



CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Patient Pathways Telehealth Nurse Service

ALL PARTNER ORGANISATIONS

Evaluation 2020



Patient Pathways Telehealth Nurse Service

An initiative funded by the Federal Department of Health



NURSES 
A VOICE TO LEAD
NURSING THE WORLD
TO HEALTH





Patient Pathways Telehealth Nurse Service

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“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”

*The Hon Greg Hunt MP,
Minister For Health, Member for Flinders
12 January 2019, Media Release*

Lifeline for people with rare diseases in health system maze

By [Kate Aubusson](#)

January 12, 2019 – 12.00am



A new trial aims to help people with rare and debilitating diseases access support, treatments and clinical trials amid a malaise of confusion, red-tape and dead ends.



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“A lot of my clients are housebound, or bedbound, so I think that they feel like this service is something that's really important to their community. My focus is how we educate patients and doctors to work well together and I do that by developing care plans that people can really use to take to their doctor and to help their doctors work out what care they need. I've had a lot of positive feedback from designing and making care plans better”

Laura, Emerge Australia

“A few with children have actually written feedback, which is amazing because I know how busy these families with complex children and siblings' lives are. I think if they've taken the time that it just speaks volumes”

Kelly, Cerebral Palsy Support Network

“I'm getting great feedback from the patients saying, 'It's wonderful. I'm so glad that we've got a nurse that we can contact and ask questions, and she gets in touch with us and checks in with us’

Shannon, Pancare

“I think I'm mostly useful for those who have a new diagnosis. The feedback that I've got has been really great that I've been able to give them information and then point them in the right direction within the health system and also funnel them in to that kind of peer support, which I think is so important”

Kim, Tuberous Sclerosis Australia

“I've had really positive. They couldn't thank me enough for everything I had done”

Michele, Save Our Sons

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 2020

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)

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 following an announcement by the Hon Greg Hunt MP, Minister for Health in 2019.

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 Catherine Holliday cmholliday@cc-dr.org

Table A: Areas of evaluation

Evaluation area	Field(s) of evaluation	Description
Demographics [Gender]	Gender	For the health service, this is important information to establish whether there are any gender identify preferences the patient may have and also standard data collection in a clinical setting. For the evaluation, it is important information to understand whether more men or women are accessing the service.
Demographics [Age]	Date of Birth	For evaluation, this is important to understand the age groups most commonly accessing the health service.
Demographics [Ethnicity]	Ethnicity + Ethnicity other	For the health service, this is important to understand if there are any cultural sensitivities that the nurse needs to be aware of. For evaluation, this is important to understand whether people from different backgrounds are accessing the health service.
Demographics [Other language]	Other language	For the health service, this is important to understand if translation services are needed for the patient. For evaluation, this is important to understand if people from different backgrounds are accessing the health service. (There is an assumption that if this field is left blank, there are no other languages spoken)
Demographics [Location]	Postcode + Patient City	For the health service, this is important to understand whether the person lives in a rural, regional or metropolitan area and whether they are able to access appropriate care. For the evaluation, we can identify regional/rural/metropolitan location and calculate socioeconomic status from the postcode. Both are important information about who is accessing the health service. Please enter the postcode as a first preference, but if you cannot for some reason find this or ask the patient, please enter the city/town that they live in.
Demographics [Accessibility]	Accessibility of treatment location	For the health service, this is important information to understand whether travel to treatment/care is an issue and whether support is needed for the patient/family. There is an option “Not applicable. No regular treatment” for those where this is the case. For the evaluation, it is important information to understand if people that need to travel longer distances to treatment/care are accessing the health service more or less.
Demographics [Home status]	Home status	For the health service, this is important information to understand whether people are living on their own or have family support within their household. For evaluation, it is important information to understand whether people living on their own or with family are more or less likely to access the health service.

Evaluation area	Field(s) of evaluation	Description
Relationship with GP and primary care	General Practitioner Status	<p>For the health service, this is important information to establish whether the patient has a general practitioner that is addressing their health needs. It will be up to each organisation as to how they manage this information in terms of care planning, that is, some will be happy to suggest general practitioners to go to, others will want to only help the patient understand how important it is to have a general practitioner that they are comfortable with. For the evaluation, this is important information to understand whether patients using the health service are more or less likely to have a good relationship with their general practitioner. We can assess from the responses that a discussion has been had and that the general practitioner status has been addressed.</p> <p>In this field you can select as many options as are relevant including:</p> <ul style="list-style-type: none"> • Patient has regular GP • Patient does not have regular GP • Patient would like a new GP referral • 'Patient reminded of right and importance to choose their GP'
Point in patient pathways that patient joined service	Current Stage of Clinical Pathway	For the health service, this is important information to understand whether the patient has been recently diagnosed, has started treatment or is at the stage of chronic disease management. For the evaluation, this is important information to understand whether there are any trends in the stage of clinical pathways that patients are accessing the service.
Most common concerns and questions	Side Effects and Symptoms (at consultation)	For the health service, this is important information to understand the current side effects or symptoms that the patient is or has been managing. This will then lead into a discussion about what they are concerned about going forward (Most common symptoms - future concerns). For evaluation, this is important information to understand the most common concerns patients and nurses are dealing with. The assumption is that the 'Most common symptoms - future concerns' is what is discussed as part of the consultation or care plan going forward and considered to be an action taken by the nurse.
	Side Effects and Symptoms (Future concerns)	

Evaluation area	Field(s) of evaluation	Description
Clinical trials	Clinical trial status	For the health service, this is important information to understand whether clinical trials have been discussed and if it is something that the patient is interested in. Keep in mind, clinical trials may be in relation to supportive care or allied health interventions (such as exercise programs) and not only treatment-based. For the evaluation, this is important information to demonstrate that nurses are asking 100% of patients about clinical trials. Baseline data that we have collected separately suggests that around only 15 – 25% are asked about clinical trials in the clinic or hospital setting. This is an important gap that can be filled through the health service. Even if no trials are available, it is important to explain to a patient why this is.
Pain management status	Pain Management Status	For the health service, this is an important question to ask as pain of any type is often overlooked by clinicians. The patient should be asked if there is any pain they are having and if/how this is managed. For the evaluation, this is important information to demonstrate that nurses are filling this unmet need by asking all patients about their pain management.
Number of services in patient's existing care plan at time of consultation	Allied health accessed	For the health service, this field asks the nurse to talk to the patient about the allied health services that they have accessed to date. This is important information as it then allows the nurse to see the gaps in care and what referrals are needed, whether it is physiotherapy, counselling or so on. Please note that Peer Support groups will be added to this section. This is important information for organisations that run peer support group and recognises this kind of support as part of a care plan. The assumption is that the allied health referral are either discussed with the patient during the consultation and/or included in their care plan. For the evaluation, this shows us the number and types of referrals made by the nurse through the health service.
Number of referrals required	Allied health referrals Complementary therapy referrals	
Average length of time per initial consultation	Length of consultation	For the evaluation, this is important information to understand how long initial consultations are taking. If the initial consultation is short and a subsequent consultation is considered the primary consultation, this is the time that should be entered. If an initial or primary consultation is conducted over a number of calls, the length of time should be added together.
Average length of time per follow-up consultation	Length of Time Spent on Follow-up	For the evaluation, this is important information to understand how much time is spent on follow-up. If there are a number of follow-ups, the length of time should be added together as each call or activity is conducted.

Evaluation area	Field(s) of evaluation	Description
Has the patient been referred to palliative care	Palliative Care Status	For the health service, this is only needed where relevant. Where it is not relevant, simply enter N/A. For patients where palliative care is relevant, this is especially important to have a discussion about palliative care and ensure timely referrals are made. For the evaluation, it is important information to demonstrate that palliative care is being addressed through the health service.
Information requested	Information Accessed	For the health service, this field asks the nurse to talk to the patient about the information that they have accessed to date. This is important information as it then allows the nurse to see the gaps in information and what needs to be provided. The assumption is that the 'information provided by the nurse' are either discussed with the patient during the consultation, provided and/or included in their care plan. For the evaluation, this shows us the number and types of information provided by the nurse through the health service.
Number of cases	Case Record Type	For the evaluation, the number of cases is the number of individuals helped through the service. This is something that is automatically generated by counting the number of cases. It is important to remember that cost effectiveness calculations are done by volume of patient numbers.
Busy times throughout year for consultations	Date of consultation or Date/Time Opened	For the evaluation, this tells us whether there are any times of the year that are particularly busy or times of the day when consultations are preferred. This information is autogenerated.
Time of day consultations preferred	Date/Time Opened (Time of case record)	

Summary

Section 1	Summary
Consultation with patient or next of kin	There were 1,245 people that accessed the Patient Pathways telehealth service from August 2019 to the end of October 2020. The majority of people were patients (n=705, 56.63%) followed by next of kin/legal guardians (n=321, 25.78%)
Patient 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=428, 34/38%). There were 180 (14.46%) patients under 18 years of age, 128 (10.28%) patients aged 55 to 64 years of age and 91 (7.31%) patients aged 18 to 24 years of age.
Patient gender	The majority of people accessing the Patient Pathways telehealth service were female (n=799, 64.18%), with 343 (27.55%) men and a small number of people who were intersex, transgender or non-binary (n=8, 0.64%).
Home status	There were 336 (26.99%) people who lived in a family home without dependents, 333 (26.75%) that lived in a family home with children and 150 (12.05%) people that lived alone.
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=625, 50.20%). This was followed by people that were newly diagnosed (n=85, 6.83%).
Diagnosis	There were a total of 1245 people accessing the Patient Pathways telehealth service across 11 partner organisations.
Ethnicity	The majority of people accessing the Patient Pathways telehealth service were Caucasian (n=724, 58.15%). There were 34 (2.73%) people that did not wish to disclose their ethnicity.
Other languages spoken	The majority of people accessing the Patient Pathways telehealth nurse service did not speak another language (n=1190, 95.58%). Mandarin was the most common second language spoken (n=12, 0.96%).
State	The majority of people accessing the Patient Pathways telehealth service were from Victoria (n=548, 44.02%). This is in part due to a number of Victorian-based organisations. There were 232 (18.63%) people from New South Wales, 151 (12.13%) from Queensland and 84 (11.08%) from Western Australia.
Region	The majority of patients came from major cities (n=631, 50.68%), with 243 (19.52%) coming from regional Australia.
Socioeconomic status	There were 417 (33.49%) people coming from low to medium socioeconomic areas and 457 (36.71%) people coming from higher socioeconomic areas.

Section 1	Summary
Access to healthcare	The majority of people were able to access care within 30 minutes (n=283, 22.73%). There were 261 (20.96%) people needing to travel up to 60 minutes and 131 (10.52%) needing to travel up to 90 minutes or more.
Section 2	Summary
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=512, 41.12%). This was followed by a health professional referral (n=149, 11.97%) and Facebook (n=122, 9.80%).
Initial consultations timing by quarter	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 steady increase of 108 patients in the first quarter of service compared with 356 in the most recent quarter.
Initial consultations time of day	The majority of consultations were recorded in the middle of the day with 181 (14.54%) at 12.00pm, 149 (11.97%) at 1.00pm and 161 (12.93%) at 2.00pm.
Duration of initial consultation and follow-up	The majority of initial consultation took 60 minutes (n=285, 22.89%), followed by 90 minutes (n=209, 16.79%). This reflects the complex needs of the patients that access the service. Likewise, follow-up activities from the initial consultation most commonly took 60 minutes (n=326, 26.18%) or 90 minutes (25.30%). Across all patients, the average time per patient in initial and follow-up was 94.92 minutes.

Highlights

- 1245 patients have accessed the program within a 15 month period.
- There were 9247 referrals or interventions made by Patient Pathways telehealth nurses at an average of 7.43 per patient.
- On average, each patient in the Patient Pathways program received 7.43 assessments or interventions. Using MBS item 10997 (\$12.40) as a comparator, 7.43 assessments/interventions would bill to \$92.13. With an average cost per patient of \$65.84 in the Patient Pathways program, this is a cost saving per patient of \$26.29 and \$3.54 per assessments/intervention.
- Dr Catherine 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.
- The program was funded for 10 partner organisations to be involved. In 2020, the program increased from 11 partner organisations to 15

Section 3	Summary
GP status	The majority of patients had a regular general practitioner (n=780, 62.65%) with 65 (5.22%) that did not and 44 (3.53) that indicated that they would like a referral.
Number of concerns and questions	The majority of participants had three to five primary concerns at the time of the consultation (n=288, 23.13%), with an average of 3.01 concerns or questions per patient.
Most common concerns and questions	There was an average of 3.23 future concerns per patient, giving a total of 6.32 concerns or questions per patient. Across all concerns and questions now and in the future, the most common were related to fatigue, mental health and pain management.
Clinical trial status	There were 467 (37.51%) of patients that had not had any conversation about clinical trials before entering Patient Pathways. Only 32 (2.57%) had participated in a clinical trial.
Information requested	The most common information requested 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%).
Pain management plan	While pain was a concern for many patients, there were 332 (26.67%) that had no pain needing to be managed. There were also 91 (7.31%) that did not have their pain under control and 109 (87.6%) patients needing a pain management plan or revision.
Palliative care referral	There was a total of 804 (64.58%) palliative care assessments made. An assessment of 'Not applicable' was made for 741 (59.52%) people. There were 28 (2.25%) people needing a referral and 35 (2.81%) already referred to palliative care.
Number of services in patient's existing care plan	The majority of patients had one, two or three services within their care team at the time of consultation (39.76%).
Services in patient's existing care plan	The most common services accessed were dieticians (n=262, 21.04%), physiotherapists (n=229, 18.39%), specialist nurse/care coordinator (n=158, 12.69%) and occupational therapists (n=149, 11.97%).
Number of referrals/interventions required	Patient Pathways telehealth nurses conduct a range of nurse-led interventions and referrals. Overall, there were 9247 referrals or interventions made at an average of 7.43 per patient.
Referrals to specialists and allied health	The most common referrals to specialists and allied health were for counselling (n=246, 19.76%), followed by nutritionist/dietician (n=205, 16.47%) and nurse specialist/nurse coordinators (n=120, 9.64%).
Nurse-led interventions (Referral to complementary support)	The most common complementary support referrals were for peer support (n=194, 15.58%) including support groups and other patient organisation peer support initiatives.

Section 3	Summary
Nurse-led interventions (Discussion, information and education)	There were 840 (67.47%) clinical trials interventions including providing information, assessing clinical trial status and having discussions about clinical trials. There were 413 (33.17%) discussions and/or information provision about standard, current treatments, 279 (22.41%) about dietary habits, 263 (21.12%) about disease cause, and 278 (22.33%) about mental health.
Nurse-led interventions (Assessments)	There were 873 (70.12%) patients who were able to access symptom management through the program, 849 (68.19%) that received a home status assessment, 774 (62.17%) that received a palliative care assessment, 773 (62.09%) that received a primary care assessment and 771 (61.93%) that received a pain management assessment.
Section 4	Summary
Cost per patient	Each nurse is directly employed by the respective partner organisation and receives a salary determined by their employer, guided by state-based nurse awards. The average hourly rate for nurses in the Patient Pathways telehealth service was \$41.67 and this is comparable with a practice nurse. With an average time per patient of 1.58 hours, this results in an average cost per patient of \$65.84.
Cost comparison	On average, each patient in the Patient Pathways program received 7.43 assessments or interventions. Using the MBS item 10997 amount of \$12.40, 7.43 assessments/interventions would bill to \$92.13. With an average cost per patient of \$65.84 in the Patient Pathways program, this is a cost saving per patient of \$26.29 and \$3.54 per assessments/intervention.
Full time equivalent (FTE)	Each organisation employs a part-time nurse ranging from 0.2FTE to 0.6FTE and all of the organisations have contributed data to this evaluation. Collectively, this equates to 4.46 FTE nurses working on the program.
Time spent as an FTE	The time taken on subsequent follow-up has been collected by nurses and across all organisations calculates collectively to 1.34 FTE per week. This combined with 1.0FTE of time spent on the initial patient call calculates to 2.34 FTE (52.36%) on activities classified as direct patient support. The remaining time 2.13 FTE (47.64%) is attributed to Organisational duties and external engagement. The current ratio of direct patient support to organisational responsibilities is 52:48. As programs establish, we would recommend this ratio shift over a three-year period to 70:30.
Maximum capacity at current funding levels	Using the current total investment of \$350,000 per annum and an average cost of \$65.84 per patient, the maximum capacity across a minimum of ten patient organisations would be 10.22 patients per week per service. This however does not allow time for organisational responsibilities.
Funding model	A funding formular has been developed based on volume of patients per service. It is recommended that this level of funding be used in future iterations of the Patient Pathways program, plus 30% to account for organisational activities and 30% oncosts.



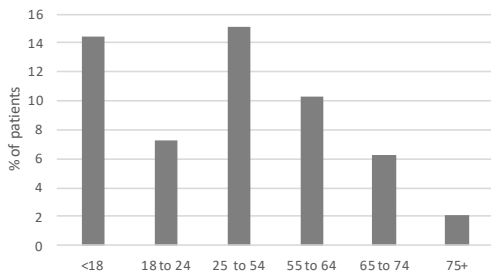
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Patient Pathways Telehealth Nurse Service

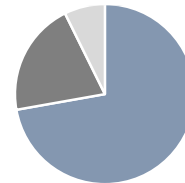
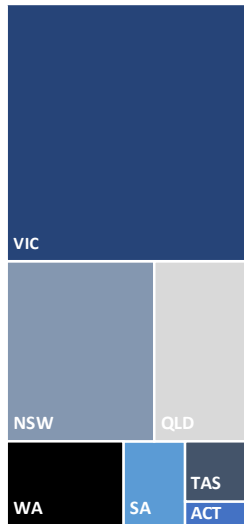
An initiative funded by the Federal Department of Health



Gender

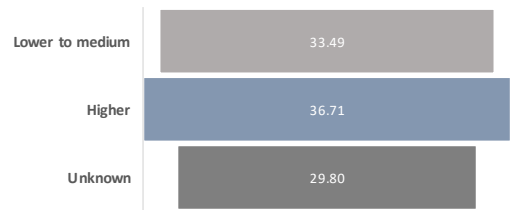


Age

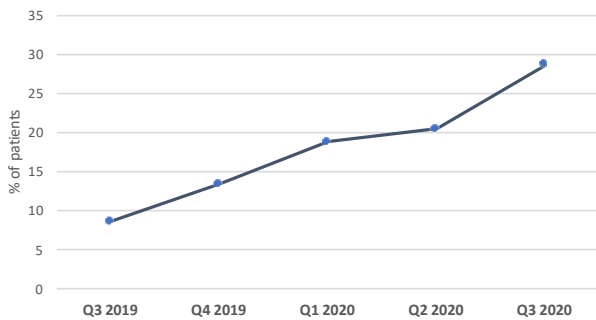


- Major Cities of Australia
- Inner Regional Australia
- Outer Regional Australia/Remote

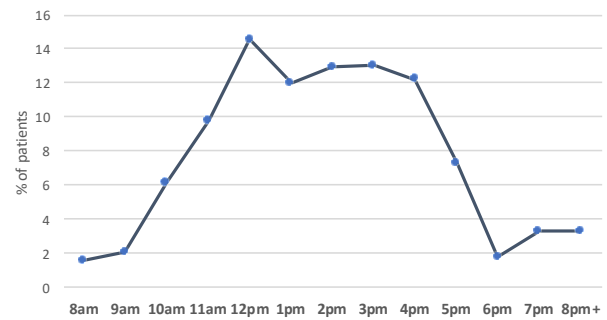
Location



Socioeconomic status



Access to Patient Pathway services over time



Time of day patients access Patient Pathway services

7867

Number of concerns across all patients

1245

Number of patients accessing Patient Pathways

95

Average minutes per patient

6.32

Average number of concerns per patient

9247

Total number of nurse-led interventions and referrals

7.43

Interventions per patient



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1. Treatment options
2. Disease management
3. Psychological/social support

Most common requests for information

Ongoing chronic disease management

Most common point of clinical pathway when entering Patient Pathways service

873

Number of symptom management assessments

840

Number of clinical trial status assessments

771

Number of pain management assessments

704

Number of multidisciplinary team assessments

773

Number of primary care assessments

849

Number of home status support assessments

774

Number of palliative care assessments

Partner Organisations



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Part 1: Demographics

Consultation with

There were 1,245 people that accessed the Patient Pathways telehealth service from August 2019 to the end of October 2020. The majority of people were patients (n=705, 56.63%) followed by next of kin/legal guardians (n=321, 25.78%).

Table 1: Consultation with

Consultation with	n=1245	Percent
Patient	705	56.63
Next of Kin/Legal Guardian	321	25.78
Clinician	38	3.05
Both Patient and Next of Kin	61	4.90
Consultation with not identified	120	9.64

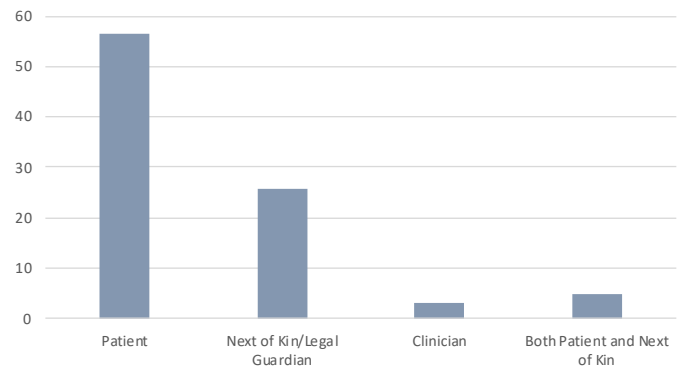


Figure 1.1: Consultation with
(% of all people accessing Patient Pathways)

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=428, 34.38%). There were 180 (14.46%) patients under 18 years of age, 128 (10.28%) patients aged 55 to 64 years of age and 91 (7.31%) patients aged 18 to 24 years of age.

Table 1.2: Age

Age	n=1245	Percent
<18	180	14.46
18 to 24	91	7.31
25 to 54	428	34.38
55 to 64	128	10.28
65 to 74	78	6.27
75+	26	2.09
Age not identified	314	25.22

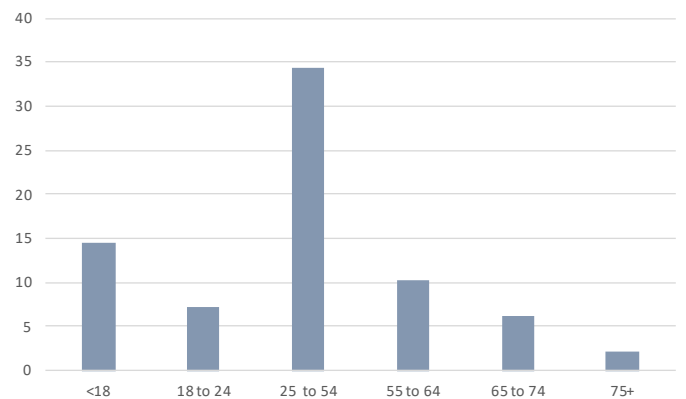


Figure 1.2: Age
(% of all people accessing Patient Pathways)

Gender

The majority of people accessing the Patient Pathways telehealth service were female (n=799, 64.18%), with 343 (27.55%) men and a small number of people who were intersex, transgender or non-binary (n=8, 0.64%).

Table 1.3: Gender

Gender	n=1245	Percent
Female	799	64.18
Male	343	27.55
Non-binary	5	0.40
Inter-sex	1	0.08
Transgender	2	0.16
Gender not identified	95	7.63

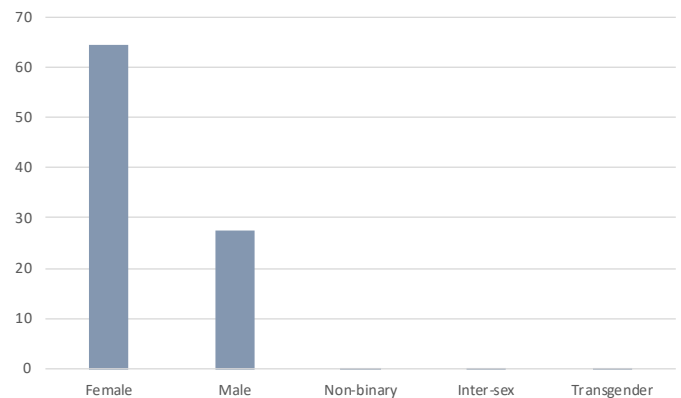


Figure 1.3: Gender
(% of all people accessing Patient Pathways)

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 336 (26.99%) people who lived in a family home without dependents, 333 (26.75%) that lived in a family home with children and 150 (12.05%) people that lived alone.

Table 1.4: Home status

Home status	n=1245	Percent
Lives alone	150	12.05
Lives with family (including dependants who are children and elderly)	12	0.96
Lives with family (including dependants who are children)	333	26.75
Lives with family (including dependants who are elderly)	18	1.45
Lives with family (no dependants at home)	336	26.99
Other	102	8.19
Home status not assessed	294	23.61

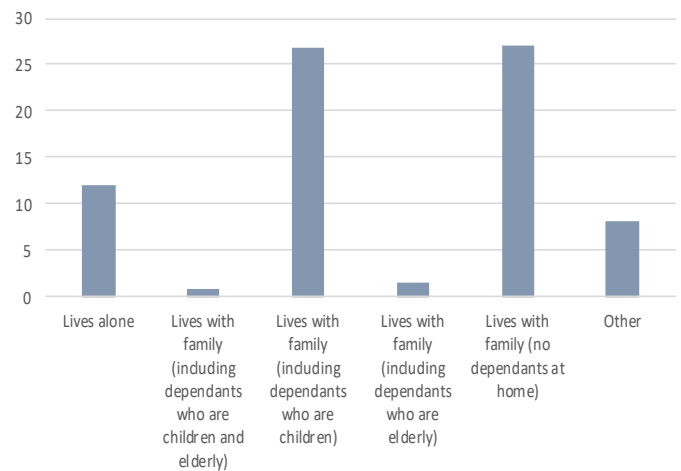


Figure 1.4: Home status
(% of all people accessing Patient Pathways)

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=625, 50.20%). This was followed by people that were newly diagnosed (n=85, 6.83%).

Table 1.5: Point that patient joined service

Point in patient pathways that patient joined service	n=1245	Percent
Diagnosis	85	6.83
Pre-treatment	30	2.41
Maintenance post primary treatment	32	2.57
Ongoing chronic condition – active management	625	50.20
Ongoing chronic condition: no management	83	6.67
Recurrence - with treatment	8	0.64
Recurrence - no treatment	8	0.64
Palliative	22	1.77
Other	19	1.53
Point in pathway not assessed	333	26.75

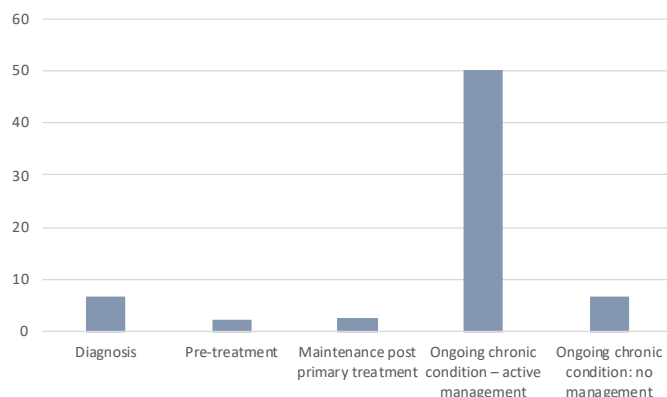


Figure 1.5: Point that patient joined service (% of all people accessing Patient Pathways)

Diagnosis

There were a total of 1245 people accessing the Patient Pathways telehealth service across 15 partner organisations. Patients accessing the Genetic, Rare and Complex disease service were referred from five partner organisations including Genetic Alliance Australia, Syndromes Without A Name, Genetic and Rare Disease Network and the Genetic Support Network Victoria.

Table 1.6: Diagnosis

Organisation	n=1245	Percent
Mito Foundation	90	7.23
Emerge Australia	261	20.96
Cerebral Palsy Support Network	66	5.30
Maddie Riewoldt's Vision	49	3.94
Save Our Sons	60	4.82
Metabolic Dietary Disorders Australia	92	7.39
Genetic, Rare & Complex Disease	120	9.64
Eating Disorders Victoria	225	18.07
Crohn's & Colitis Australia	128	10.28
Pancare	60	4.82
Tuberous Sclerosis Australia	94	7.55

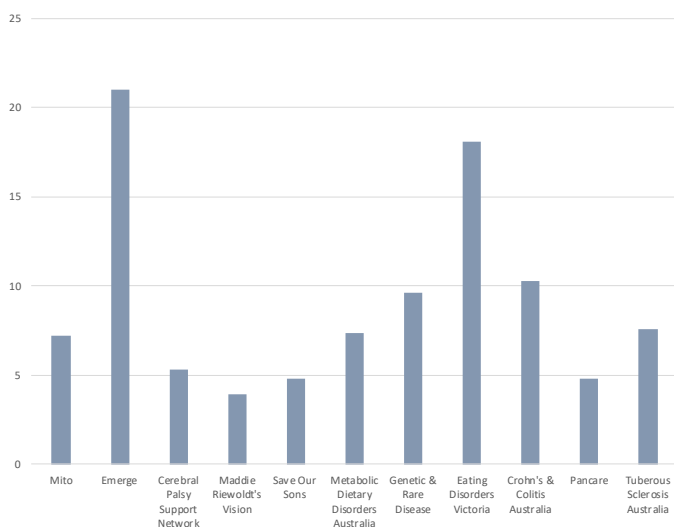


Figure 1.6: Diagnosis (% of all people accessing Patient Pathways)

Ethnicity

The majority of people accessing the Patient Pathways telehealth service were caucasian (n=724, 58.15%). There were 34 (2.73%) people that did not wish to disclose their ethnicity.

Table 1.7: Ethnicity

Ethnicity	n=1245	Percent
African	7	0.56
Arab	4	0.32
Asian	38	3.05
Caucasian/White	724	58.15
Hispanic/Latino	5	0.40
ATSI	14	1.12
Pacific Islander	6	0.48
Does not wish to disclose	34	2.73
Other	16	1.29
Ethnicity not identified	397	31.89

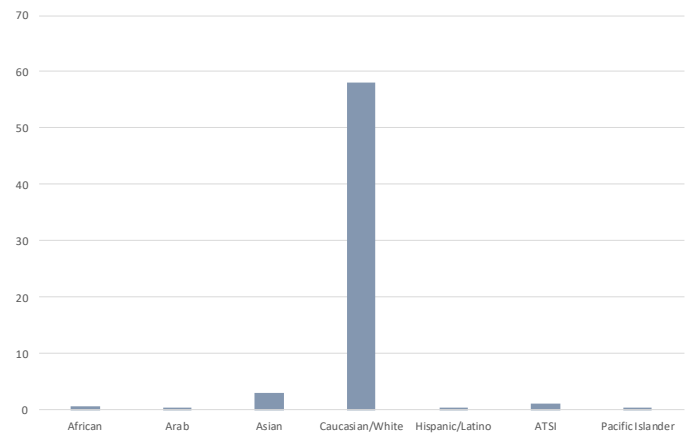


Figure 1.7: Ethnicity
(% of all people accessing Patient Pathways)

Other languages spoken

The majority of people accessing the Patient Pathways telehealth nurse service did not speak another language (n=1190, 95.58%). Mandarin was the most common second language spoken (n=12, 0.96%).

Table 1.8: Other languages spoken

Other languages spoken	n=1245	Percent
African dialect	2	0.16
Arabic	6	0.48
Cantonese	2	0.16
Filipino	2	0.16
French	2	0.16
German	3	0.24
Greek	5	0.40
Hebrew	2	0.16
Hindi	2	0.16
Italian	4	0.32
Mandarin	12	0.96
Punjabi	3	0.24
Russian	1	0.08
Serbian	2	0.16
Spanish	1	0.08
Non-verbal/Auslan	6	0.48
No other languages	1190	95.58

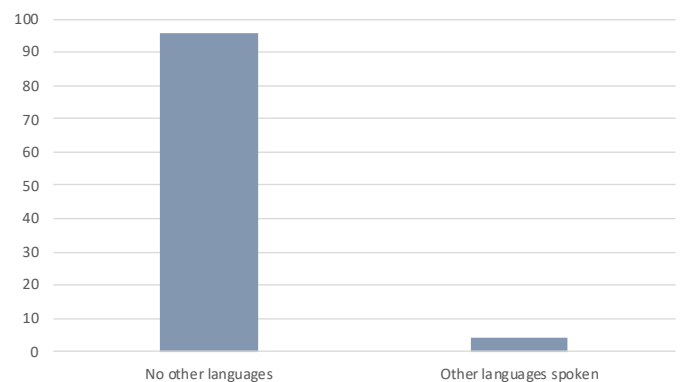


Figure 1.8: Other languages spoken
(% of all people accessing Patient Pathways)

State

The majority of people accessing the Patient Pathways telehealth service were from Victoria (n=548, 44.02%). This is in part due to a number of Victorian-based organisations. There were 232 (18.63%) people from New South Wales, 151 (12.13%) from Queensland and 84 (11.08%) from Western Australia.

Table 1.9: State

State	n=1245	Percent
ACT	13	1.04
NSW	232	18.63
NT	1	0.08
QLD	151	12.13
SA	44	3.53
TAS	34	2.73
VIC	548	44.02
WA	84	6.75
State not identified	138	11.08

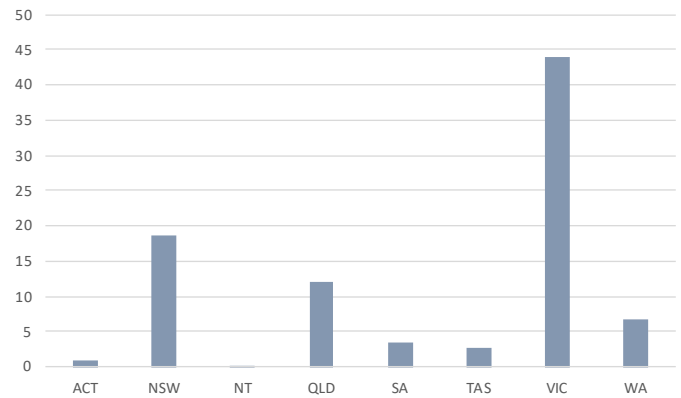


Figure 1.9: State
(% of all people accessing Patient Pathways)

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=631, 50.68%), with 243 (19.52%) coming from regional Australia.

Table 1.10: Region

Region	n=1245	Percent
Major Cities of Australia	631	50.68
Inner Regional Australia	179	14.38
Outer Regional Australia/Remote	64	5.14
No postcode recorded	371	29.80

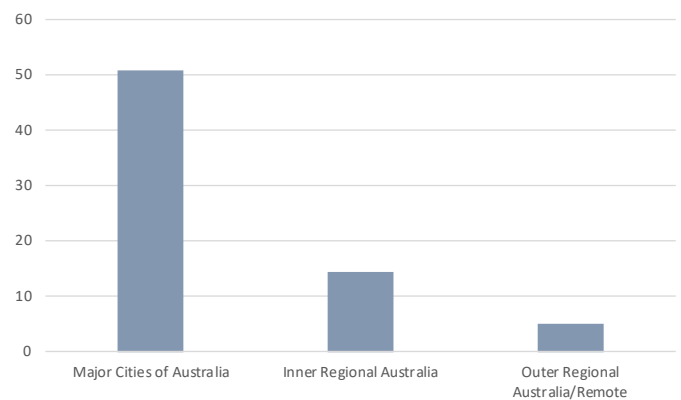


Figure 1.10: Region
(% of all people accessing Patient Pathways)

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

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 417 (33.49%) people coming from low to medium socioeconomic areas and 457 (36.71%) people coming from higher socioeconomic areas².

Table 1.11: Socioeconomic status

Socioeconomic status	n=1245	Percent
1	47	3.78
2	49	3.94
3	54	4.34
4	101	8.11
5	63	5.06
6	103	8.27
7	85	6.83
8	106	8.51
9	125	10.04
10	141	11.33
No postcode recorded	371	29.80

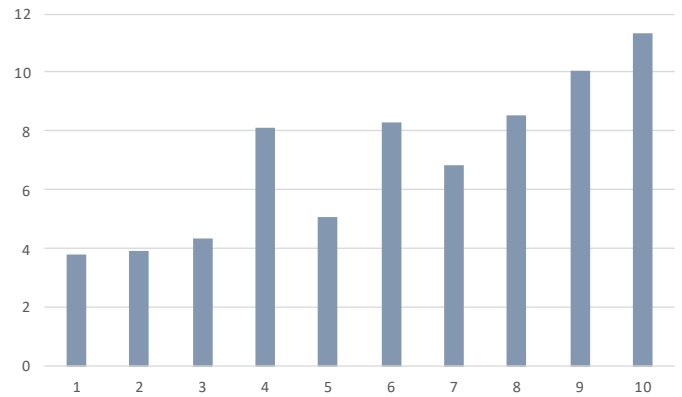


Figure 1.11: Socioeconomic status (% of all people accessing Patient Pathways)

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=283, 22.73%). There were 261 (20.96%) people needing to travel up to 60 minutes and 131 (10.52%) needing to travel up to 90 minutes or more.

Table 1.12: Access to healthcare

Access to treatment (Time to travel)	n=1245	Percent
<30 minutes	283	22.73
31 to 60 minutes	261	20.96
61 to 90 minutes	51	4.10
>90 minutes	80	6.43
N/A (No treatment)	155	12.45
Access to treatment not assessed	415	33.33

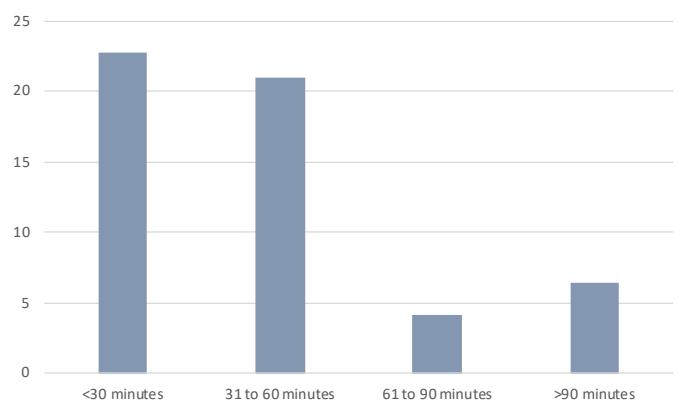


Figure 1.12: Access to healthcare (% of all people accessing Patient Pathways)

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

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=512, 41.12%). This was followed by a health professional referral (n=149, 11.97%) and Facebook (n=122, 9.80%).

Table 2.1: Referred from

Organisation	n=1245	Percent
Facebook	122	9.80
Health professional	149	11.97
Helpline	14	1.12
Relative	7	0.56
Support group/other internal service	233	18.71
Website	512	41.12
Referral source not identified	208	16.71

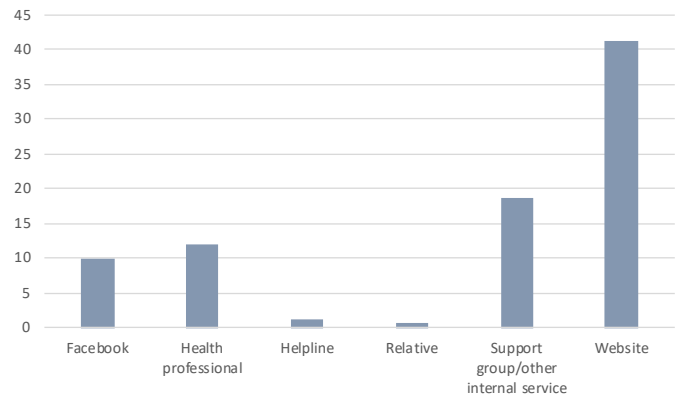


Figure 2.1: Referred from
(% of all people accessing Patient Pathways)

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 steady increase of 108 patients in the first quarter of service compared with 356 in the most recent quarter.

Table 2.2: Initial consultations timing by quarter

Consultation date	n=1245	Percent
Q1 2019	0	N/A
Q2 2019	2	N/A
Q3 2019	108	8.67
Q4 2019	167	13.41
Q1 2020	234	18.80
Q2 2020	254	20.40
Q3 2020	356	28.59
Q4 2020 (October only)	124	9.96

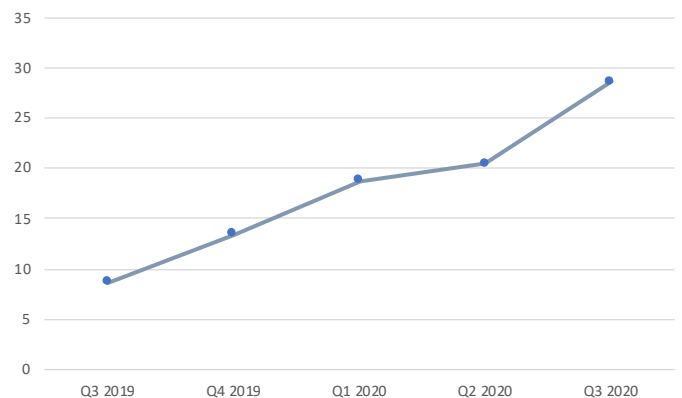


Figure 2.2: Initial consultations timing by quarter
(% of all people accessing Patient Pathways)

Initial consultations time of day

Patient Pathways partner organisations offer services, primarily within working hours. The times reflected in table 2.3 and figure 2.3 are in Australian Eastern Standard Time.

The majority of consultations were recorded in the middle of the day with 181 (14.54%) at 12.00pm, 149 (11.97%) at 1.00pm and 161 (12.93%) at 2.00pm. These charts aim to give a sense of times during the day where there is higher/lower consultation activity.

Table 2.3: Initial consultations time of day

Time of day consultations preferred	n=1245	Percent
8am	20	1.61
9am	26	2.09
10am	77	6.18
11am	122	9.80
12pm	181	14.54
1pm	149	11.97
2pm	161	12.93
3pm	162	13.01
4pm	152	12.21
5pm	91	7.31
6pm	22	1.77
7pm	41	3.29
8pm+	41	3.29

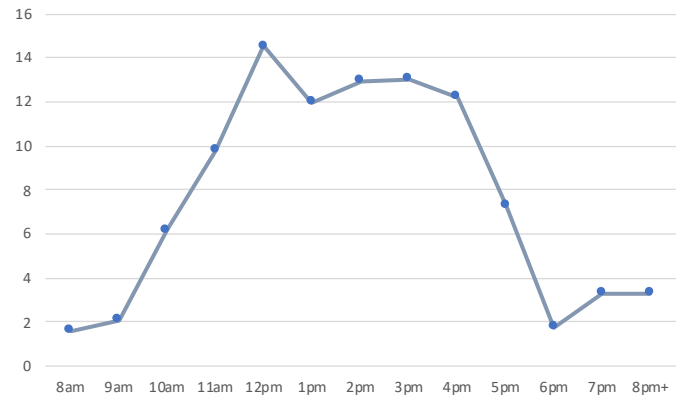


Figure 2.3: Initial consultations time of day (% of all people accessing Patient Pathways)

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.

The majority of initial consultation took 60 minutes (n=285, 22.89%), followed by 90 minutes (n=209, 16.79%). This reflects the complex needs of the patients that access the service. Likewise, follow-up activities from the initial consultation most commonly took 60 minutes (n=326, 26.18%) or 90 minutes (25.30%). Across all patients, the average time per patient in initial and follow-up was 94.92 minutes.

Table 2.4: Duration of initial consultation

Length of time per initial consultator	(n=1245)	Percent
Less than 30 minutes	157	12.61
30 minutes	142	11.41
40 minutes	62	4.98
50 minutes	120	9.64
60 minutes	285	22.89
70 minutes	31	2.49
80 minutes	29	2.33
90 minutes	209	16.79
Length of consultation not recorded	210	16.87

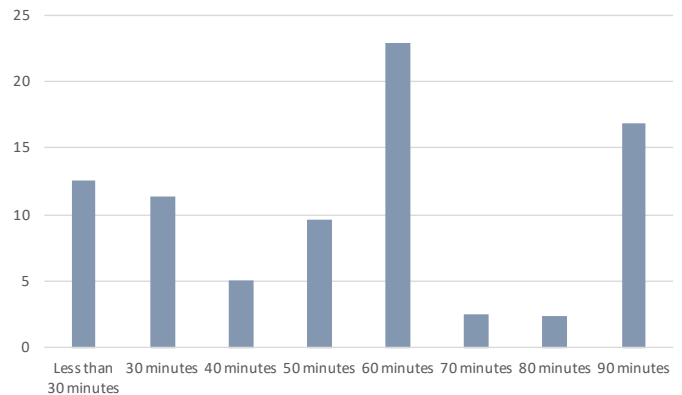


Figure 2.4: Duration of initial consultation (% of all people accessing Patient Pathways)

Follow up for initial consultation duration

Table 2.5: Follow up for initial consultation duration

Length of time for follow up	(n=1245)	Percent
Under 30 minutes	94	7.55
30 minutes	112	9.00
40 minutes	35	2.81
50 minutes	31	2.49
60 minutes	326	26.18
70 minutes	15	1.20
80 minutes	5	0.40
90 minutes	315	25.30
No time recorded	312	25.06

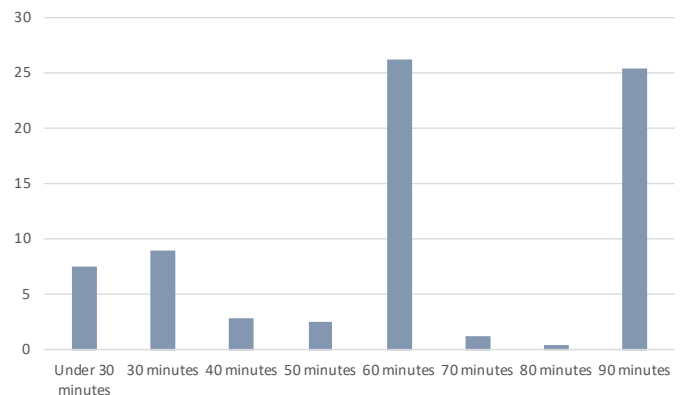


Figure 2.5: Follow up for initial consultation duration (% of all people accessing Patient Pathways)

Table 2.6: Average time per patient

Description (n=1245)	Minutes	Hours
Time across all cases on calls (initial call and follow-up)	118170	1969.50
Time per patient	94.92	1.58

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=780, 62.65%) with 65 (5.22%) that did not and 44 (3.53) that indicated that they would like a referral.

Table 3.1: GP status

GP status	n=1245*	Percent
Patient does not have a regular GP	65	5.22
Patient has regular GP	780	62.65
Patient would like a new GP referral	44	3.53
Patient reminded of right and importance to choose their GP	34	2.73
No primary care assessment	376	30.20

*More than one option possible per patient

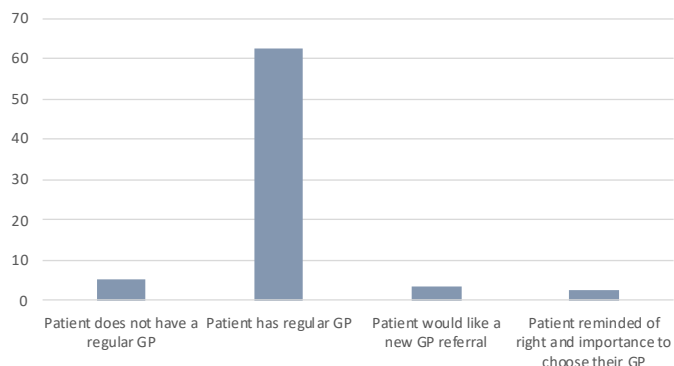


Figure 3.1: GP status
(% of all people accessing Patient Pathways)

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.

The majority of participants had three to five primary concerns at the time of the consultation (n=288, 23.13%), with an average of 3.01 concerns or questions per patient. There was an average of 3.23 future concerns per patient, giving a total of 6.32 concerns or questions per patient. Across all concerns and questions now and in the future, the most common were related to fatigue, mental health and pain management.

Table 3.2: Number of concerns/questions at consultation

Symptoms concerns at consultation	n=1245	Percent
1	107	8.59
2	83	6.67
3	98	7.87
4	93	7.47
5	97	7.79
6	68	5.46
7	74	5.94
8	47	3.78
9	27	2.17
10	37	2.97
11+	46	3.69
No symptoms concerns recorded	468	37.59

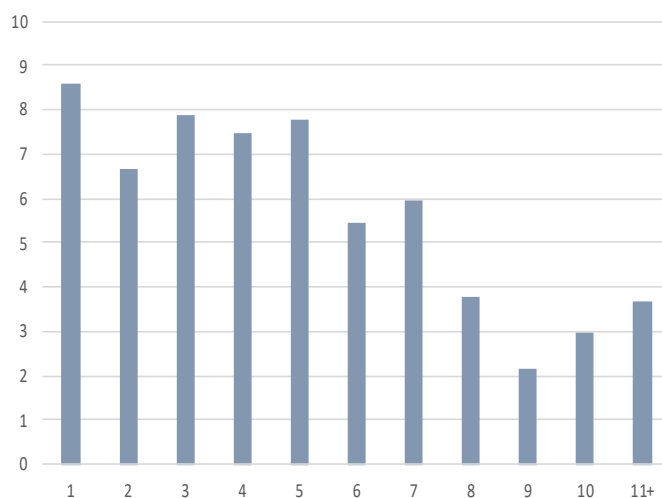


Figure 3.2: No. of concerns/questions at consultation
(% of all people accessing Patient Pathways)

Most common concerns and questions at consultation time

Table 3.3: Most common concerns and questions at consultation time

Symptoms concerns at consultation	n=1245*	Percent
Fatigue	353	28.35
Mental health disorders including anxiety, depression.	221	17.75
Joint, bone, muscle or generalised pain	194	15.58
Abdominal bloating	142	11.41
Diarrhoea	125	10.04
Sleep disorders	109	8.76
Blood in the stool	100	8.03
Problems thinking, remembering or concentrating	95	7.63
Flu-like symptoms	91	7.31
Headaches	84	6.75
Feeling dizzy or sick	79	6.35
Adopting an overly restrictive diet	69	5.54
Irritable Bowel Syndrome	68	5.46
Constipation	60	4.82
Anaemia	57	4.58
Fast or irregular heartbeats (heart palpitations)	57	4.58
Inability to tolerate a healthy diet	57	4.58
Intellectual disability	52	4.18

*More than one option possible per patient

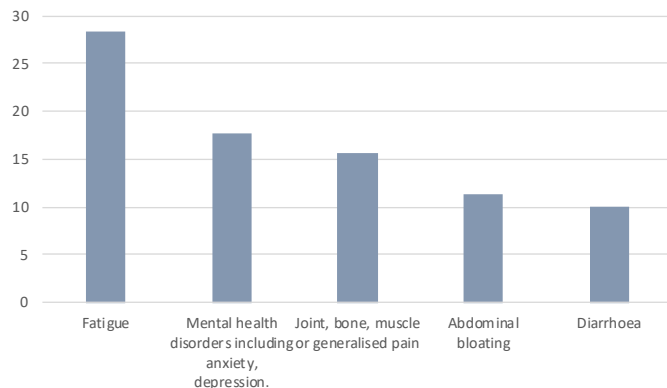


Figure 3.3: Most common concerns/questions at consultation (% of all people accessing Patient Pathways)

Number of symptom concerns in the future

Table 3.4: Number of symptom concerns in the future

Symptom concerns in the future	n=1245	Percent
1	96	7.71
2	89	7.15
3	86	6.91
4	110	8.84
5	67	5.38
6	39	3.13
7	28	2.25
8	32	2.57
9	28	2.25
10	38	3.05
11+	127	10.20
No future questions/concerns recorded	505	40.56

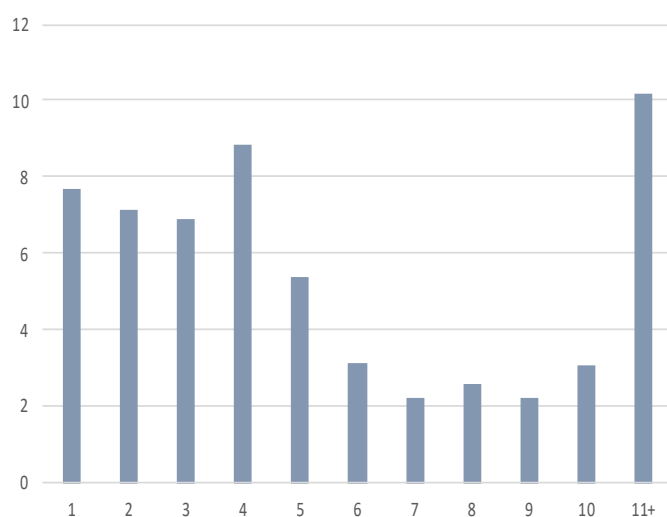


Figure 3.4: Number of symptom concerns in the future (% of all people accessing Patient Pathways)

Most common symptom concerns in the future

Table 3.5: Most common symptom concerns in the future

Most common concern future	(n=1245)*	Percent
Joint, bone, muscle or generalised pain	349	28.03
Fatigue	339	27.00
Mental health disorders including anxiety, depression.	161	12.93
Abdominal pain	132	10.60
Constipation	126	10.12
Diarrhea	124	9.96
Anaemia	122	9.80
Blood in your stool	120	9.64
Fever	120	9.64
Problems thinking, remembering or concentrating	101	8.11
Sleep disorders	101	8.11
Inability to tolerate a healthy diet	96	7.71
Flu-like symptoms	87	6.99
Cardiac arrhythmias	86	6.91
Inability to maintain appropriate weight	83	6.67
Feeling dizzy or sick	78	6.27
Headaches	69	5.54
Irritable Bowel Syndrome	67	5.38
Adopting an overly restrictive diet	59	4.74

*More than one option possible per patient

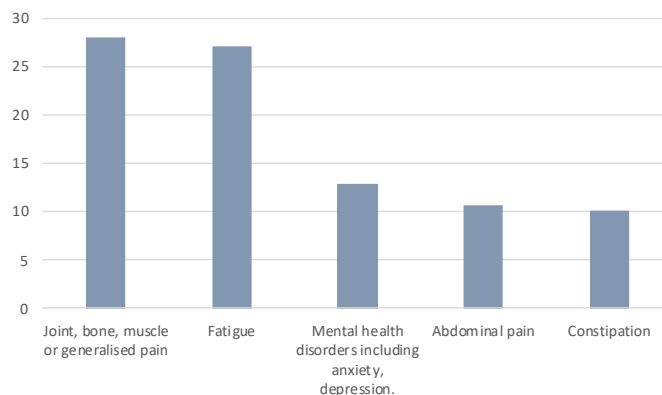


Figure 3.5: Most common symptom concerns in the future (% of all people accessing Patient Pathways)

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.

There were 467 (37.51%) of patients that had not had any conversation about clinical trials before entering Patient Pathways. Only 32 (2.57%) had participated in a clinical trial.

Table 3.6: Clinical trial status

Clinical trials	(n=1245)*	Percent
Patient has participated in a clinical trial	32	2.57
Clinical trial(s) have been discussed	171	13.73
Clinical trial(s) have not been discussed	467	37.51
Clinical trials not appropriate at this stage (as determined by nurse)	46	3.69
No clinical trial assessment	406	32.61

*More than one option possible per patient

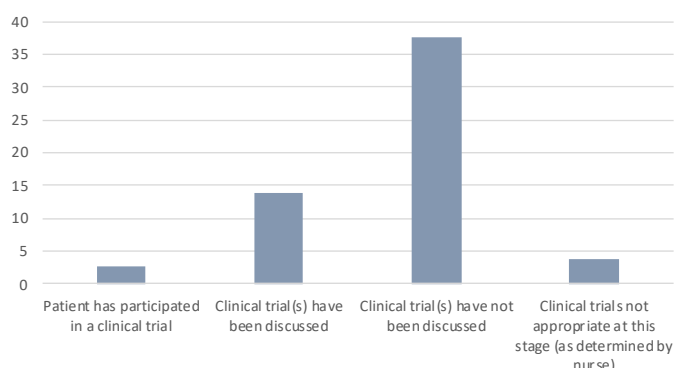


Figure 3.6: Clinical trial status (% of all people accessing Patient Pathways)

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 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%).

Table 3.7: Information requested

Information gaps	(n=1245)*	Percent
Clinical trials	137	11.00
Complementary therapies	99	7.95
Dietary information	258	20.72
Disease cause	259	20.80
Disease management	406	32.61
Hereditary considerations	145	11.65
How to interpret test results	196	15.74
My Health Record Accessed	24	1.93
Physical activity	198	15.90
Psychological/social support	292	23.45
Treatment options	413	33.17

*More than one option possible per patient

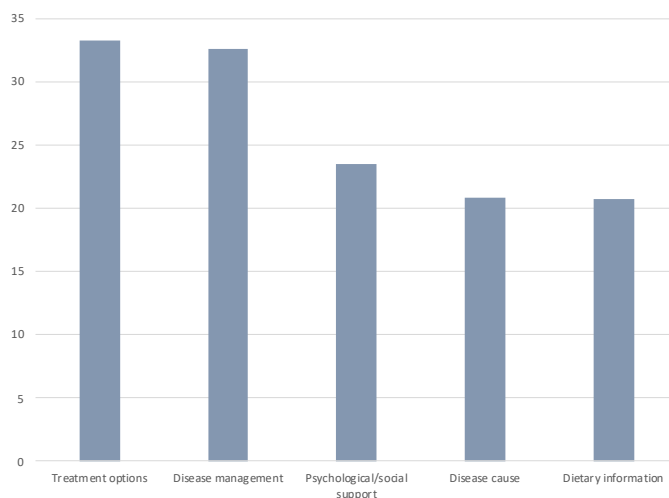


Figure 3.7: Information requested
(% of all people accessing Patient Pathways)

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 332 (26.67%) that had no pain needing to be managed. There were also 91 (7.31%) that did not have their pain under control and 109 (87.6%) patients needing a pain management plan or revision.

Table 3.8: Pain management plan

Pain management plan	(n=1245)*	Percent
Pain currently controlled	195	15.66
Pain currently not under control	91	7.31
No pain noted/not applicable	332	26.67
Pain management plan needs revision	37	2.97
Pain management plan needed	72	5.78
Pain management plan in place	128	10.28
No pain assessment recorded	473	37.99

*More than one option possible per patient

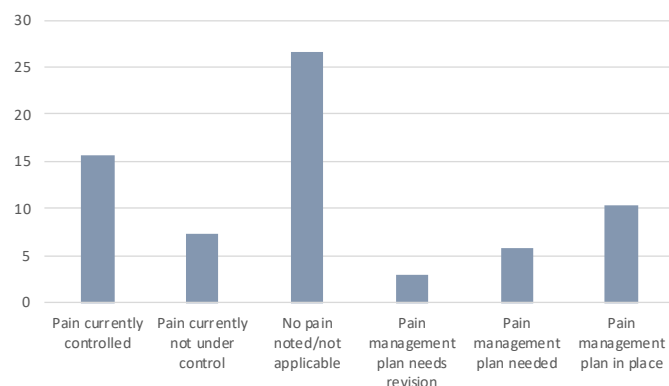


Figure 3.8: Pain management plan
(% of all people accessing Patient Pathways)

Palliative care

Palliative care is often confused with hospice care and end of life, however it is a specialised type of care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness to improve quality of life for both the patient and the family. Palliative care is based on the needs of the patient, not on the patient's prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

There were a total of 804 (64.58%) palliative care assessments made. An assessment of 'Not applicable' was made for 741 (59.52%) people. There were 28 (2.25%) people needing a referral and 35 (2.81%) already referred to palliative care.

Table 3.9: Palliative care

Palliative care	(n=1245)*	Percent
Patient requires palliative care referral	28	2.25
Patient already referred to palliative care	35	2.81
Not applicable	741	59.52
No palliative care assessment	441	35.42

*More than one option possible per patient

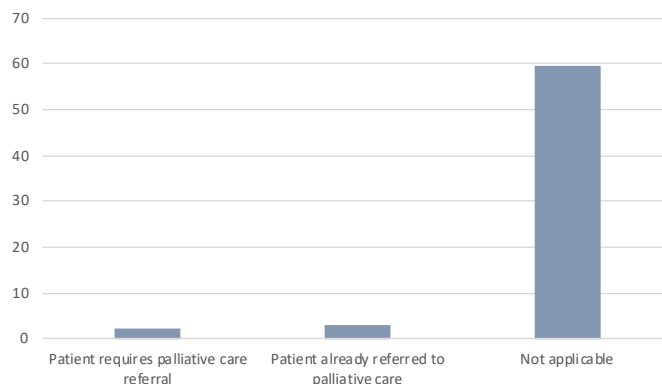


Figure 3.9: Palliative care (% of all people accessing Patient Pathways)

Number of 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. The majority of patients had one, two or three services within their care team at the time of consultation (39.76%). The most common services accessed were dietitians (n=262, 21.04%), physiotherapists (n=229, 18.39%), specialist nurse/care coordinator (n=158, 12.69%) and occupational therapists (n=149, 11.97%).

Table 3.10: Number of services in existing care plan

Number of existing services	(n=1245)	Percent
1	212	17.03
2	157	12.61
3	126	10.12
4	63	5.06
5	42	3.37
6	25	2.01
7	28	2.25
8	19	1.53
9	5	0.40
10	11	0.88
11+	5	0.40
No services recorded	542	43.53

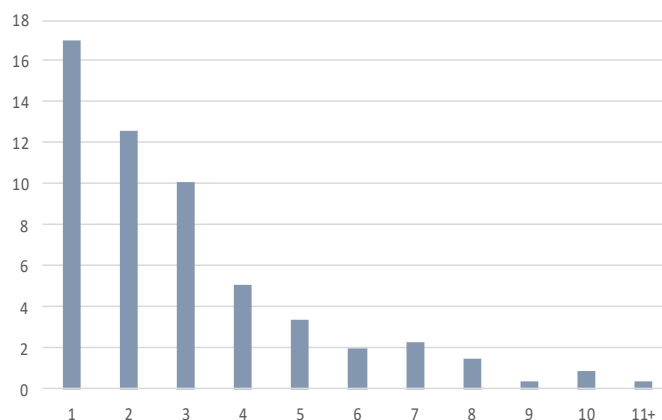


Figure 3.10: Number of services in existing care plan (% of all people accessing Patient Pathways)

Services in existing care plan

Table 3.11: Services in existing care plan

Services existing at consultation	(n=1245)*	Percent
Counselling	146	11.73
Dentist	74	5.94
Dietician	262	21.04
Exercise physiologist	66	5.30
Genetic counselling	49	3.94
Home care	45	3.61
No services recorded	424	34.06
Nutritionist	35	2.81
Occupational therapist	149	11.97
Pharmacists	128	10.28
Physiotherapist	229	18.39
Podiatrist	44	3.53
Psychologist	103	8.27
Rehabilitation service	29	2.33
Social work	58	4.66
Specialist nurse/care coordinator	158	12.69
Speech pathologist	58	4.66
Stoma therapist	12	0.96

*More than one option possible per patient

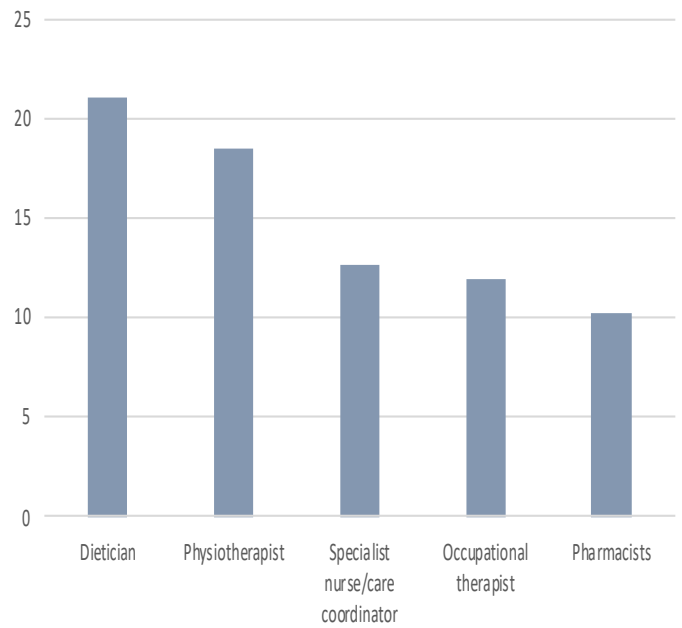


Figure 3.11: Services in existing care plan
(% of all people accessing Patient Pathways)

Number of referrals/interventions required

Patient Pathways telehealth nurses conduct a range of nurse-led interventions and referrals. Overall there were 9247 referrals or interventions made at an average of 7.43 per patient. Where a nurse indicates in the Patient Pathways database that information was provided, a referral or assessment was made, these were then calculated to identify the nurse-led interventions presented below.

The most common referrals to specialists and allied health were for counselling (n=246, 19.76%), followed by nutritionist/dietician (n=205, 16.47%) and nurse specialist/nurse coordinators (n=120, 9.64%). 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.

Table 3.12: Number of referrals/interventions required

Number of referrals/interventions	(n=1245)	Percent
1	105	8.43
2	43	3.45
3	34	2.73
4	43	3.45
5	45	3.61
6	70	5.62
7	114	9.16
8	94	7.55
9	124	9.96
10	87	6.99
11	51	4.10
12	31	2.49
13	36	2.89
14	56	4.50
15	34	2.73
16	112	9.00
No referrals/interventions recorded	166	13.33

**More than one option possible per patient*

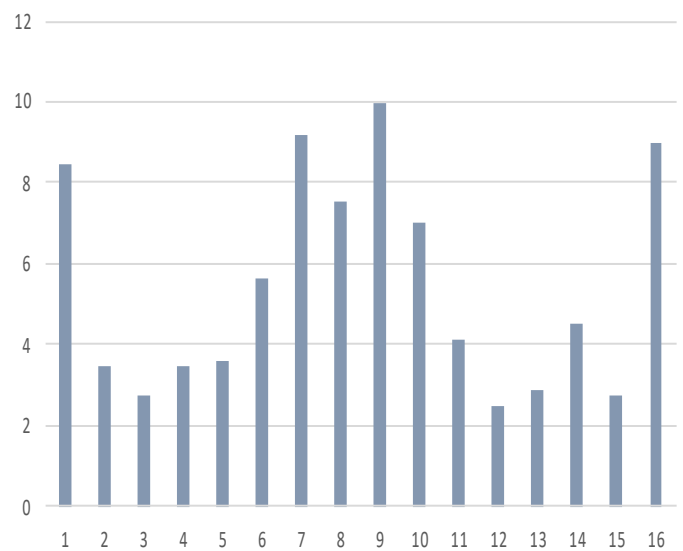


Figure 3.12: Number of referrals/interventions required (% of all people accessing Patient Pathways)

Referrals to specialists and allied health

Table 3.13: Referrals to specialists and allied health

Specialist and allied health referral	(n=1245)*	Percent
Consult with other clinician/case manager	27	2.17
Counselling or psychologist	246	19.76
Dentist	12	0.96
Exercise physiologist	100	8.03
General Practitioner	33	2.65
Genetic counselling	32	2.57
Home care	22	1.77
NDIS provider	0	0.00
Neurologist	0	0.00
Nurse coordinator/Specialist nurse	120	9.64
Nutritionist/Dietician	205	16.47
Occupational therapist	55	4.42
Other allied health	7	0.56
Paediatrician	0	0.00
Palliative care	19	1.53
Pharmacist	4	0.32
Physiotherapist	57	4.58
Podiatrist	10	0.80
Rehabilitation specialist	7	0.56
Social Work	52	4.18
Speech pathologist	18	1.45

*More than one option possible per patient

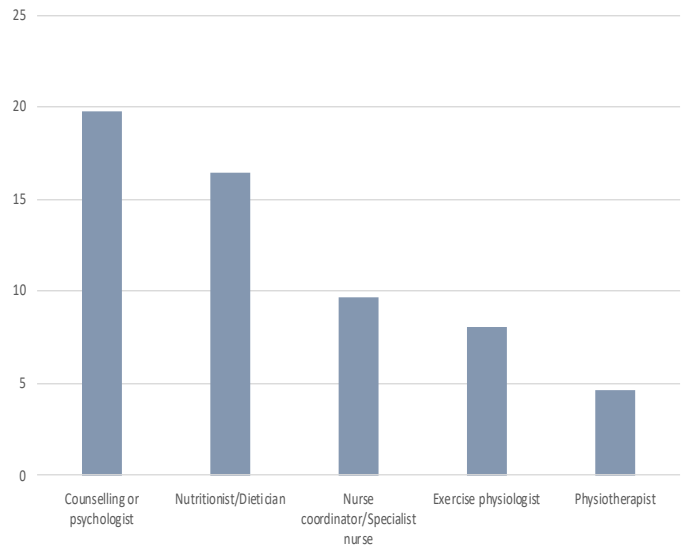


Figure 3.13: Referrals to specialists and allied health (% of all people accessing Patient Pathways)

Referral to complementary support

While allied health, specialist and most complementary support referrals need a physician, the remainder of referrals are nurse-delivered interventions. The most common complementary support referrals were for peer support (n=194, 15.58%) including support groups and other patient organisation peer support initiatives. There were 840 (67.47%) clinical trials interventions including providing information, assessing clinical trial status and having discussions about clinical trials. There were 413 (33.17%) discussions and/or information provision about standard, current treatments, 279 (22.41%) about dietary habits, 263 (21.12%) about disease cause, and 278 (22.33%) about mental health.

Table 3.14: Referral to complementary support

Complementary support referral	(n=1245)*	Percent
Hydrotherapist	25	2.01
Massage therapist	19	1.53
Naturopath	6	0.48
Osteopath	1	0.08
Peer support	194	15.58

*More than one option possible per patient

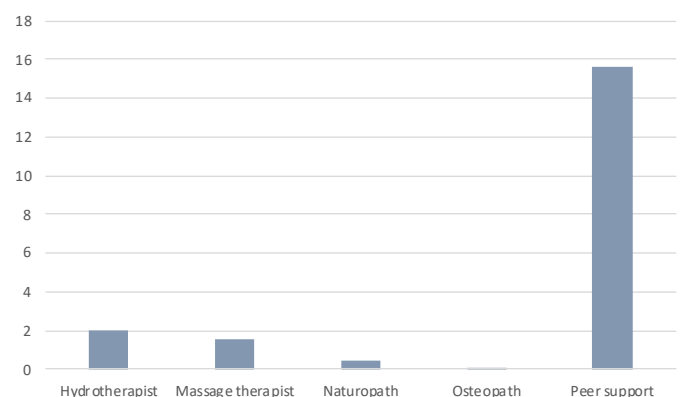


Figure 3.14: Referral to complementary support (% of all people accessing Patient Pathways)

Discussion, information and education

An important part of the Patient Pathways telehealth nurse role is making assessments across key clinical areas. There were 873 (70.12%) patients who were able to access symptom management through the program, 849 (68.19%) that received a home status assessment, 774 (62.17%) that received a palliative care assessment, 773 (62.09%) that received a primary care assessment and 771 (61.93%) that received a pain management assessment.

Table 3.15: Discussion, information and education

Discussion/Information/Education	(n=1245)*	Percent
Chronic disease care plan	40	3.21
Clinical trials	840	67.47
Complementary therapies	99	7.95
Condition/disease/Disease cause	263	21.12
Diet/nutrition/eating habits	279	22.41
Genetic testing	106	8.51
How to interpret results	196	15.74
Interpretation services	0	0.00
Mental health care plan	43	3.45
Mental/emotional health	278	22.33
My health record	24	1.93
NDIS	0	0.00
Public/private health systems	0	0.00
Second opinions	0	0.00
Standard/current treatments	413	33.17

*More than one option possible per patient

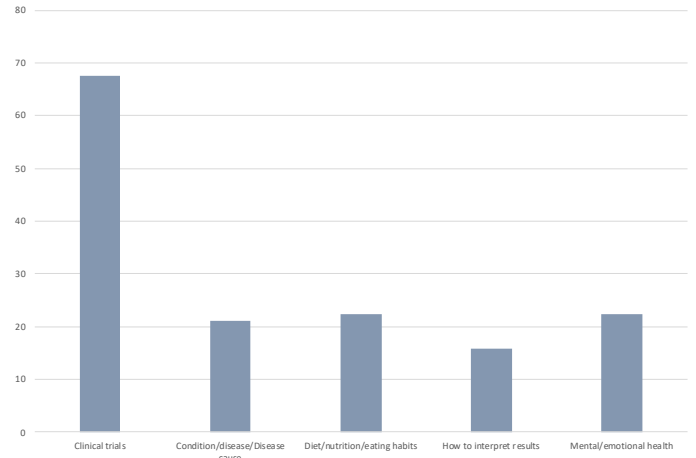


Figure 3.15: Discussion, information and education (% of all people accessing Patient Pathways)

Assessments and interventions

Table 3.16: Assessments and interventions

Assessment, planning and follow-up	(n=1245)*	Percent
Home status assessment	849	68.19
Multi-disciplinary Teams (Services available through health system)	704	56.55
Pacing and working within abilities	106	8.51
Pain management	771	61.93
Palliative care assessment	774	62.17
Primary care assessment	773	62.09
Prompt list development	120	9.64
Self care including exercise and meditation (stress relief activities)	283	22.73
Symptom management	873	70.12
Symptom tracking	142	11.41

*More than one option possible per patient

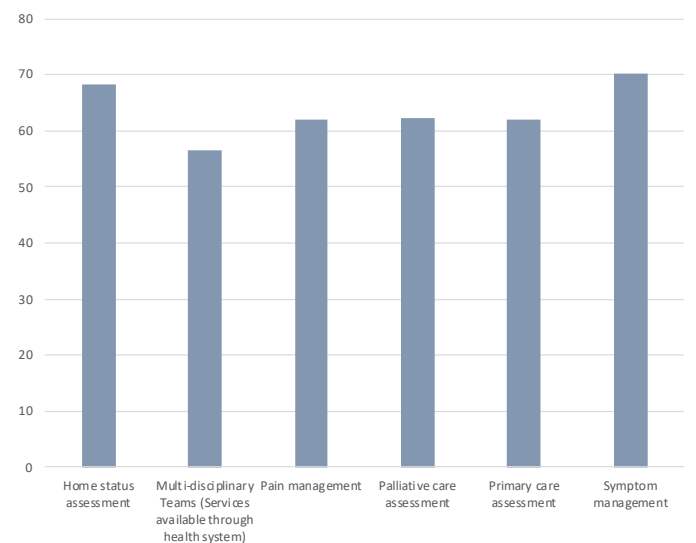


Figure 3.16: Assessments and interventions (% of all people accessing Patient Pathways)

Part 4: Cost evaluation and recommendations

Time per patient

Within the Patient Pathways database, nurses are able to record the amount of time spent on the initial consultation and on follow-up. The average time spent on calls and follow-up after the initial consultation 94.91 minutes (1.58 hours) per patient.

Table 4.1: Time per patient (initial call and follow-up)

Organisation	Metabolic Dietary Disorders Association (n=92)		Mito Foundation (n=90)	
	Minutes	Hours	Minutes	Hours
Time across all cases on calls and follow-up	11470	389.83	9740	347.23
Number of cases for calculation	92		90	
Time per patient	124.67	2.08	108.22	1.8
Organisation	Pancare (n=60)		Rare and Genetic Conditions (n=120)	
	Minutes	Hours	Minutes	Hours
Time across all cases on calls and follow-up	4000	87.92	13700	
Number of cases for calculation	60		120	
Time per patient	66.67	1.11	114.17	1.9
Organisation	Save Our Sons (n=60)		Tuberous Sclerosis	
	Minutes	Hours	Minutes	Hours
Time across all cases on calls and follow-up	5150	134.95	5020	127.92
Number of cases for calculation	60		94	
Time per patient	85.83	1.43	53.40	0.89
Organisation	Cerebral Palsy Support Network (n=66)		Crohn's & Colitis Australia (n=128)	
	Minutes	Hours	Minutes	Hours
Time across all cases on calls and follow-up	6060	174.48	22000	366.67
Number of cases for calculation	66		128	
Time per patient	91.82		171.88	2.86
Organisation	Eating Disorders Victoria		Emerge Australia (n=261)	
	Minutes	Hours	Minutes	Hours
Time across all cases on calls and follow-up	10250	478.68	24740	412.33
Number of cases for calculation	225		261	
Time per patient	45.56	0.76	94.79	1.58
Organisation	Maddie Riewoldt's Vision		All organisations (n=1245)	
	Minutes	Hours	Minutes	Hours
Time across all cases on calls and follow-up	6040	403.35	118170	1969.5
Number of cases for calculation	49		1245	
Time per patient	123.27	2.05	94.91	1.58

Cost per patient

Each nurse is directly employed by the respective partner organisation and receives a salary determined by their employer, guided by state-based nurse awards. The average hourly rate for nurses in the Patient Pathways telehealth service was \$41.67 and this is comparable with a 6th year registered nurse hourly rate, with an eighth year and thereafter rate being \$45.45. With an average time per patient of 1.58 hours, this results in an average cost per patient of \$65.84¹.

To calculate a cost comparison, the Medical Benefits Scheme item 10997 was used. This is a practice nurse item for a service provided by a practice nurse, for services consistent with Chronic Health/GP Management Plan, Team Care Arrangements or Multidisciplinary Care Plan. We acknowledge that it is not possible to conduct a completely direct comparison with this item as there are limitations on how it is implemented in practice, for example a limitation of five services per person per calendar year. However it provides a reasonable comparison in relation to nurse activities under chronic disease monitoring and support, and is a modest, low cost MBS item with a benefit of \$12.40. As part of the service under MBS a nurse can:

- Check on clinical progress
- Monitor medication compliance
- Provide self-management advice
- Collect information to support the review of a care plan

On average, each patient in the Patient Pathways program received 7.43 assessments or interventions (see Section 3.12). Using the MBS item 10997 amount of \$12.40, 7.43 assessments/interventions would bill to \$92.13. With an average cost per patient of \$65.84 in the Patient Pathways program, this is a cost saving per patient of \$26.29 and \$3.54 per assessments/intervention. As noted, there is a limit of five services per person per calendar year under MBS item 10997. If the maximum five services per patient were reached, this would be at a cost of \$62.00 per patient, making the Patient Pathways cost per patient \$3.48 more than the maximum. However, this would also include an additional 2.43 services for that additional cost.

Table 4.2: Cost per patient calculations

Description	Value
A. Average salary per hour Patient Pathways telehealth nurse	\$41.67
B. Average time per patient	1.58 hours
C. Average cost per patient in Patient Pathways	\$65.84
D. Average number of assessments/interventions	7.43
E. MBS item no. 10997	\$12.40
F. Comparative cost (using MBS item 10977 across 7.43 activities)	\$92.13
G. Cost saving per patient (F-C)	\$26.29
H. Cost per assessment/intervention in patient pathways (C ÷ D)	\$8.86
I. Cost saving per assessment/intervention (E-H)	\$3.54

¹ Public Health System Nurses' & Midwives' (State) Award 2019 www.nswnma.asn.au › wp-content › uploads › 2019/08

Other costs and activities

Each organisation employs a part-time nurse ranging from 0.2FTE to 0.6FTE and all of the organisations have contributed data to this evaluation. Collectively, this equates to 4.46 FTE nurses working on the program.

Beyond the initial consultation and follow-up, there are other commitments and activities that Patient Pathways nurses are engaged with. As the number of patients entering the program continues to rise (See figure 2.2) we anticipate that over time, the time spent on other activities and development of patient materials will decrease, however as a new program, there is an expected and reasonable amount of work being done to develop patient information and work on increasing awareness of this new service. As Patient Pathways telehealth nurses are employed by partner organisation and integrated within their communities, there are also reasonable internal organisation meetings and requirements expected of them. Organisational duties and external engagement activities include:

- Clinical outreach
- Regional outreach
- Promotion of service
- Continuing Professional Development and Learning
- Internal organisational meetings and requirements

There is also ongoing patient support beyond initial consultation where nurses may receive ad-hoc calls from patients or longer-term follow-up. As new challenges and situations arise, nurses are actively developing tools, information and educational materials for their patients that can be used going forward. The time taken on subsequent follow-up - including education and tool resource development - has been collected by nurses and across all organisations and calculates collectively to 1.34 FTE per week. This combined with 1.0FTE of time spent on the initial patient call calculates to 2.34 FTE (52.36%) and these activities are classified as direct patient support. The remaining time 2.13 FTE (47.64%) is attributed to organisational duties and external engagement.

To summarise, direct patient support activities include:

- Ad-hoc patient follow-up
- Patient support group facilitation
- Patient information webinars
- Development of patient support tools
- Development of patient education materials

Table 4.3: Time per activities as an FTE

Time per week	Minutes dedicated	FTE	Percentage
Minutes for 4.46 FTE	529074	4.46	100.00
Initial calls and follow-up	118170	1.00	22.34
Additional ad-hoc follow-up	158862	1.34	30.03
Organisational activities	252042	2.13	47.64

Recommendations

Patient Pathways is a new program and understandably, it takes time to build momentum. We have seen that momentum build over time with a steady increase in uptake which we expect to continue. All organisations involved should be congratulated on building such a strong network and steady uptake of services in such a short period of time.

Using the current total investment of \$350,000 per annum and an average cost of \$65.84 per patient for direct patient costs, the maximum capacity across a minimum of ten patient organisations would be 10.22 patients per week per service, noting that this does not allow time for organisational responsibilities.

The current ratio of direct patient support to organisational responsibilities is 52:48. As programs establish, we would recommend this ratio shift over a three-year period to 70:30, bringing the number of patients per week per service to 7.16 (at the current rate of investment).

There is a particular challenge in rare disease where it may take longer to reach a minimum viable volume. In such cases, there is a possibility to have one nurse between two or three organisations for rare disease, as has been the case with the rare, genetic and complex disease service shared between Genetic Alliance Australia, Syndromes Without A Name, Genetic and Rare Disease Network, the Genetic Support Network Victoria.

A funding formular has been developed based on volume of patients per service. Table 4.6 outlines costs per five patients. It is recommended that this level of funding be used in future iterations of the Patient Pathways program, plus 30% to account for organisational activities and 30% oncosts. To note is that there should be some flexibility in identifying the level of nurse that needs to be employed. As mentioned, this costing is based on an hourly rate of \$41.67 which is comparable to a 6th year registered nurse, with an eighth year and thereafter rate being slightly more at \$45.45. Table 4.7 shows the variation in costing when based on an eighth year and thereafter rate.

Table 4.4: Volume of patients at full capacity

Description	Value
A. Total investment per annum	\$350,000
B. Average cost per patient in Patient Pathways	\$65.84
C. Number of patients per year at full scale with current funding	5'316
D. Minimum no. of services	10
E. Number of patients per week per service at full scale with	10.22
F. Number of patients per week per \$100,000 investment	2.92

Table 4.5: Funding per volume of patients per week

Patient volume per week	Direct patient costs	30% organisation activities	30% Oncosts	Total
5	\$17'118	\$5'136	\$5'136	\$27'389.44
10	\$34'237	\$10'271	\$10'271	\$54'778.88
15	\$51'355	\$15'407	\$15'407	\$82'168.32
20	\$68'474	\$20'542	\$20'542	\$109'557.76
25	\$85'592	\$25'678	\$25'678	\$136'947.20
30	\$102'710	\$30'813	\$30'813	\$164'336.64

Table 4.6: Funding per volume of patients per week (based on an eighth year and thereafter rate)

Patient volume per week	Direct patient costs	30% organisation activities	30% Oncosts	Total
5	\$18'671	\$5'601	\$5'601	\$29'872.96
10	\$37'341	\$11'202	\$11'202	\$59'745.92
15	\$56'012	\$16'804	\$16'804	\$89'618.88
20	\$74'682	\$22'405	\$22'405	\$119'491.84
25	\$93'353	\$28'006	\$28'006	\$149'364.80
30	\$112'024	\$33'607	\$33'607	\$179'237.76