would take time to reach a steady intake of patients. Over the quarters, it is clear that the number of patients accessing the service is increasing over time, with a constant flow of patients across each quarter in 2021.

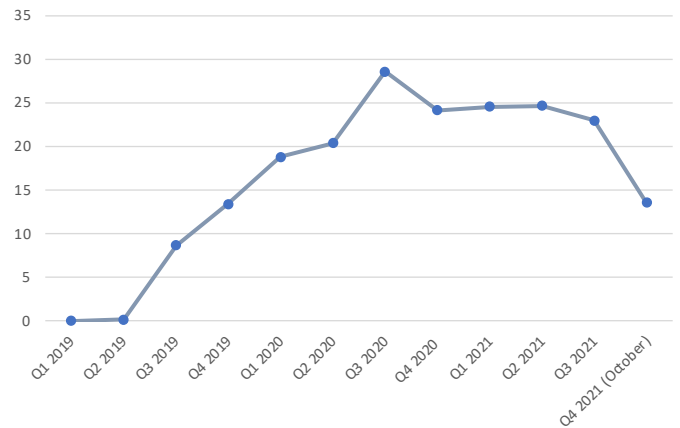


Table 2.2: Initial consultations timing by quarter

Figure 2.2: Initial consultations timing by quarter (% of all people accessing Patient Pathways)

Timing by quarter	2020		2021	
	n=1245	Percent	n=1091	Percent
Q1 2019	0	N/A	Q4 2020 (November and December)	155
Q2 2019	2	N/A	Q1 2021	268
Q3 2019	108	8.67	Q2 2021	269
Q4 2019	167	13.41	Q3 2021	251
Q1 2020	234	18.80	Q4 2021 (October)	148
Q2 2020	254	20.40		
Q3 2020	356	28.59		
Q4 2020 (October only)	124	9.96		

Duration of initial consultation

The Patient Pathways telehealth services delivers 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. In general, the more thorough the initial consultation is, the less subsequent follow-up is needed.

The majority of initial consultation took less than 30 minutes (n=589, 25.21%). There were 385 consults (16.48%) that took 60 minutes, 347 (14.85%) that took 30 minutes and 340 (14.55%) taking 90 minutes or more. Initial follow-up at the point of consultation most commonly took 60 minutes (25.90%) or under 30 minutes (n=584, 25.00%).

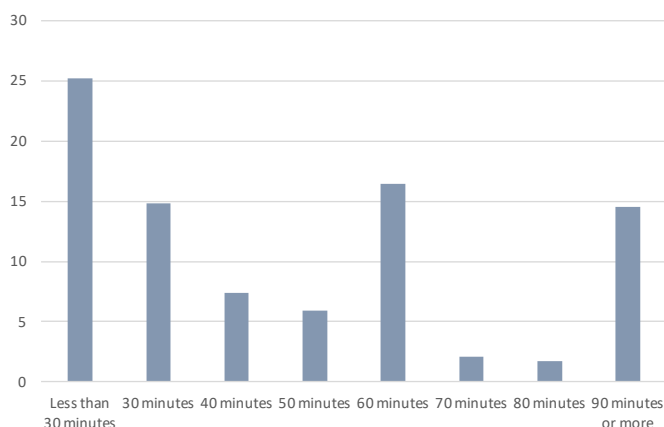


Table 2.3: Duration of initial consultation

Figure 2.3: Duration of initial consultation (% of all people accessing Patient Pathways)

Length of time per initial consultation	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Less than 30 minutes	157	12.61	432	39.60	589	25.21
30 minutes	142	11.41	205	18.79	347	14.85
40 minutes	62	4.98	110	10.08	172	7.36
50 minutes	120	9.64	19	1.74	139	5.95
60 minutes	285	22.89	100	9.17	385	16.48
70 minutes	31	2.49	18	1.65	49	2.10
80 minutes	29	2.33	11	1.01	40	1.71
90 minutes or more	209	16.79	131	12.01	340	14.55
Length of consultation not recorded	210	16.87	65	5.96	275	11.77

Follow up at initial consultation duration

In addition to the initial consultation and follow-up, there is sometimes a need for subsequent follow-up. Across all patients, the average time per patient in initial and subsequent calls and follow-up was 1.61 hours. 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.

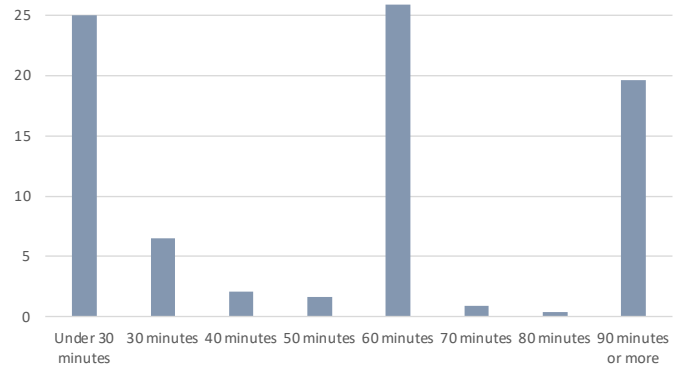


Table 2.4: Follow up for initial consultation duration

Figure 2.5: Follow up for initial consultation duration (% of all people accessing Patient Pathways)

Length of follow up	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Under 30 minutes	94	7.55	490	44.91	584	25.00
30 minutes	112	9.00	40	3.67	152	6.51
40 minutes	35	2.81	14	1.28	49	2.10
50 minutes	31	2.49	8	0.73	39	1.67
60 minutes	326	26.18	279	25.57	605	25.90
70 minutes	15	1.20	7	0.64	22	0.94
80 minutes	5	0.40	4	0.37	9	0.39
90 minutes or more	315	25.30	144	13.20	459	19.65
No time recorded	312	25.06	105	9.62	417	17.85

Part 3: Nurse-led interventions and activities

GP status

Understanding whether the patient has a regular general practitioner is an important assessment. It allows the 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=1680, 71.92%) with 95 (4.07%) that did not and 82 (3.51%) that indicated that they would like a referral.

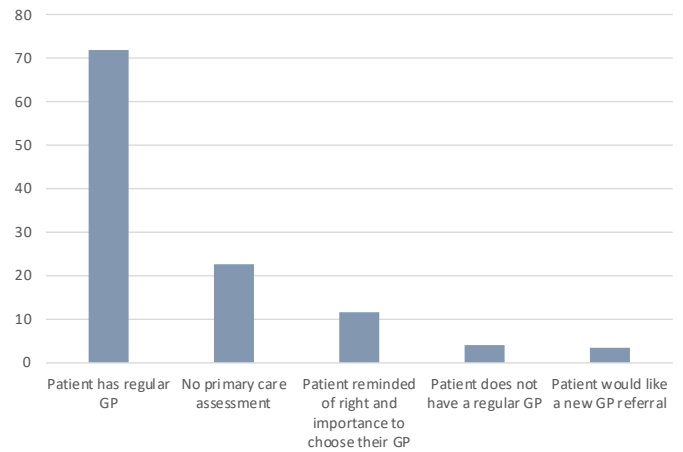


Table 3.1: GP status

Figure 3.1: GP status
(of all people accessing Patient Pathways)

GP status	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Patient does not have a regular GP	65	5.22	30	2.75	95	4.07
Patient has regular GP	780	62.65	900	82.49	1680	71.92
Patient would like a new GP referral	44	3.53	38	3.48	82	3.51
Patient reminded of right and importance to choose their GP	34	2.73	236	21.63	270	11.56
No primary care assessment	376	30.20	153	14.02	529	22.65

*More than one option possible per patient

Number of concerns/questions at consultation

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.

In the first review of the program, there was an average of 3.01 concerns or questions per patient. In this review, the average number of concerns per patient was 4.75. The total average of concerns at consultation per patient across the program is 3.88.

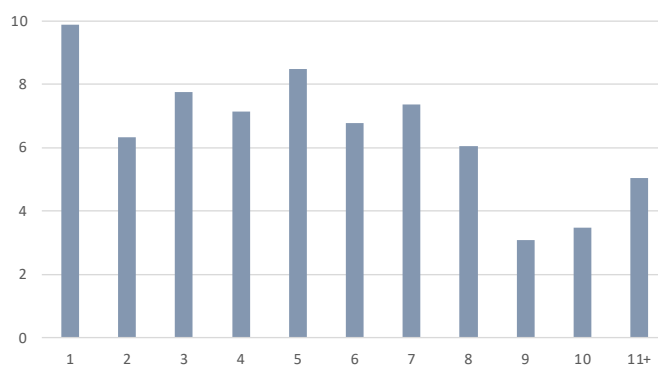


Table 3.2: Number of concerns/questions at consultation

Figure 3.2: No. of concerns/questions at consultation (% of all people accessing Patient Pathways)

Symptoms concerns at consultation	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
1	107	8.59	124	11.37	231	9.89
2	83	6.67	65	5.96	148	6.34
3	98	7.87	83	7.61	181	7.75
4	93	7.47	74	6.78	167	7.15
5	97	7.79	101	9.26	198	8.48
6	68	5.46	90	8.25	158	6.76
7	74	5.94	98	8.98	172	7.36
8	47	3.78	94	8.62	141	6.04
9	27	2.17	45	4.12	72	3.08
10	37	2.97	44	4.03	81	3.47
11+	46	3.69	72	6.60	118	5.05
General enquiry	468	37.59	201	18.42	669	28.64

Number of symptom concerns in the future

In the first review of the program, there was an average of 3.23 future concerns per patient. In this review, the average number of future concerns per patient is 3.65. The average of future concerns per patient across the program is 3.44.

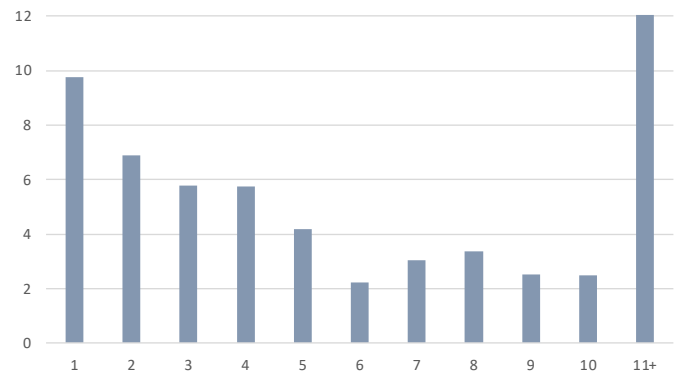


Table 3.4: Number of symptom concerns in the future

Figure 3.4: Number of symptom concerns in the future (% of all people accessing Patient Pathways)

Symptom concerns in the future	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
1	96	7.71	132	12.10	228	9.76
2	89	7.15	72	6.60	161	6.89
3	86	6.91	49	4.49	135	5.78
4	110	8.84	24	2.20	134	5.74
5	67	5.38	31	2.84	98	4.20
6	39	3.13	13	1.19	52	2.23
7	28	2.25	43	3.94	71	3.04
8	32	2.57	47	4.31	79	3.38
9	28	2.25	31	2.84	59	2.53
10	38	3.05	20	1.83	58	2.48
11+	127	10.20	154	14.12	281	12.03
No future questions/concerns recorded	505	40.56	475	43.54	980	41.95

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 Patient Pathways telehealth service.

In the 2020 review, there were 467 (37.51%) patients that had not had any conversation about clinical trials before entering Patient Pathways. Only 32 (2.57%) had participated in a clinical trial. In the 2021 review there were 547 (50.14%) patients that had not had any conversation about clinical trials before entering Patient Pathways

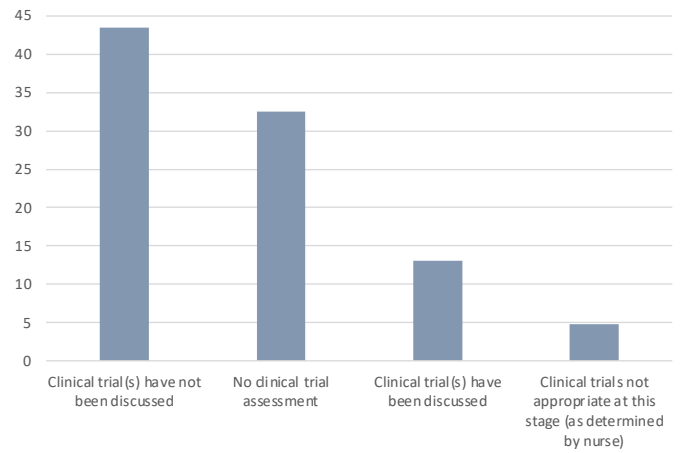


Table 3.6: Clinical trial status

Figure 3.6: Clinical trial status

(% of all people accessing Patient Pathways)

Clinical trials	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Patient has participated in a clinical trial	32	2.57	14	1.28	46	1.97
Clinical trial(s) have been discussed	171	13.73	133	12.19	304	13.01
Clinical trial(s) have not been discussed	467	37.51	547	50.14	1014	43.41
Clinical trials not appropriate at this stage (as determined by nurse)	46	3.69	65	5.96	111	4.75
No clinical trial assessment	406	32.61	354	32.45	760	32.53

**More than one option possible per patient*

Information requested

Patient Pathways 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 in the 2020 evaluation was in relation to treatment information (n=413, 33.17%), followed by disease management (406, 32.61%) and psychological/social support (n=292, 23.45%). The most common information requested in the 2021 evaluation followed the same pattern and overall, the most requested information related to treatment information (n=1260, 53.94%), followed by disease management (694, 29.71%) and psychological/social support (n=547, 23.42%).

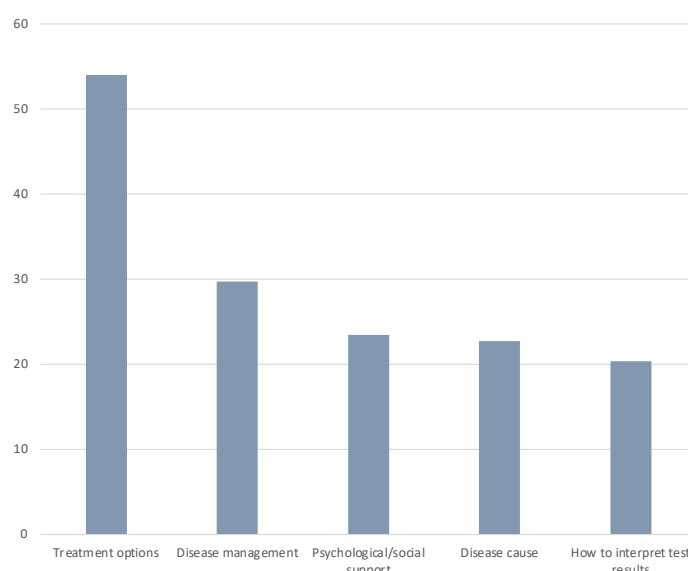


Table 3.7: Information requested

Figure 3.7: Information requested (% of all people accessing Patient Pathways)

Information gaps	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Clinical trials	137	11.00	236	21.63	373	15.97
Complementary therapies	99	7.95	19	1.74	118	5.05
Dietary information	258	20.72	132	12.10	390	16.70
Disease cause	259	20.80	271	24.84	530	22.69
Disease management	406	32.61	288	26.40	694	29.71
Hereditary considerations	145	11.65	228	20.90	373	15.97
How to interpret test results	196	15.74	280	25.66	476	20.38
My Health Record Accessed	24	1.93	79	7.24	103	4.41
Physical activity	198	15.90	124	11.37	322	13.78
Psychological/social support	292	23.45	255	23.37	547	23.42
Treatment options	413	33.17	847	77.64	1260	53.94

*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 528 (22.60%) that had no pain needing to be managed. There were also 243 (10.02%) that did not have their pain under control and 242 (10.36%) patients needing a pain management plan or revision.

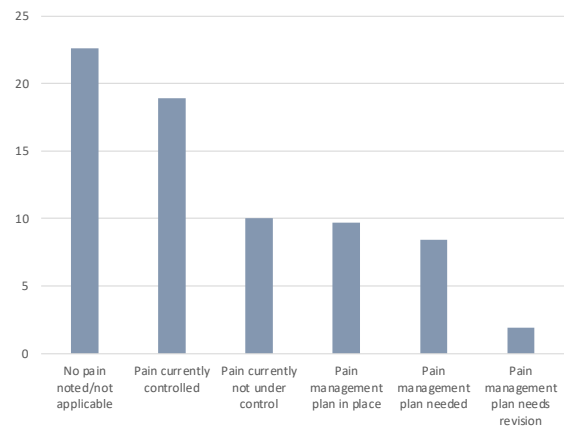


Table 3.8: Pain management plan

Figure 3.8: Pain management plan (% of all people accessing Patient Pathways)

Pain management plan	2020		2021		Total program	
	n=1245	Percent	n=1091	Percent	n=2336	Percent
Pain currently controlled	195	15.66	247	22.64	442	18.92
Pain currently not under control	91	7.31	143	13.11	234	10.02
No pain noted/not applicable	332	26.67	196	17.97	528	22.60
Pain management plan needs revision	37	2.97	8	0.73	45	1.93
Pain management plan needed	72	5.78	125	11.46	197	8.43
Pain management plan in place	128	10.28	98	8.98	226	9.67
No pain assessment recorded	473	37.99	412	37.76	885	37.89

*More than one option possible per patient

Number of opportunities, services, referrals and interventions

Patient Pathways telehealth nurses conduct a range of nurse-led interventions and referrals. Overall there were 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.

Table 3.8: Opportunities, services, referrals and interventions

Number of services, opportunities and referrals	2020	2021	Total
	n=1245	n=1091	n=2336
Allied health and supportive care referrals	1271	1541	2812
Primary care assessments	773	938	1711
Pain assessments	771	679	1450
Palliative care assessment	774	205	979
Clinical trial assessment	840	737	1577
Information provision, discussions and interventions	2392	4313	6705
Symptom management assessments	873	838	1711
MDT assessment	704	572	1276
Home status assessment	849	797	1646
Total	9247	10620	19867
Average interventions per patient	7.43	9.73	8.50

**More than one option possible per patient*