

Paediatric Outcomes 2024 Mid-Year Report

Enterprise One Pain Management Service

Background

The electronic Persistent Pain Outcomes Collaboration (ePPOC) is a program which aims to improve services and outcomes for people experiencing chronic pain. It involves the collection of a standard set of data items and assessment tools by specialist pain services throughout Australia and New Zealand, allowing measurement of patient outcomes as a result of treatment. The information collected is also used to develop an Australasian benchmarking system for the pain sector, facilitating better outcomes and best practice interventions for people experiencing chronic pain.

ePPOC is a sub-program of the Australasian Health Outcomes Consortium (AHOC) at the University of Wollongong. Further information about ePPOC is available at <https://www.uow.edu.au/australasian-health-outcomes-consortium/eppoc/>. Other enquiries can be directed to eppoc@uow.edu.au or (+61) 2 42214020.

Acknowledgements

We acknowledge the Traditional Custodians of the lands on which the University of Wollongong is situated. We pay our respects to Aboriginal Elders past and present, who are the knowledge holders and teachers. We acknowledge their continued spiritual and cultural connection to Country. As we share knowledge, teaching, learning and research within this University we also pay respect to the knowledge embedded forever within the Aboriginal Custodianship of Country.

We also want to acknowledge the valuable contribution made by:

- The many staff from pain management services who have spent considerable time collecting, collating and correcting the data and without whose effort this report would not be possible
- Members of the ePPOC Clinical and Management Advisory Committee
- Agency for Clinical Innovation (ACI) for funding the establishment of this initiative

Disclaimer

ePPOC has made every effort to ensure that the data used in this report are accurate. Data submitted to ePPOC are checked for anomalies and services are asked to review and re-submit their corrected data prior to the production of the ePPOC report suite if necessary. We would advise readers to use their professional judgement in considering all information contained in this report.

Contents

The ePPOC report suite	1
This report	1
Participating pain management services.....	1
Report period and scope	1
Patient profile	3
Socio-demographic details.....	3
Clinical characteristics	6
Work status and productivity.....	13
School impact.....	14
Carer impact.....	14
The episode of care.....	15
Waiting time	15
Episode start	16
Services provided.....	16
Treatment pathways	17
Episode end.....	17
Patient outcomes at the end of the episode	19
Pain	19
Quality of Life	22
Functional disability	24
Pain-related worry	25
Medication use	25
Health service utilisation.....	27
Work status and productivity.....	28
School impact.....	29
Carer impact.....	29
Patient outcomes at post-episode follow-up.....	30
Pain	30
Quality of Life	33
Functional disability	35
Pain-related worry	35
Medication use	36
Health service utilisation.....	38
Work status and productivity.....	39
School impact.....	39
Carer impact.....	40
Appendix A – Additional patient outcomes	41
Change from pathway start to pathway end	41
Appendix B – Data quality and completeness.....	50
Appendix C – Tips for interpreting the report	54

Appendix D – Pain services that submitted data for this report..... 56

Appendix E – Assessment tools..... 57

Appendix F – List of figures 60

Appendix G – List of tables..... 62

The ePPOC report suite

ePPOC produces a report suite for your service every six months which includes the following components:

- a Dashboard: a one-page infographic presenting information about your patients, the treatments you provided and the outcomes your patients achieved.
- an Executive Summary: a summary of your report, where your service data is presented alongside data from all services for comparative purposes, and including benchmark and indicator information.
- this Report: a detailed report presenting data and information on your service's patient profile, episodes of care and patient outcomes, alongside that for all services.

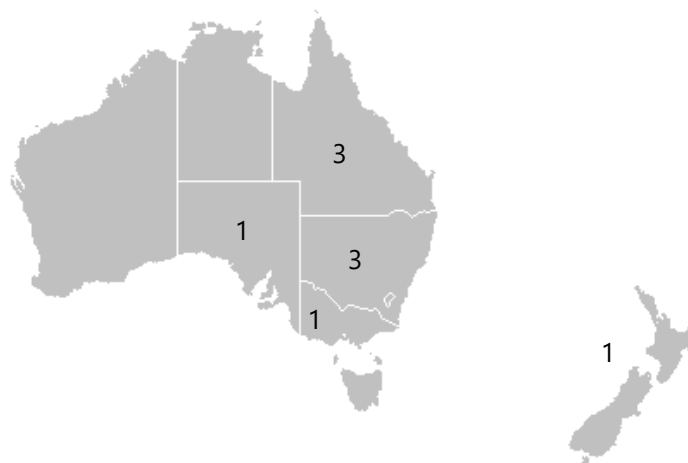
The dashboard and executive summary are stand-alone documents available from the ePPOC Online Portal (EOP).

This report

Participating pain management services

Nine paediatric pain management services provided data for this report. These services are located across Australia (Figure 1) and listed in Appendix D.

Figure 1 – Location of participating pain services



Report period and scope

This report provides information about pain service activity that occurred during the period 1 July 2023 to 30 June 2024. Information is collected from patients and/or their carers/parents, as appropriate.

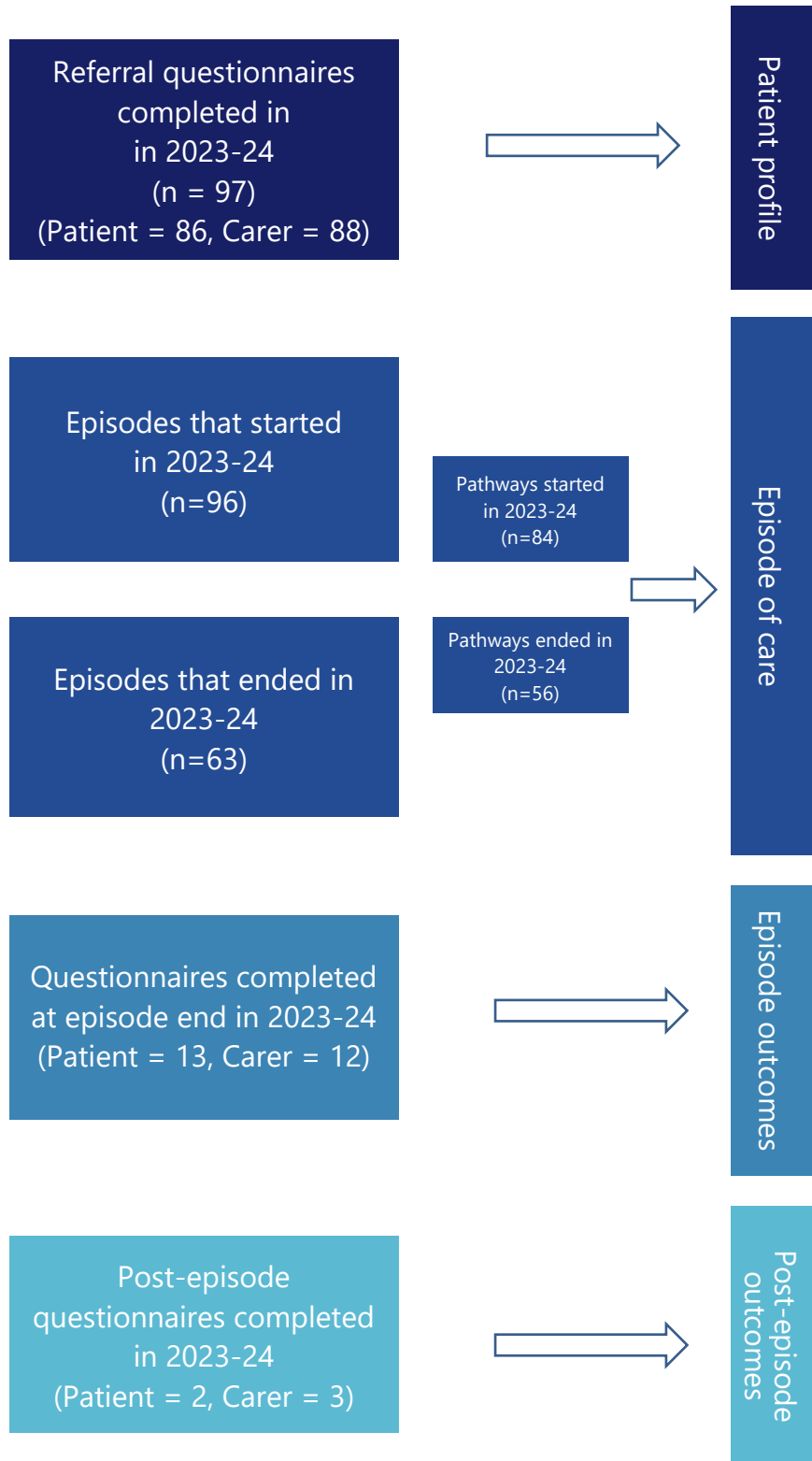
Sections of the report describe:

- The **profile of patients** who began their engagement with the pain service during this period (i.e. completed a referral questionnaire)
- The **episodes of care** that began, services that were provided and the episodes that ended during this period
- **Patient outcomes at the end of the episode** where the patients/carers completed the relevant outcome questionnaires during the period
- **Post-episode patient outcomes** where the patients/carers completed the relevant outcome questionnaires during the period

This information and the report section in which it is presented is depicted in Figure 2.

Note that the same individuals may not be represented in each section of the report.

Figure 2 – The information described in each (colour coded) section of the report



Patient profile

This section provides socio-demographic and clinical information about the people who completed an ePPOC Referral Questionnaire during the period 1 July 2023 to 30 June 2024.

Socio-demographic details

Table 1 – Sex	Enterprise One		All services	
	Number	%	Number	%
Male	38	39.2	155	33.8
Female	57	58.8	296	64.6
Not stated/described	2	2.1	7	1.5
Total	97	100.0	458	100.0

Table 2 – Age (years)	Enterprise One		All services	
	Average	Median	Average	Median
All patients	12.6	13.0	12.7	13.0
- Male	11.1	11.5	12.0	12.0
- Female	13.5	14.0	13.0	14.0
- Sex not stated/described	-	-	-	-

Figure 3 – Age group by sex

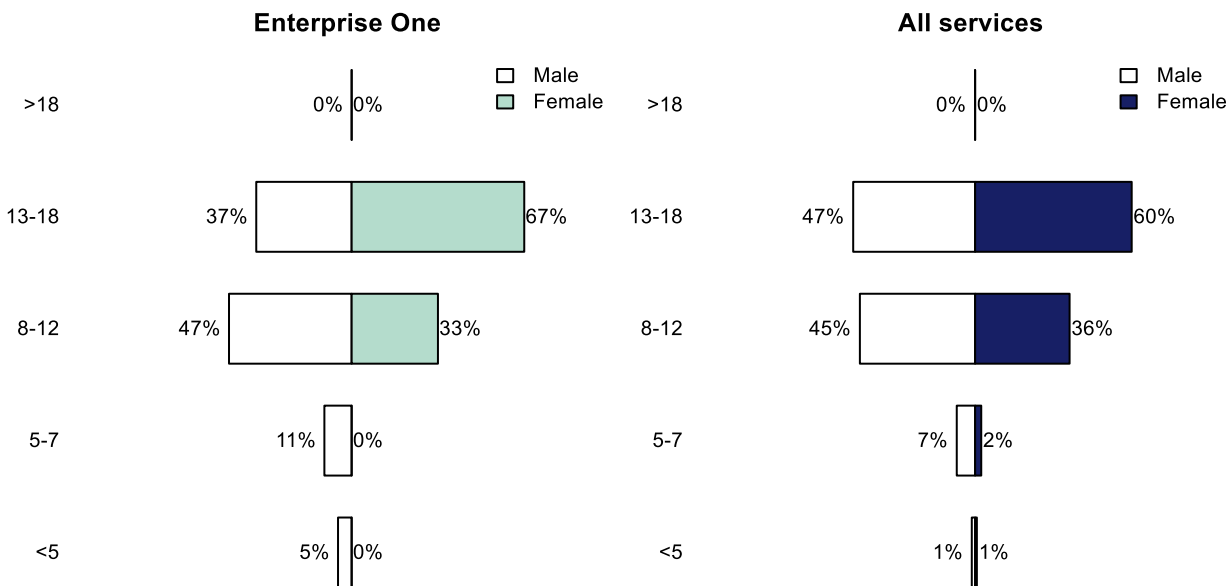
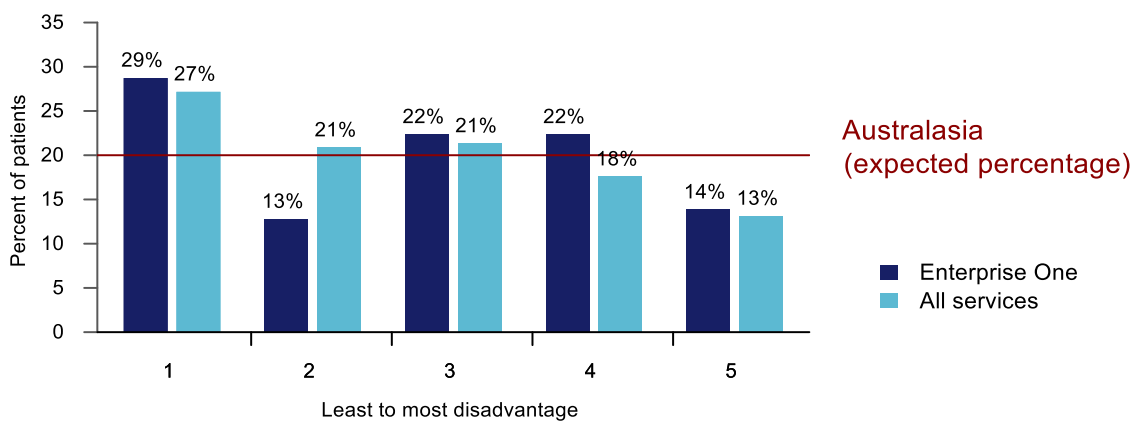


Table 3 – Indigenous status	Enterprise One		All services	
	Number	%	Number	%
Aboriginal but not Torres Strait Islander	8	8.8	28	6.6
Torres Strait Islander but not Aboriginal	0	0.0	0	0.0
Both Aboriginal & Torres Strait Islander	1	1.1	1	0.2
Neither Aboriginal nor Torres Strait Islander	82	90.1	398	93.2
Total	91	100.0	427	100.0

Table 4 – Country of birth	Enterprise One		All services	
	Number	%	Number	%
Australia	84	86.6	399	88.1
New Zealand	5	5.2	23	5.1
Other	8	8.2	31	6.8
Total	97	100.0	453	100.0

Figure 4 – Socioeconomic area disadvantage based on patient postcode



This chart shows patient residential area grouped into five disadvantage quintiles (from least to most disadvantage) such that across the Australian and New Zealand populations, 20% of people live in each disadvantage quintile. It is important to note that the level of disadvantage relates to the *area* the patient lives in rather than the patient.

The chart compares the proportion of your patients who live in each disadvantage quintile to the population of all people seeking pain management in Australasia (*All services*).

The red line shows the expected distribution of disadvantage – Australasia (*expected percentage*).

Table 5 – Referral source	Enterprise One		All services	
	Number	%	Number	%
General practitioner/nurse practitioner	18	18.6	76	16.6
Specialist practitioner	61	62.9	273	59.6
Other pain management service	0	0.0	0	0.0
Public hospital	17	17.5	105	22.9
Private hospital	0	0.0	2	0.4
Rehabilitation provider/private insurer	0	0.0	1	0.2
Other	1	1.0	1	0.2
Total	97	100.0	458	100.0

Table 6 – Has your child previously attended a specialist pain service at a children’s hospital?	Enterprise One		All services	
	Number	%	Number	%
Yes	12	13.8	60	14.7
No	75	86.2	348	85.3
Total	87	100.0	408	100.0

Table 7 – School level	Enterprise One		All services	
	Number	%	Number	%
Preschool	0	0.0	1	0.2
Primary school	31	35.2	151	35.4
High school	55	62.5	264	61.8
Other	2	2.3	11	2.6
Total	88	100.0	427	100.0

Clinical characteristics

Health and comorbidities

Figure 5 – Distribution of Body Mass Index

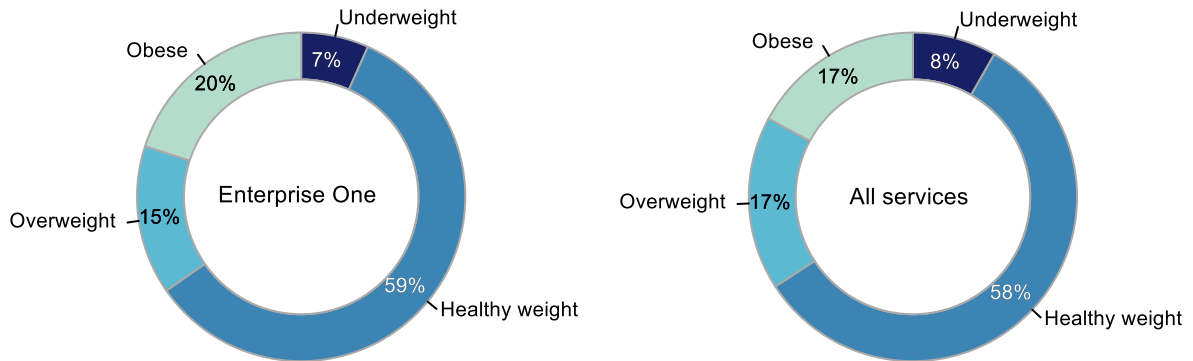


Table 8 – Pain-related health service use in the past 3 months (average number of times used)

	Enterprise One	All services
General practitioner	2.8	2.8
Medical specialist	3.6	2.9
Other health professionals	4.1	4.1
Other therapists	1.0	1.2
Emergency department presentations	2.0	1.2
Hospital admissions	0.5	0.4
Diagnostic tests	2.3	2.1

Table 9 – Comorbidities and disabilities

	Enterprise One		All services	
	Number	%	Number	%
Comorbidities				
- Chronic disease	24	24.7	113	24.7
- Mental health condition	38	39.2	166	36.2
- Cancer	1	1.0	9	2.0
Disabilities				
- Sight impairment	7	7.2	38	8.3
- Hearing impairment	3	3.1	12	2.6
- Intellectual disability	8	8.2	29	6.3
- Physical disability	14	14.4	67	14.6

Pain characteristics

Table 10 – How the main pain began (the precipitating event)	Enterprise One		All services	
	Number	%	Number	%
Injury	11	12.6	73	17.7
After surgery	6	6.9	29	7.0
Illness	7	8.0	55	13.3
No known cause	44	50.6	166	40.3
Other	19	21.8	89	21.6
Total	87	100.0	412	100.0

Table 11 – Pain duration – how long the main pain has been present	Enterprise One		All services	
	Number	%	Number	%
Less than 3 months	5	5.7	33	8.0
3 to 12 months	24	27.6	110	26.8
More than 12 months	58	66.7	268	65.2
Total	87	100.0	411	100.0

Table 12 – Main pain area	Enterprise One		All services	
	Number	%	Number	%
Head	10	13.3	54	14.8
Neck	2	2.7	8	2.2
Chest	5	6.7	19	5.2
Back	9	12.0	53	14.5
Leg	11	14.7	51	13.9
Arm/shoulder	2	2.7	12	3.3
Abdomen	17	22.7	63	17.2
Hands	3	4.0	7	1.9
Feet	3	4.0	32	8.7
Groin/pubic area	4	5.3	10	2.7
Buttocks	0	0.0	0	0.0
Knee	5	6.7	35	9.6
Hip	4	5.3	22	6.0
Total	75	100.0	366	100.0

Table 13 – Number of pain areas	Enterprise One		All services	
	Number	%	Number	%
1	27	31.4	97	23.5
2-3	32	37.2	148	35.8
4-6	11	12.8	93	22.5
7-9	10	11.6	51	12.3
10+	6	7.0	24	5.8
Total	86	100.0	413	100.0

Symptom severity

Age-appropriate outcome measures are collected from patients and carers, as shown in Table 14 and described in Appendix E – Assessment tools.

Table 14 – Assessment tools collected	Completed by
Faces of Pain Scale – Revised	5-7 year olds
Brief Pain Inventory (BPI) pain severity questions	8-18 year olds; Carers
Pediatric Quality of Life Inventory (PedsQL)	5-18 year olds; Carers
Functional Disability Inventory (FDI)	8-18 year olds
Bath Adolescent Pain Questionnaire – pain related worries questions (BAPQ)	13-18 year olds
Bath Parent Impact Questionnaire (BPIQ)	Carers

Table 15 – Assessment tool scores, average (std. deviation)	Enterprise One		All services	
	Patient	Carer	Patient	Carer
Young children (5-7 years)	(n=1)	(n=6)	(n=1)	(n=19)
Pain severity	-	5.8 (2.2)	-	4.7 (2.0)
Quality of life Total score	0.0 (-)	32.9 (17.9)	0.0 (-)	46.0 (20.8)
- Psychosocial	-	46.3 (14.8)	-	55.7 (16.5)
- Physical	-	25.0 (21.7)	-	33.6 (27.7)
- Sleep	-	33.3 (20.4)	-	40.8 (33.6)
Children (8-12 years)	(n=33)	(n=33)	(n=169)	(n=167)
Pain severity	5.4 (2.0)	5.5 (1.8)	5.3 (1.9)	5.4 (1.8)
Quality of life Total score	53.9 (18.2)	46.1 (20.5)	48.8 (18.2)	44.4 (18.7)
- Psychosocial	57.6 (18.0)	48.7 (20.7)	53.2 (19.0)	49.5 (19.4)
- Physical	47.3 (24.8)	41.5 (24.5)	40.7 (22.6)	34.8 (23.1)
- Sleep	43.2 (31.4)	34.8 (26.5)	35.2 (29.6)	34.7 (29.3)
Functional disability	22.9 (12.6)	-	25.6 (12.0)	-
Adolescents (13-18 years)	(n=52)	(n=49)	(n=244)	(n=243)
Pain severity	5.1 (1.7)	5.1 (1.7)	5.1 (1.7)	5.3 (1.7)
Quality of life Total score	46.5 (17.0)	44.7 (15.9)	46.1 (16.7)	42.6 (15.9)
- Psychosocial	49.8 (18.6)	49.1 (16.9)	50.0 (17.6)	46.6 (16.9)
- Physical	40.5 (19.1)	36.6 (20.1)	39.0 (19.3)	35.2 (20.7)
- Sleep	26.9 (27.0)	28.1 (26.3)	33.3 (31.6)	30.0 (28.0)
Functional disability	26.7 (11.8)	-	26.4 (11.1)	-
Pain-related worries	15.2 (5.6)	-	15.7 (5.5)	-
All ages	(n=86)	(n=88)	(n=414)	(n=429)
Pain severity	5.3 (1.8)	5.3 (1.8)	5.2 (1.8)	5.3 (1.8)
Quality of life Total score	48.8 (18.4)	44.6 (17.9)	47.1 (17.5)	43.5 (17.2)
- Psychosocial	52.8 (18.7)	48.8 (18.1)	51.3 (18.2)	48.1 (18.0)
- Physical	43.2 (21.7)	37.7 (22.1)	39.7 (20.7)	35.0 (21.9)
- Sleep	33.2 (29.7)	31.0 (26.0)	34.1 (30.8)	32.3 (28.8)
Functional disability	25.2 (12.2)	-	26.1 (11.4)	-

The distribution of scores by severity category are shown in Figure 6 and Figure 7 for pain and functional disability. PedsQL information is reported in Table 16 (percent of patients at risk of impaired quality of life) and Figure 8 (distribution of sleep item scores by severity category)

Figure 6 – Pain severity category at referral (%)

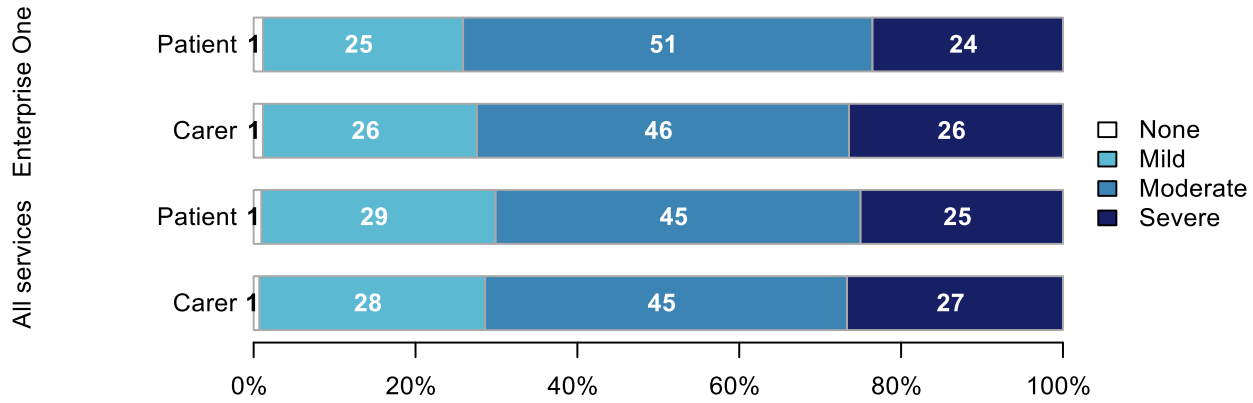
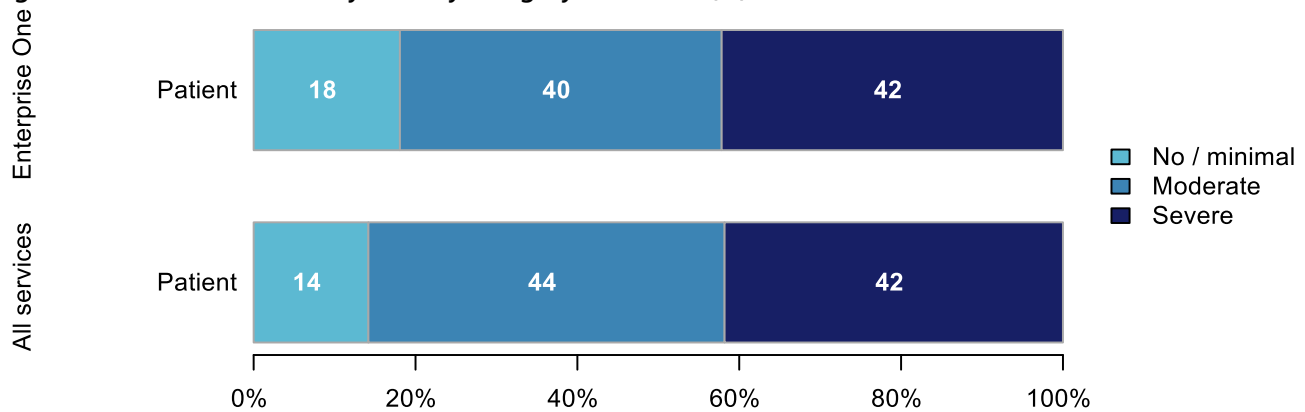


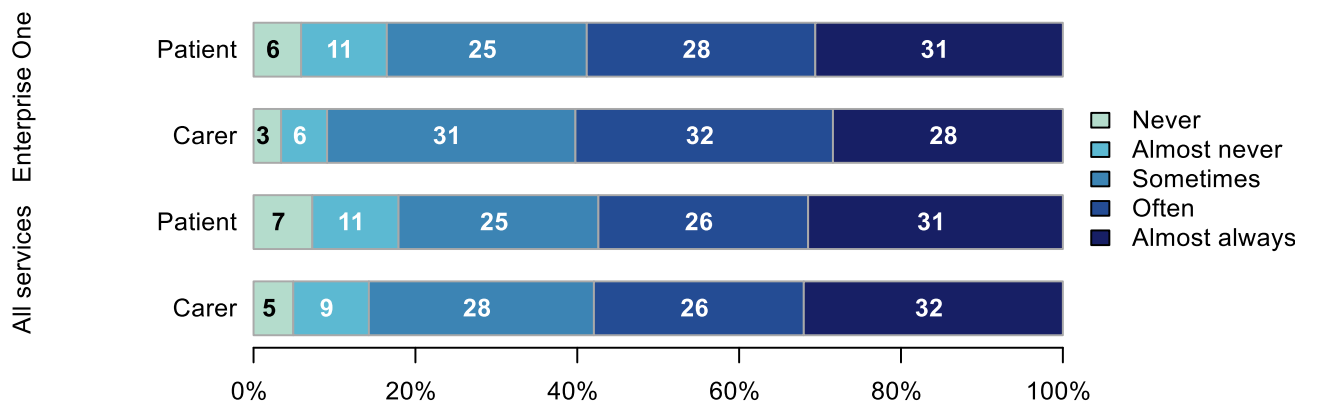
Figure 7 – Functional disability severity category at referral (%)



	Enterprise One		All services	
	Number	%	Number	%
Patient reported	74	86.0	369	89.1
Carer reported	76	87.4	385	90.2

¹ Indicated in the PedsQL by total scores below 69.7 for child self-report and below 65.4 for adult proxy report.

Figure 8 – Sleep severity category at referral (%)



Medication use

Information about the types of medications patients use and the frequency of their use is carer reported. Figure 9 through to Figure 15 below show medication use at referral by drug type and frequency of use.

Figure 9 – Paracetamol only medicines (%)

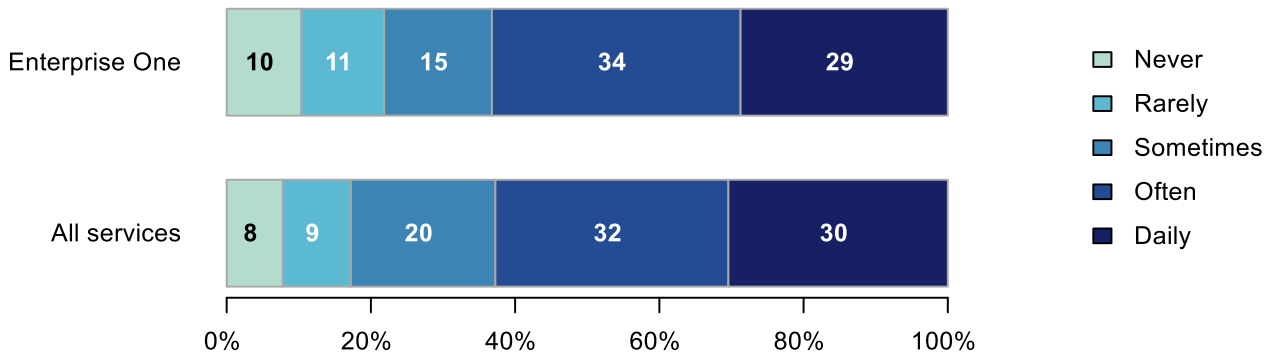


Figure 10 – Anti-inflammatory medicines - non-prescription (%)

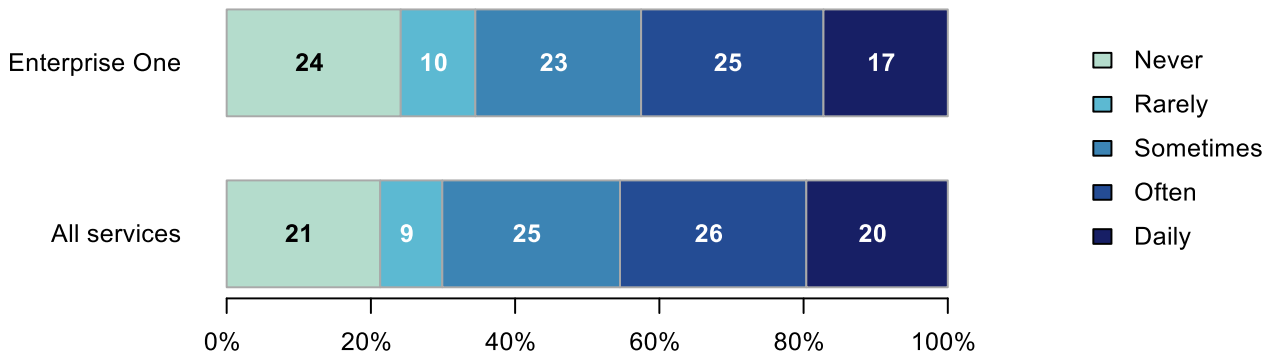


Figure 11 – Anti-inflammatory medicines – prescription (%)

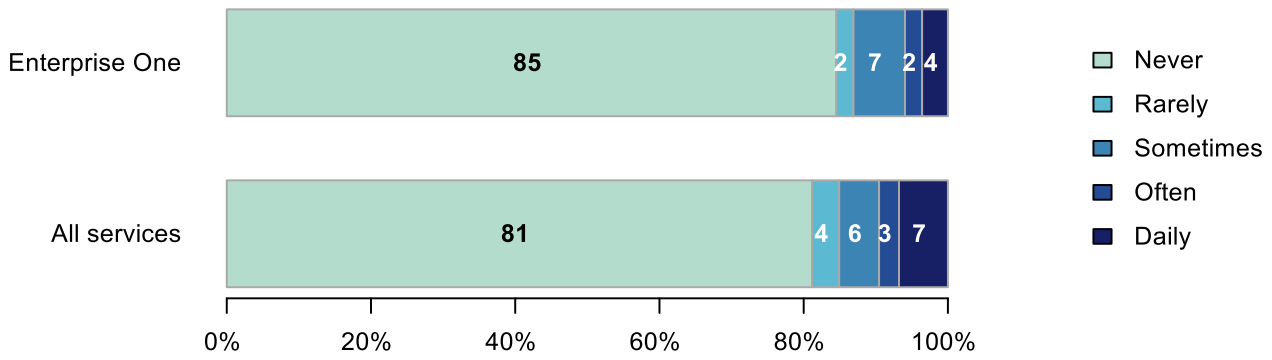


Figure 12 – Complementary or alternative medicines (%)

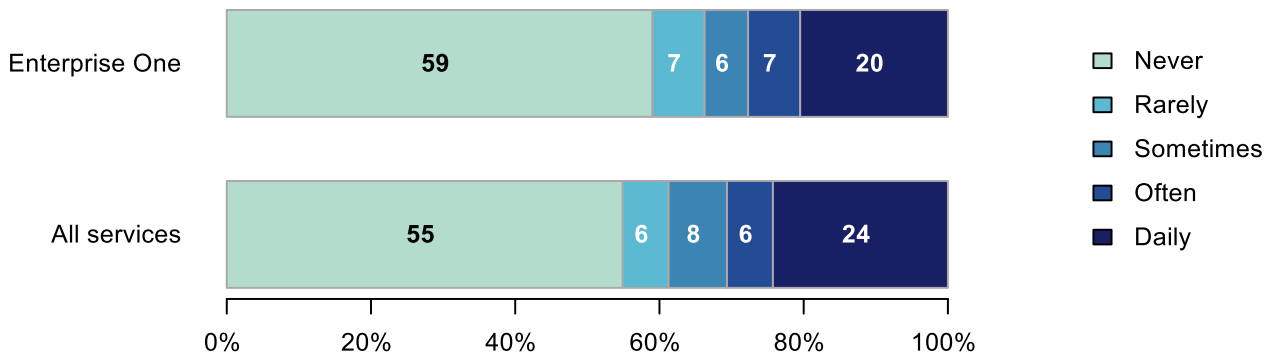


Figure 13 – Opioid medicines containing codeine (%)

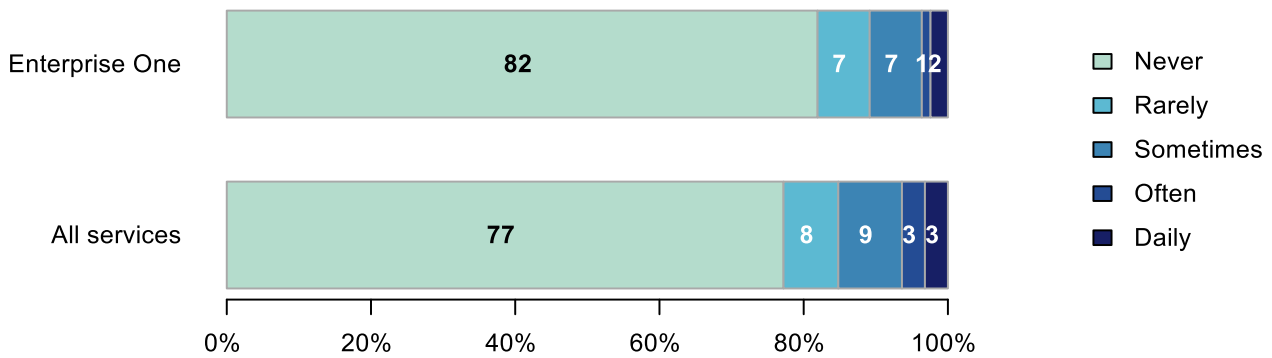


Figure 14 – Opioid medications other than codeine (%)

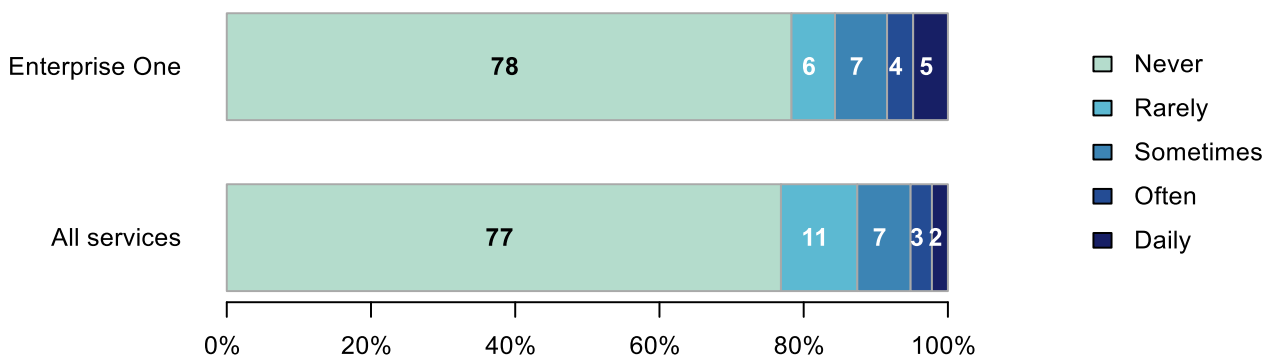
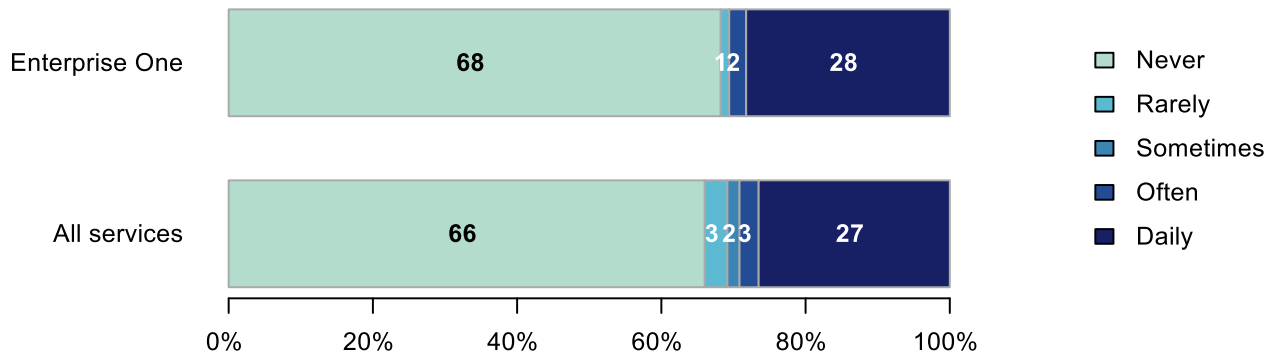


Figure 15 – Medication for nerve pain (%)



Work status and productivity

Information about work status is shown in Table 17 and Table 19 for adolescents and carers.

For patients and/or carers who reported that they were working full- or part-time, additional information was collected (Table 18 and Table 20). This information allowed calculation of:

- The percent of time missed from work due to pain (absenteeism)
- The percent of work impairment while working due to pain (lost productivity)
- Overall work impairment due to pain, reported as a percentage. Overall work impairment takes into account both absenteeism and lost productivity.

Table 17 – Employment status (adolescents)	Enterprise One	All services
	n (%)	n (%)
Working full-time	1 (1.9)	1 (0.4)
Working part-time	8 (15.4)	57 (23.7)
Unable to work due to pain	4 (7.7)	28 (11.6)
Unable to work due to a condition other than pain	1 (1.9)	7 (2.9)
Not working by choice	10 (19.2)	26 (10.8)
Seeking employment	4 (7.7)	12 (5.0)
Too young to work	24 (46.2)	110 (45.6)
Total	52 (100.0)	241 (100.0)

Table 18 – Work productivity and impairment (%) for adolescents working full- or part-time	Enterprise One	All services
	Work time missed due to pain	43.6
Pain affected work productivity	53.3	52.1
Overall work impairment	67.7	56.8

Table 19 – Employment status (carer)	Enterprise One	All services
	n (%)	n (%)
Working full-time	24 (27.6)	136 (32.5)
Working part-time	31 (35.6)	160 (38.3)
Unable to work due to child's pain	16 (18.4)	60 (14.4)
Not working by choice	13 (14.9)	50 (12.0)
Seeking employment	3 (3.4)	12 (2.9)
Total	87 (100.0)	418 (100.0)

Table 20 – Work productivity and impairment (%) for carers working full- or part-time	Enterprise One	All services
	Work time missed due to pain	16.0
Pain affected work productivity	33.8	40.4
Overall work impairment	40.3	48.4

School impact

Table 21 – School days missed in the previous two weeks (average days)	Enterprise One	All services
Young child	2.8	2.7
Child	4.1	3.9
Adolescent	4.9	4.6

Carer impact

The impact of the child's pain on the carer is measured using the Bath Adolescent Pain Parent Impact Questionnaire. This is completed by carers regardless of the age of the patient. Average scores for each of the sub-scales is shown in Table 22.

Table 22 – Scores on the Bath Parent Impact Questionnaire, average (std. deviation)	Enterprise One	All services
	(n=79)	(n=383)
Depression	14.3 (7.3)	15.6 (6.7)
Anxiety	9.8 (5.7)	10.5 (5.5)
Catastrophising	10.7 (4.5)	10.7 (4.3)
Self-blame/helplessness	13.8 (6.2)	13.5 (6.2)
Partner relationship	10.8 (6.7)	11.0 (5.8)
Leisure functioning	16.7 (6.2)	17.5 (5.5)
Parental behaviour	27.6 (6.1)	28.1 (6.1)
Parental strain	8.8 (5.3)	8.9 (5.3)

The episode of care

An episode of care is a continuous period of care for a person in one pain management service. An episode begins with the first clinical contact with the patient and ends when active treatment at the pain service is completed. This section of the report provides a description of waiting time, how episodes started and ended, and the services provided to patients.

Waiting time

Wait time is measured from:

- referral to the start of the episode (i.e. the date the referral is received at the pain management service to the first clinical contact); and
- referral to the start of the first treatment pathway (i.e. the date the referral is received at the pain management service to the date that active treatment begins, e.g. a group pain program, procedure, series of individual appointments)

Table 23 – Waiting time	Enterprise One	All services
Time from referral to the start of the episode		
– average (days)	55.4	53.8
– median (days)	26.0	26.0
Time from referral to the start of the first treatment pathway		
– average (days)	105.2	98.7
– median (days)	59.0	56.0

Figure 16 – Time from referral to episode start, shown as a percent of people in each time category

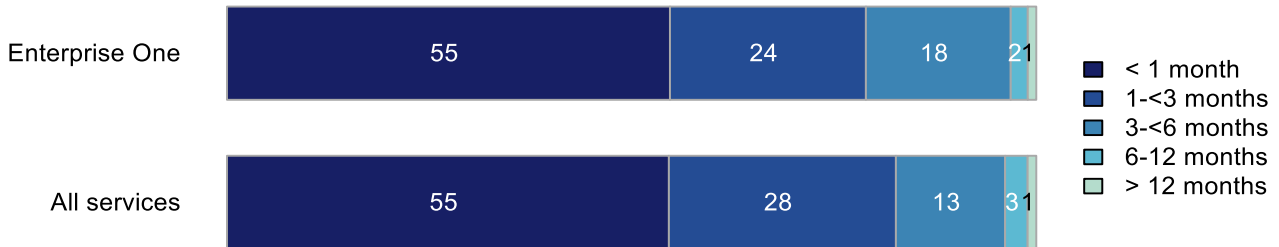
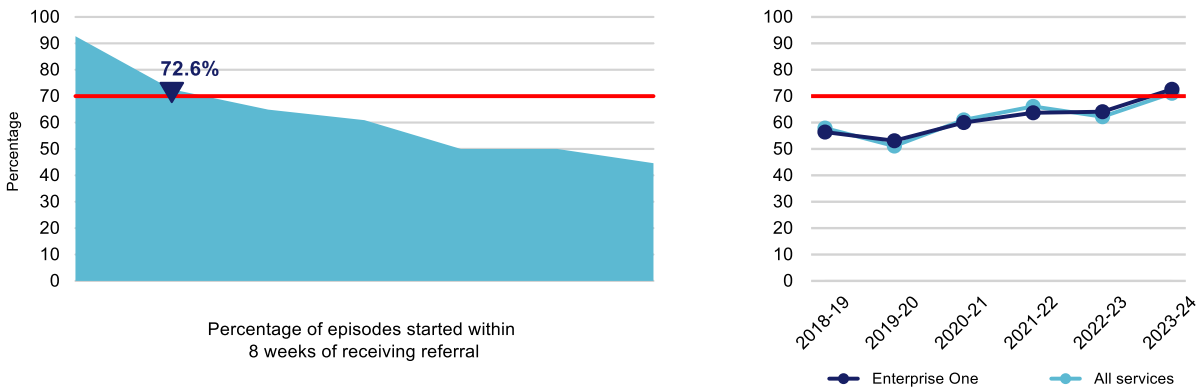


Figure 17 compares the proportion of patients at your service who were seen within eight weeks, compared to all other services. The time series chart shows change in this measure over the past five years.

Figure 17 – Wait time (patients seen within 8 weeks), benchmark profile and time series



Episode start

During the period 1 July 2023 to 30 June 2024, 96 patients started an episode of care at your service.

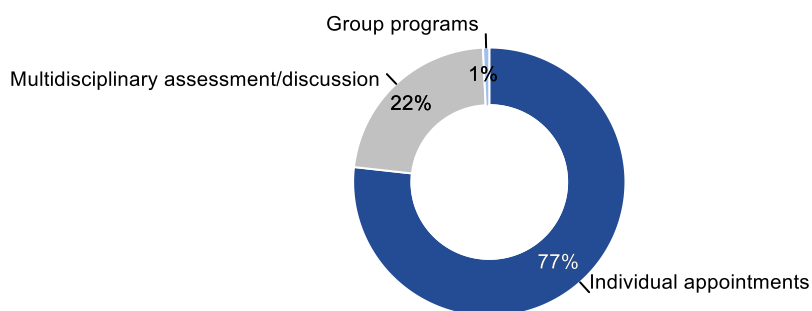
Table 24 – How the episode started	Enterprise One		All services	
	Number	%	Number	%
Multidisciplinary assessment/treatment	54	56.3	267	56.1
Single clinician assessment/treatment	42	43.8	209	43.9
Education/orientation program	0	0.0	0	0.0
Total	96	100.0	476	100.0

Services provided

Table 25 – Service events provided at your service (total hours)	Total hours	Via telehealth ²
Individual appointment with ...		
– medical practitioner	90.0	6.0
– physiotherapist	42.0	10.5
– psychologist	82.0	8.0
– occupational therapist	8.0	3.8
– nurse	3.0	1.5
– one or more clinicians	206.3	28.1
– other	34.8	11.8
Multidisciplinary team assessment	99.0	1.5
Multidisciplinary panel discussion	37.5	0.0
Telephone/email consultation with patient/carer	28.5	0.5
Telephone/email consultation with another clinician	19.2	0.0
Pain management program – group	4.5	0.0
Pain management program – individual	0.0	0.0
Procedural intervention		
– implant (drug delivery/refill)	0.0	0.0
– implant (neurostimulation/trial)	0.0	0.0
– non-implant (for therapeutic intent)	0.0	0.0
– cancer block	0.0	0.0
– other (for diagnostic intent)	0.0	0.0
Education/orientation program	0.0	0.0
Other	0.3	0.0
Total	655.0	71.6

² Telehealth hours are a subset of total hours

Figure 18 – Service events, percentage by type



Treatment pathways

84 treatment pathways were started during the period 1 July 2023 to 30 June 2024. The number and proportion of each type are shown in Table 26.

	Enterprise One		All services	
	Number	%	Number	%
Group pain program	4	4.8	18	4.3
Individual appointments	78	92.9	390	93.8
Concurrent (group and individual)	2	2.4	8	1.9
Other	0	0.0	0	0.0
Total	84	100.0	416	100.0

	Enterprise One		All services	
	Number	%	Number	%
Care plan only	1	1.2	6	1.5
Remotely supported care	1	1.2	3	0.7
In clinic care	81	97.6	399	97.8
Total	83	100.0	408	100.0

Episode end

During this period, 63 patients completed an episode of care at your service.

	Enterprise One		All services	
	Number	%	Number	%
Treatment complete – self management/referral to primary care	41	65.1	219	64.0
Referral to another pain service	4	6.3	10	2.9
Patient discontinued by choice	4	6.3	26	7.6
Died	0	0.0	1	0.3
Active treatment complete – ongoing review	8	12.7	47	13.7
Lost to follow-up/not for follow-up	6	9.5	38	11.1
Total	63	100.0	342	100.0

Table 29 – Length of the episode (lapsed days)	Enterprise One	All services
Average	357.6	336.6
Median	300.5	274.0

Table 30 – Length of the episode (lapsed days) - distribution	Enterprise One		All services	
	Number	%	Number	%
Less than 1 month	1	1.7	12	3.6
1 to < 3 months	5	8.6	14	4.3
3 to < 6 months	15	25.9	85	25.8
6 to <9 months	5	8.6	37	11.2
9 to 12 months	9	15.5	67	20.4
More than 12 months	23	39.7	114	34.7
Total	63	100.0	342	100.0

Table 31 shows the average service events (total and by telehealth mode) delivered for an episode of care.

Table 31 – Service duration (average hours)	Enterprise One		All services	
	Total	Telehealth	Total	Telehealth
Individual appointment with ...				
– medical practitioner	1.3	0.2	1.0	0.2
– physiotherapist	0.8	0.2	1.0	0.1
– psychologist	1.3	0.4	1.7	0.4
– occupational therapist	0.4	0.3	0.4	0.2
– nurse	0.1	0.0	0.0	0.0
– one or more clinicians	3.5	1.4	4.1	1.1
– other	1.0	0.6	0.8	0.3
Multidisciplinary team assessment	2.2	0.1	2.2	0.2
Multidisciplinary panel discussion	0.8	0.0	0.9	0.0
Telephone/email consultation with patient/carer	0.4	0.0	0.5	0.0
Telephone/email consultation with another clinician	0.5	0.0	0.5	0.0
Pain management program – group	0.0	0.0	0.0	0.0
Pain management program – individual	0.0	0.0	0.1	0.0
Procedural intervention				
– implant (drug delivery/refill)	0.0	0.0	0.0	0.0
– implant (neurostimulation/trial)	0.0	0.0	0.0	0.0
– non-implant (for therapeutic intent)	0.0	0.0	0.0	0.0
– cancer block	0.0	0.0	0.0	0.0
– other (for non-therapeutic intent)	0.0	0.0	0.0	0.0
Education/orientation program	0.0	0.0	0.0	0.0
Other	0.3	0.2	0.3	0.1
Total	12.3	3.5	13.3	2.6

Patient outcomes at the end of the episode

During the period 1 July 2023 to 30 June 2024, 13 of your patients completed an ePPOC questionnaire at the end of their episode of care. This section shows the outcomes for these patients, reported as change from referral to the end of the episode.

Pain

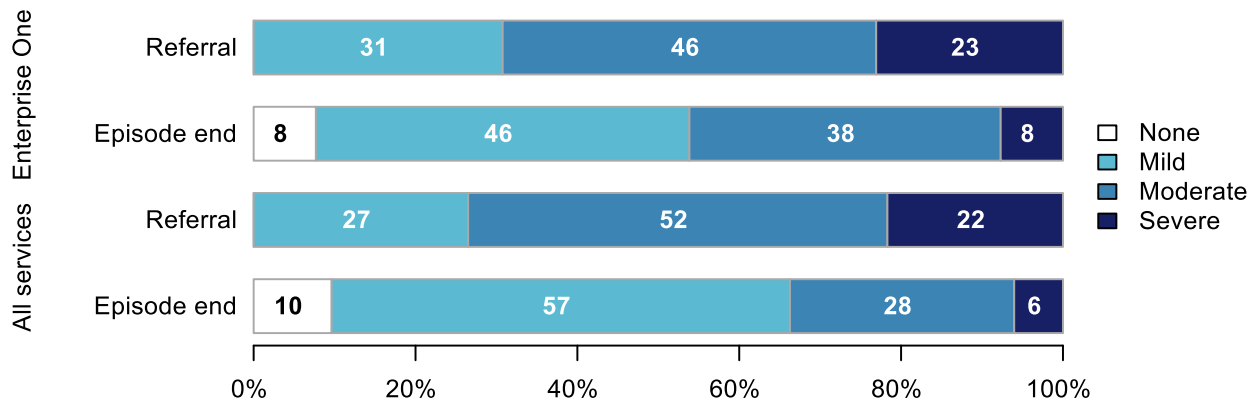
Pain severity

The severity of pain is measured using either the Faces of Pain Scale (Revised) or the Brief Pain Inventory (BPI), depending on the age of the patient. Average pain scores for patient-reported pain are shown in Table 32, with the proportion in each severity category in Figure 19.

Average pain scores reported by the carer are shown in Table 33.

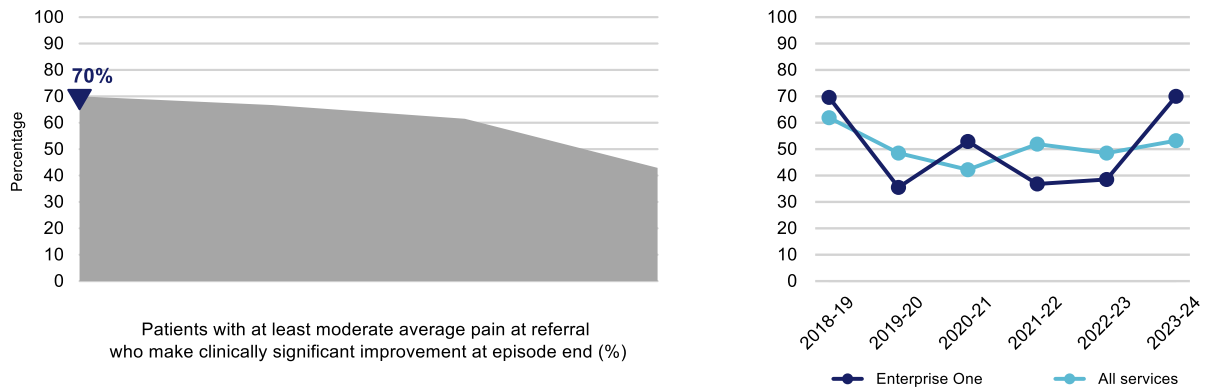
	Enterprise One n = 13		All services n = 83	
	Referral	Episode end	Referral	Episode end
Pain severity	5.5	3.5	5.5	3.2
- Worst pain	7.8	6.0	7.7	5.3
- Least pain	3.2	1.6	3.3	1.4
- Average pain	5.7	3.2	5.5	3.2
- Pain now	5.2	3.1	5.2	2.9

Figure 19 – Pain severity category at referral and episode end (patient reported)



	Enterprise One n = 12		All services n = 77	
	Referral	Episode end	Referral	Episode end
Pain severity	5.5	2.8	5.5	3.2
- Worst pain	8.4	5.2	7.7	4.8
- Least pain	3.7	1.3	3.6	2.0
- Average pain	5.9	2.9	5.7	3.2
- Pain now	4.1	1.9	4.9	2.7

Figure 20 – Average pain indicator and time series



The benchmark chart above (see Appendix C for tips on interpretation) shows the percentage of patients reporting moderate or worse pain at referral who make a clinically significant improvement at episode end.

Enterprise One:	7 of 10 (70.0%)
All services:	33 of 62 (53.2%)

Pain frequency

Pain frequency is reported by children and adolescents (i.e. 8-18 year olds) and carers. Table 34 and Figure 21 report the percent of patients reporting the frequency at which pain is experienced, at referral and at the end of the episode. Carer reported results are shown in Table 35.

Table 34 – Pain frequency at referral and episode end (%) (patient reported)	Enterprise One n = 13		All services n = 83	
	Referral	Episode end	Referral	Episode end
Always present (same intensity)	15.4	0.0	8.4	4.8
Always present (varying intensity)	46.2	38.5	65.1	36.1
Often present	15.4	7.7	16.9	9.6
Occasionally present	15.4	30.8	7.2	16.9
Rarely present	7.7	15.4	2.4	26.5
Pain no longer present	0.0	7.7	0.0	6.0
Total	100.0	100.0	100.0	100.0

Figure 21 – Pain frequency – distribution at referral and episode end (patient reported)

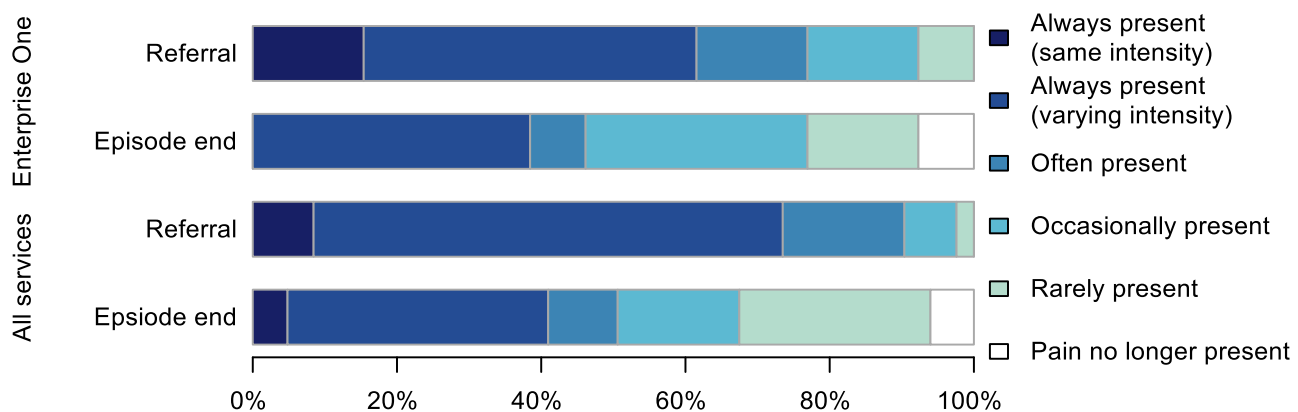


Table 35 – Pain frequency at referral and episode end (%) (carer reported)	Enterprise One n = 12		All services n = 77	
	Referral	Episode end	Referral	Episode end
Always present (same intensity)	8.3	0.0	7.8	1.3
Always present (varying intensity)	41.7	33.3	71.4	40.3
Often present	25.0	8.3	13.0	11.7
Occasionally present	16.7	16.7	5.2	9.1
Rarely present	8.3	33.3	2.6	24.7
Pain no longer present	0.0	8.3	0.0	13.0
Total	100.0	100.0	100.0	100.0

Quality of Life

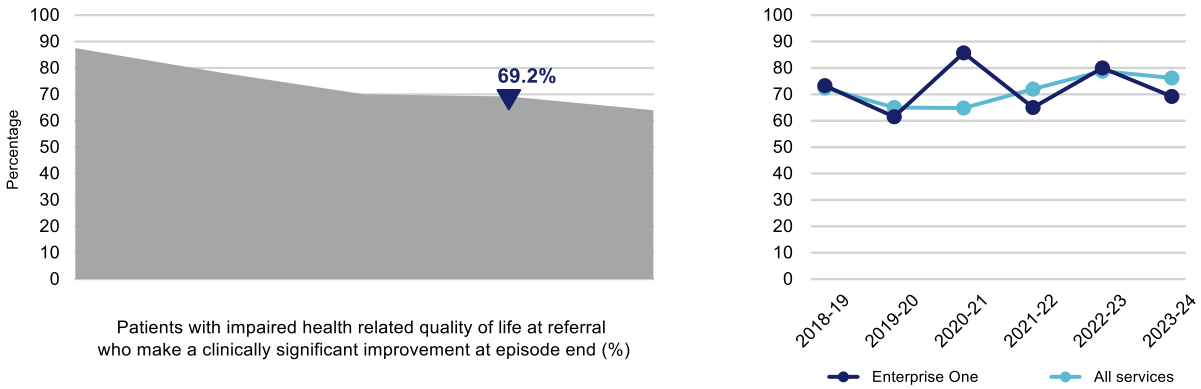
Quality of life is measured using the Pediatric Quality of Life scale (PedsQL), and is completed by carers and children of all ages. Patient-reported total and sub-scale scores are shown in Table 36, with carer scores in Table 37.

Table 36 – Quality of life score at referral and episode end (patient reported)	Enterprise One n = 13		All services n = 84	
	Referral score	Episode end	Referral score	Episode end
Sleep	28.8	53.8	29.8	53.6
Physical	44.7	58.0	37.0	60.2
Emotional	52.3	61.9	47.4	67.0
Social	56.5	62.3	60.8	71.1
School	45.8	54.6	44.1	58.0
Psychosocial	51.5	59.6	50.9	65.5
Total score	49.2	59.1	46.1	63.6

Table 37 – Quality of life score at referral and episode end (carer reported)	Enterprise One n = 12		All services n = 79	
	Referral score	Episode end	Referral score	Episode end
Sleep	27.1	43.8	32.4	52.9
Physical	38.6	57.9	30.6	54.2
Emotional	38.8	50.6	43.0	57.6
Social	46.3	50.4	50.3	62.7
School	44.2	56.3	41.9	58.6
Psychosocial	43.1	52.5	44.9	59.5
Total score	41.9	53.6	40.1	57.5

Table 38 – Patient 'at risk status' for impaired quality of life at referral and episode end (%)	Enterprise One		All services	
	Referral	Episode end	Referral	Episode end
Patient reported	12 of 13 (92.3%)	10 of 13 (76.9%)	79 of 84 (94.0%)	47 of 84 (56.0%)
Carer reported	11 of 12 (91.7%)	9 of 12 (75.0%)	76 of 79 (96.2%)	55 of 79 (69.6%)

Figure 22 – Quality of life indicator and time series



The chart above shows the percentage of patients reporting 'at risk status' for impaired health-related quality of life at referral who make a clinically significant improvement at episode end.

Enterprise One: 9 of 13 (69.2%)
 All services: 64 of 84 (76.2%)

Figure 23 – Patient reported sleep severity at referral and episode end

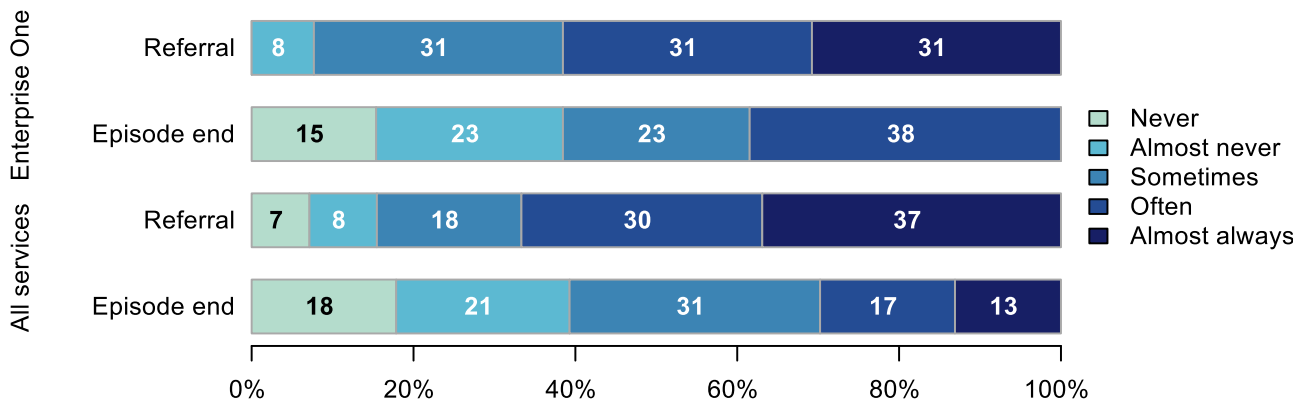
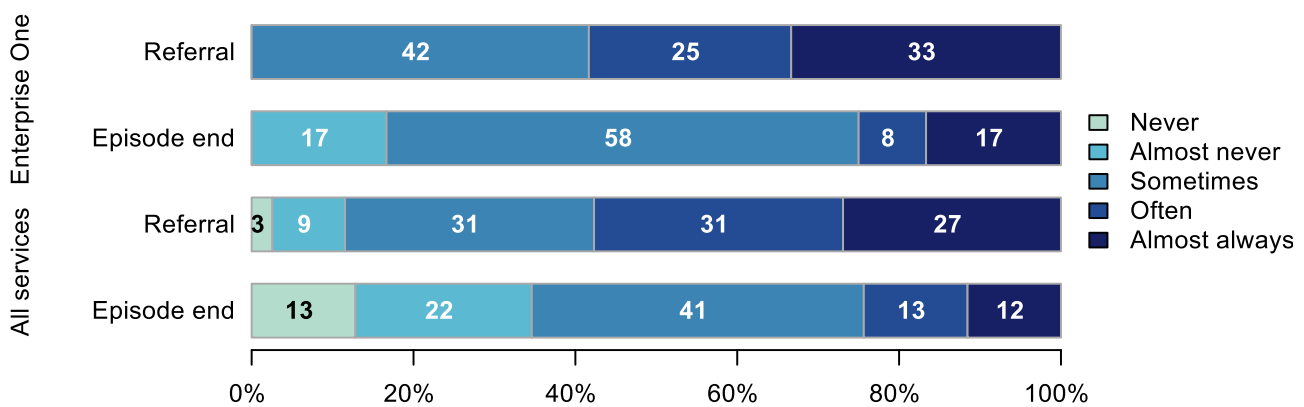


Figure 24 – Carer reported sleep severity at referral and episode end



Functional disability

Functional disability is measured using the Functional Disability Inventory, and is completed by patients aged 8 and over. Average scores at referral and episode end are shown in Table 39. The proportion of patients in each severity category at referral and episode end is shown in Figure 25.

Table 39 – Functional disability at referral and episode end	Enterprise One n = 13		All services n = 83	
	Referral score	Episode end	Referral score	Episode end
Functional disability score	23.1	13.8	27.2	15.1

Figure 25 – Disability severity category at referral and episode end

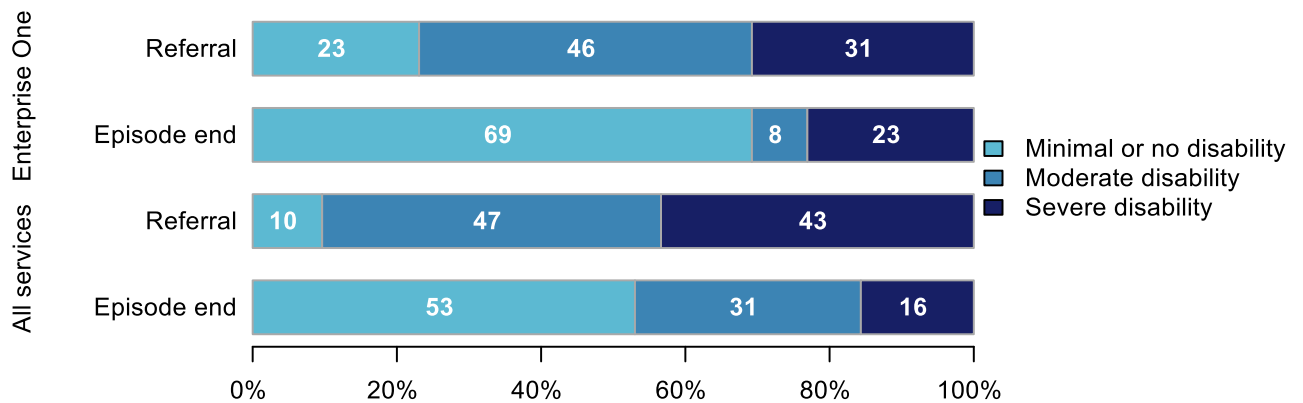
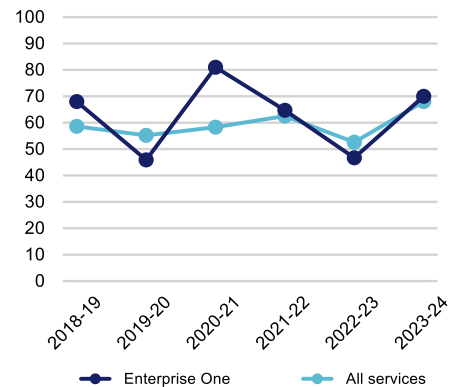
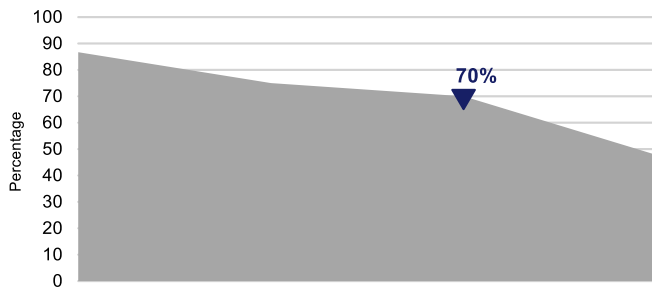


Figure 26 – Functional disability indicator and time series



The benchmark chart above shows the percentage of patients reporting moderate or worse disability at referral who make a clinically significant improvement at episode end.

Enterprise One: 7 of 10 (70.0%)
All services: 51 of 75 (68.0%)

Pain-related worry

Pain-related worries are measured using Section 5 of the Bath Adolescent Pain Questionnaire. This is completed by patients aged 13 and over.

Table 40 – Average pain-related worry scores at referral and episode end	Enterprise One n = 6		All services n = 49	
	Referral score	Episode end	Referral score	Episode end
Total score	12.3	9.9	15.6	10.4

Medication use

Figure 27 to Figure 33 show the change in use of medications by type from referral to episode end.

Figure 27 – Paracetamol only use at referral and episode end (%)

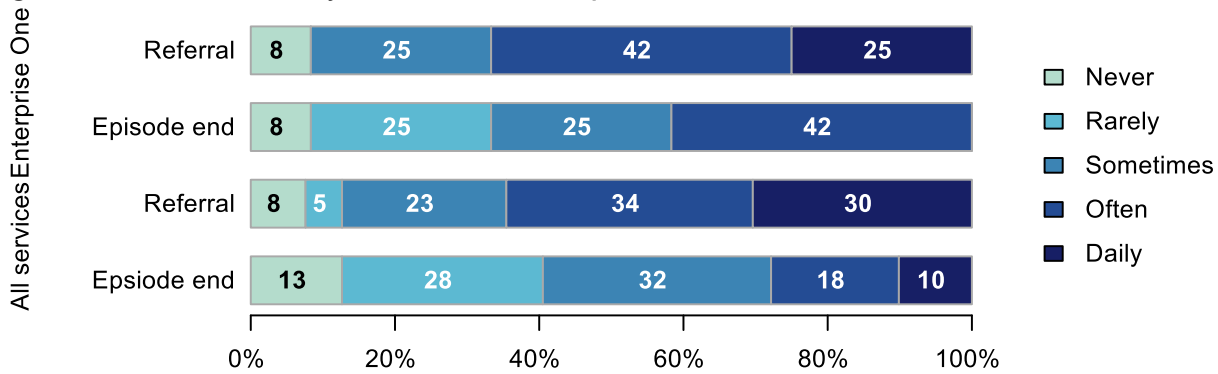


Figure 28 – Anti-inflammatory (non-prescription) use at referral and episode end (%)

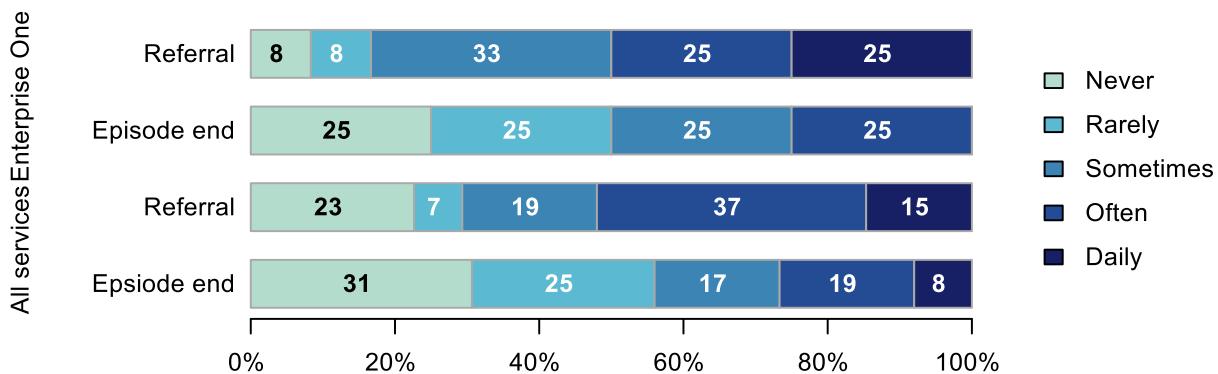


Figure 29 – Anti-inflammatory (prescription) use at referral and episode end (%)

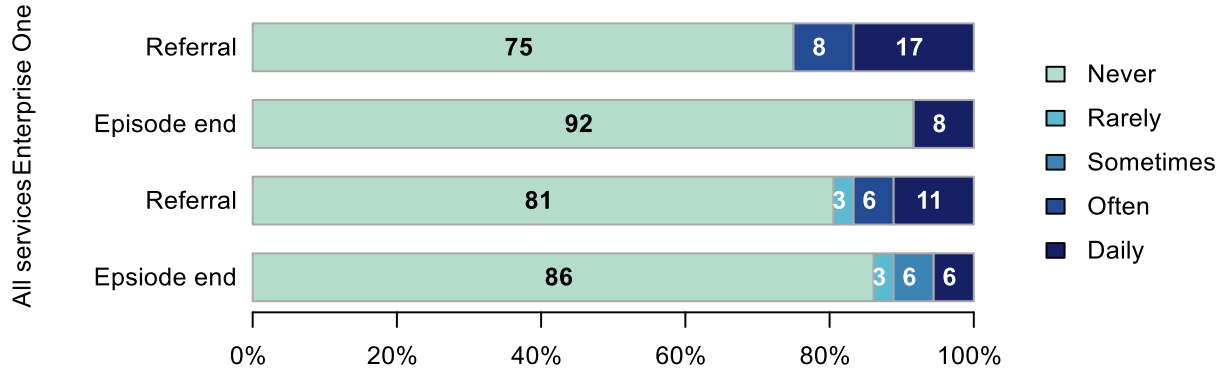


Figure 30 – Complementary or alternative medication use at referral and episode end (%)

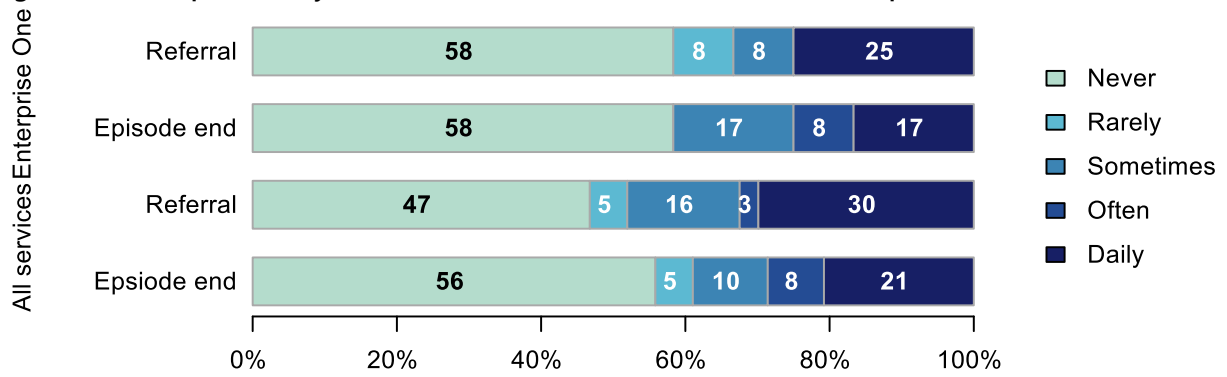


Figure 31 – Opioid medicines containing codeine use at referral and episode end (%)

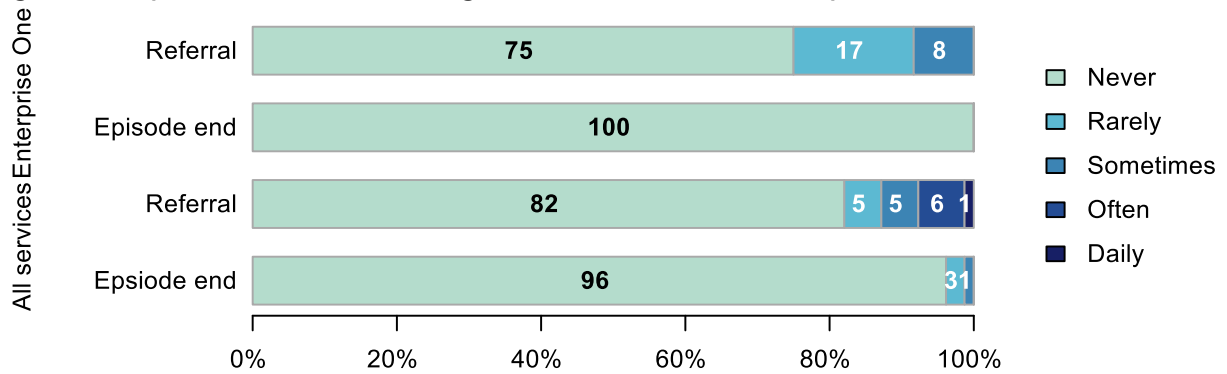


Figure 32 – Opioid medication use (other than codeine) at referral and episode end (%)

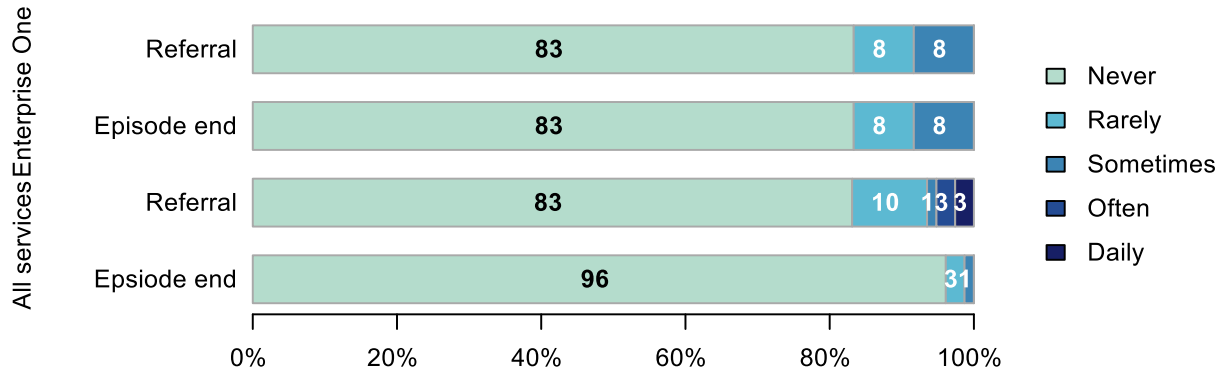
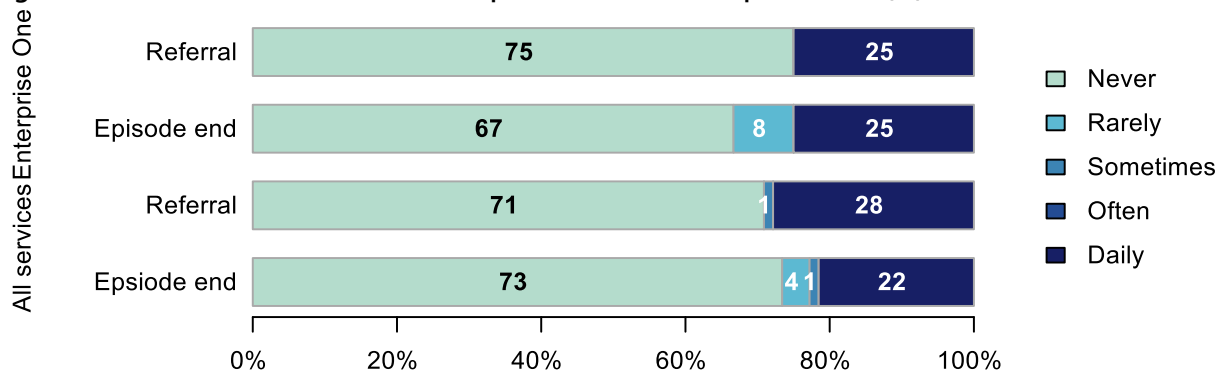


Figure 33 – Use of medications for nerve pain at referral and episode end (%)



Health service utilisation

Table 41 reports the average number of times patients used each health service type in the last three months for pain-related reasons.

Table 41 – Pain-related health service use in the past 3 months, reported at referral and episode end	Enterprise One		All services	
	Referral	Episode end	Referral	Episode end
General practitioner	1.9	1.8	2.6	1.2
Medical specialist	2.8	1.8	2.6	1.2
Other health professionals	3.3	3.0	3.2	3.8
Other therapist	1.3	0.9	1.1	0.8
Emergency department presentations	0.6	0.5	0.6	0.2
Hospital admissions	0.2	0.1	0.2	0.1
Diagnostic tests	1.5	0.9	2.0	0.5

Work status and productivity

The following information is included for carers and adolescent patients who completed an episode and reported work status and/or productivity information at referral and episode end.

Table 42 – Patient work status at referral and episode end	Enterprise One n (%)		All services n (%)	
	Referral	Episode end	Referral	Episode end
Working full-time	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Working part-time	1 (16.7)	2 (33.3)	6 (12.5)	13 (27.1)
Unable to work due to pain	2 (33.3)	2 (33.3)	13 (27.1)	10 (20.8)
Unable to work due to a condition other than pain	0 (0.0)	0 (0.0)	1 (2.1)	0 (0.0)
Not working by choice	1 (16.7)	1 (16.7)	6 (12.5)	9 (18.8)
Seeking employment	0 (0.0)	0 (0.0)	2 (4.2)	7 (14.6)
Too young to work	2 (33.3)	1 (16.7)	20 (41.7)	9 (18.8)
Total	6 (100.0)	6 (100.0)	48 (100.0)	48 (100.0)

Table 43 – Carer work status at referral and episode end	Enterprise One n (%)		All services n (%)	
	Referral	Episode end	Referral	Episode end
Working full-time	4 (33.3)	7 (58.3)	17 (23.6)	22 (30.6)
Working part-time	7 (58.3)	4 (33.3)	35 (48.6)	32 (44.4)
Unable to work due to child's pain	0 (0.0)	0 (0.0)	6 (8.3)	3 (4.2)
Not working by choice	1 (8.3)	1 (8.3)	14 (19.4)	15 (20.8)
Seeking employment	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Total	12 (100.0)	12 (100.0)	72 (100.0)	72 (100.0)

For the carers and adolescent patients who reported that they were working full or part-time at referral and episode end, additional information relating to work hours missed due to pain and lost productivity while at work was collected (Table 44 and Table 45)

Table 44 – Patient work productivity and impairment (%) for those working full- or part-time	Enterprise One		All services	
	Referral	Episode end	Referral	Episode end
Work time missed due to pain	0.0	0.0	36.7	0.0
Pain affected work productivity	30.0	20.0	50.0	26.7
Overall work impairment	30.0	20.0	56.2	26.7

Table 45 – Carer work productivity and impairment (%) for those working full- or part-time	Enterprise One		All services	
	Referral	Episode end	Referral	Episode end
Work time missed due to pain	11.6	2.4	16.8	3.1
Pain affected work productivity	30.0	20.0	33.7	16.3
Overall work impairment	37.5	21.9	42.8	18.8

School impact

Table 46 – School days missed in the previous two weeks (average days)	Enterprise One		All services	
	Referral	Episode end	Referral	Episode end
Young child	0.0	0.0	0.7	0.7
Child	4.4	0.2	3.8	0.9
Adolescent	4.4	2.6	4.3	1.3

Carer impact

The impact of the child's pain on the carer is measured using the Bath Adolescent Pain Parent Impact Questionnaire. This is completed by carers regardless of the age of the patient. Average scores for each of the sub-scales is shown in Table 47.

Table 47 – Carer impact average scores at referral and episode end	Enterprise One n = 2		All services n = 18	
	Referral score	Episode end	Referral score	Episode end
Depression	13.5	12.5	14.9	12.0
Anxiety	8.0	6.0	9.1	6.2
Catastrophising	9.5	5.0	9.0	6.2
Self-blame/helplessness	13.5	7.0	13.2	7.5
Partner relationship	11.0	14.0	9.7	9.3
Leisure functioning	18.5	16.5	16.8	13.2
Parental behaviour	23.0	15.5	28.2	21.3
Parental strain	15.0	15.0	8.9	7.5

Patient outcomes at post-episode follow-up

During the period 1 July 2023 to 30 June 2024, 2 of your patients completed a post-episode follow-up ePPOC questionnaire three to six months after the end of their episode of care.

The information in this section reports change from referral to episode end and post episode follow-up, for patients and carers who completed questionnaires at all three time points.

Pain

Pain severity

The severity of pain is measured using either the Faces of Pain Scale (Revised) or the Brief Pain Inventory (BPI), depending on the age of the patient. Average pain scores for patient-reported pain are shown in Table 48, with the proportion in each severity category in Figure 34.

	Enterprise One n = 2			All services n = 9		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Pain severity	7.5	3.8	2.3	5.2	2.9	2.8
- Worst pain	9.0	7.5	3.5	7.3	5.4	4.3
- Least pain	5.0	1.0	0.0	3.7	1.0	1.7
- Average pain	8.5	3.0	2.5	5.3	2.6	2.7
- Pain now	7.5	3.5	3.0	4.6	2.4	2.7

Figure 34 – Pain severity category at referral, episode end and post-episode follow-up (patient reported)

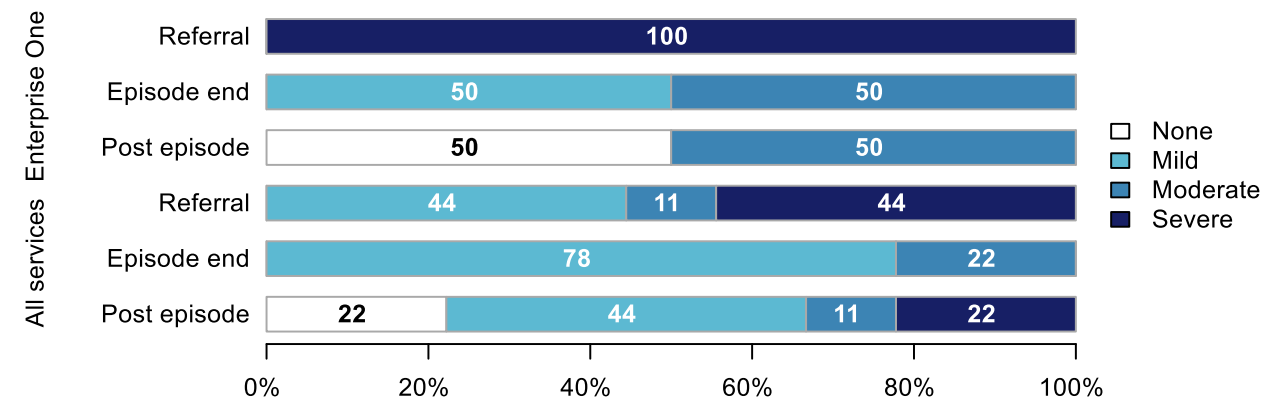


Table 49 – Pain severity at referral, episode end and post-episode follow-up (carer reported)	Enterprise One n = 2			All services n = 6		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Pain severity	6.6	0.9	0.3	4.8	2.0	1.2
- Worst pain	9.0	1.5	0.0	7.7	3.9	3.3
- Least pain	4.5	0.0	0.0	3.6	1.1	1.4
- Average pain	8.0	1.0	1.0	5.7	2.1	2.0
- Pain now	5.0	1.0	0.0	3.5	2.2	0.5

Table 50 – Proportion of patients making clinically significant improvement in Average pain	Episode end	Post-episode
Enterprise One	2 of 2 (100.0%)	2 of 2 (100.0%)
All services	4 of 5 (80.0%)	4 of 5 (80.0%)

Pain frequency

Pain frequency is reported by children and adolescents (i.e. 8-18 year olds) and carers. Table 51 and Figure 35 report the percent of patients reporting the frequency at which pain is experienced, at referral, episode end and post-episode follow-up. Carer reported results are shown in Table 52.

Table 51 – Pain frequency at referral, episode end and post-episode follow-up (patient reported)	Enterprise One n = 2			All services n = 9		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Always present (same intensity)	50.0	0.0	0.0	22.2	11.1	11.1
Always present (varying intensity)	0.0	0.0	0.0	44.4	33.3	33.3
Often present	0.0	50.0	0.0	0.0	22.2	11.1
Occasionally present	50.0	0.0	0.0	33.3	11.1	0.0
Rarely present	0.0	50.0	50.0	0.0	22.2	33.3
Pain no longer present	0.0	0.0	50.0	0.0	0.0	11.1
Total	100.0	100.0	100.0	100.0	100.0	100.0

Figure 35 – Patient-reported pain frequency at referral, episode end and post-episode follow-up

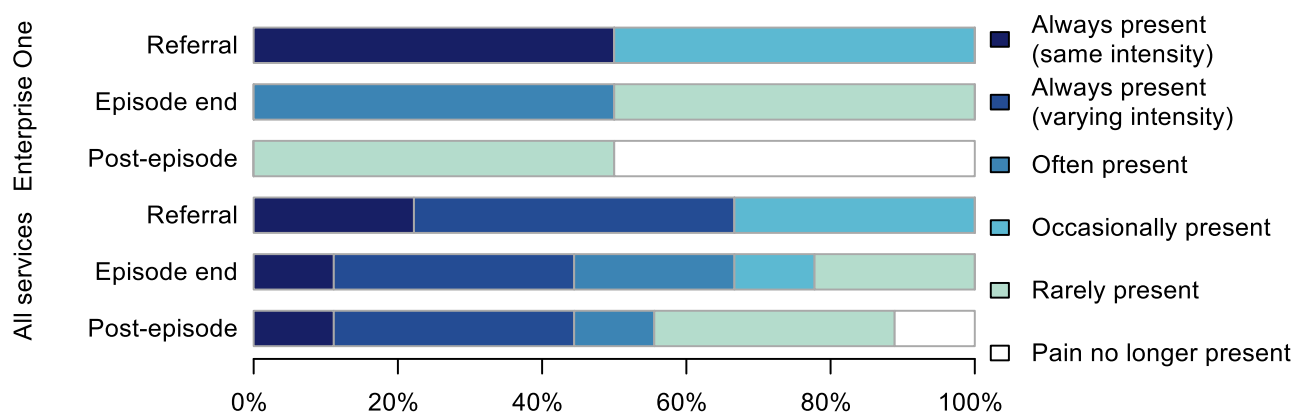


Table 52 – Pain frequency at referral, episode end and post-episode follow-up (carer reported)	Enterprise One n = 2			All services n = 7		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Always present (same intensity)	50.0	0.0	0.0	14.3	0.0	0.0
Always present (varying intensity)	0.0	0.0	0.0	57.1	42.9	42.9
Often present	50.0	0.0	0.0	14.3	0.0	0.0
Occasionally present	0.0	50.0	0.0	14.3	14.3	0.0
Rarely present	0.0	50.0	100.0	0.0	28.6	42.9
Pain no longer present	0.0	0.0	0.0	0.0	14.3	14.3
Total	100.0	100.0	100.0	100.0	100.0	100.0

Quality of Life

Quality of life is measured using the Pediatric Quality of Life scale (PedsQL), and is completed by carers and children of all ages.

Table 53 – Quality of life scores at referral, episode end and post-episode follow-up (patient reported)	Enterprise One n = 2			All services n = 9		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Sleep	12.5	50.0	37.5	41.7	66.7	52.8
Physical	53.1	76.6	93.8	47.2	75.0	73.9
Emotional	52.5	77.5	77.5	58.3	72.2	68.9
Social	72.5	85.0	95.0	71.1	81.1	78.3
School	42.5	67.5	90.0	48.9	65.6	70.0
Psychosocial	55.8	76.7	87.1	59.4	73.0	72.3
Total score	54.9	76.6	89.4	55.2	73.7	72.9

Table 54 – Quality of life scores at referral, episode end and post-episode follow-up (carer reported)	Enterprise One n = 2			All services n = 7		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Sleep	12.5	37.5	62.5	42.9	60.7	64.3
Physical	57.8	85.9	98.4	46.0	68.8	81.3
Emotional	45.0	65.0	87.5	54.3	67.1	70.7
Social	55.0	60.0	95.0	57.1	67.1	82.1
School	40.0	70.0	92.5	47.9	67.9	78.6
Psychosocial	46.7	65.0	91.7	53.1	67.4	77.1
Total score	50.5	72.3	94.0	50.6	67.9	78.6

Table 55 – Patient 'at risk status' for impaired quality of life at referral, episode end and post-episode follow-up, (%)	Enterprise One			All services		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Patient reported	2 of 2 (100.0%)	1 of 2 (50.0%)	0 of 2 (0.0%)	9 of 9 (100.0%)	3 of 9 (33.3%)	4 of 9 (44.4%)
Carer reported	2 of 2 (100.0%)	1 of 2 (50.0%)	0 of 2 (0.0%)	6 of 7 (85.7%)	4 of 7 (57.1%)	1 of 7 (14.3%)

Table 56 – Patients experiencing clinically meaningful improvement in quality of life	Episode end	Post-episode
	Enterprise One	
- Patient reported	2 of 2 (100.0%)	2 of 2 (100.0%)
- Carer reported	1 of 2 (50.0%)	2 of 2 (100.0%)
All services		
- Patient reported	7 of 9 (77.8%)	7 of 9 (77.8%)
- Carer reported	5 of 7 (71.4%)	6 of 7 (85.7%)

Figure 36 – Patient reported sleep severity at referral, episode end and follow-up (%)

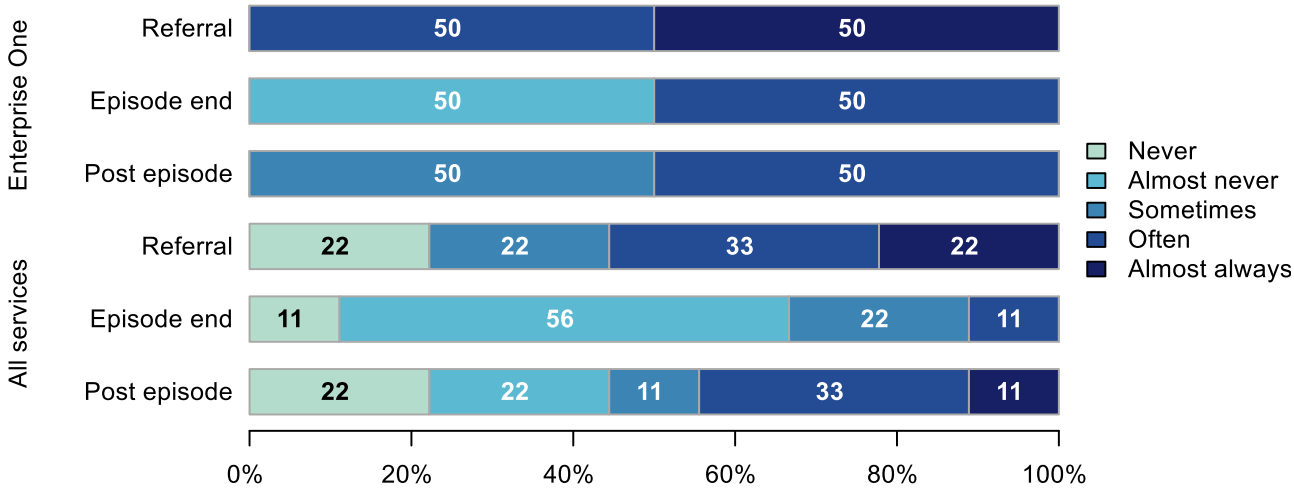
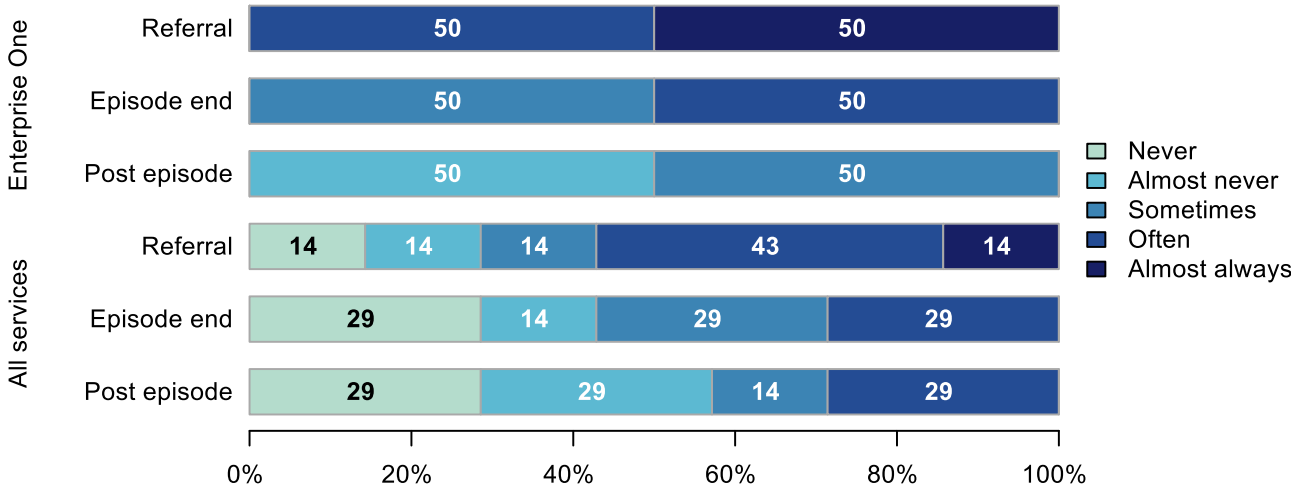


Figure 37 – Carer reported sleep severity at referral, episode end and follow-up (%)



Functional disability

Functional disability is measured using the Functional Disability Inventory, and is completed by patients aged 8 and over. Average scores at referral, episode end and post-episode follow-up are shown in Table 57. The proportion of patients in each severity category at each time point is shown in Figure 38.

Table 57 – Functional disability at referral, episode end and post-episode follow-up	Enterprise One n = 2			All services n = 9		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Functional disability score	21.0	3.0	1.5	23.1	5.9	11.9

Figure 38 – Disability severity category at referral, episode end and post-episode follow-up (%)

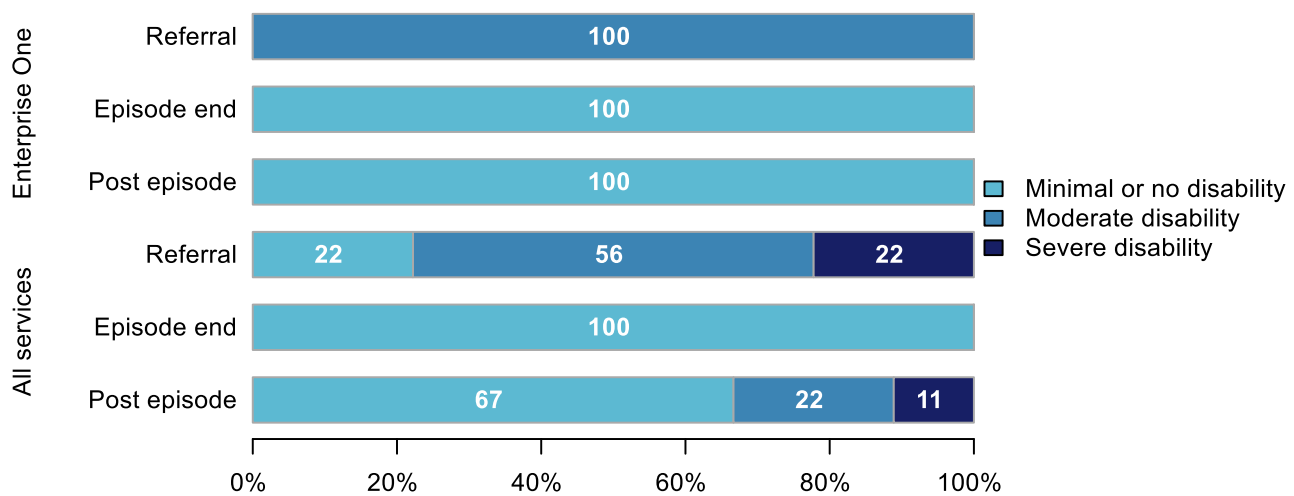


Table 58 – Proportion of patients making clinically significant improvement in functional disability	Episode end	Post-episode
Enterprise One	2 of 2 (100.0%)	2 of 2 (100.0%)
All services	7 of 7 (100.0%)	5 of 7 (71.4%)

Pain-related worry

Pain-related worries are measured using Section 5 of the Bath Adolescent Pain Questionnaire. This is completed by patients aged 13 and over.

Table 59 – Pain-related worry at referral, episode end and post-episode follow-up	Enterprise One n = 1			All services n = 5		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Total score	12.0	3.5	2.0	12.6	7.7	8.4

Medication use

Figure 39 to Figure 45 show the change in use of medications by type from referral to episode end and post-episode follow-up.

Figure 39 – Paracetamol only use at referral, episode end and post-episode (%)

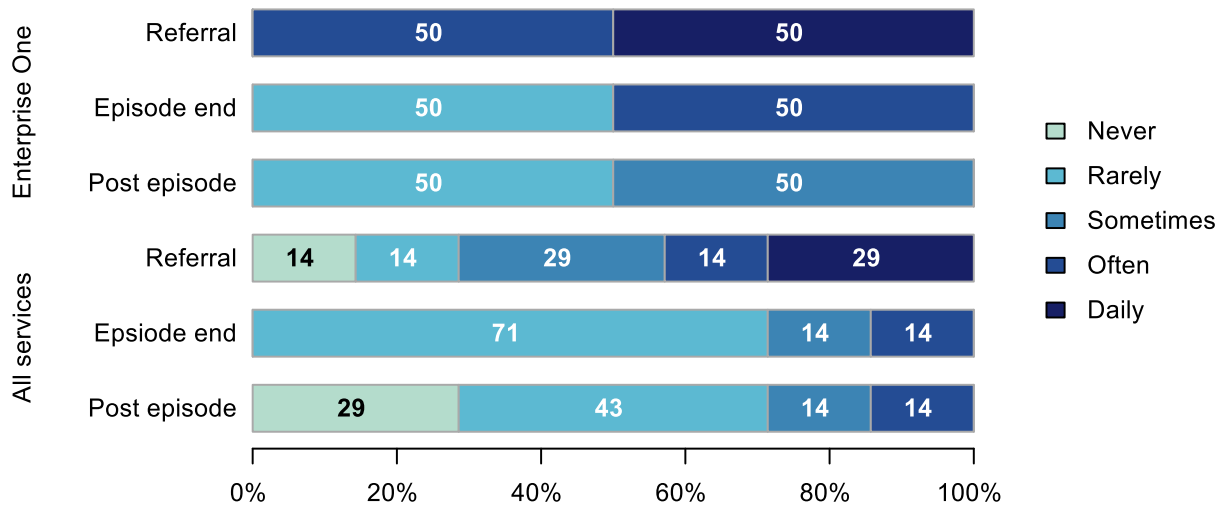


Figure 40 – Anti-inflammatory (non-prescription) use at referral, episode end and post-episode (%)

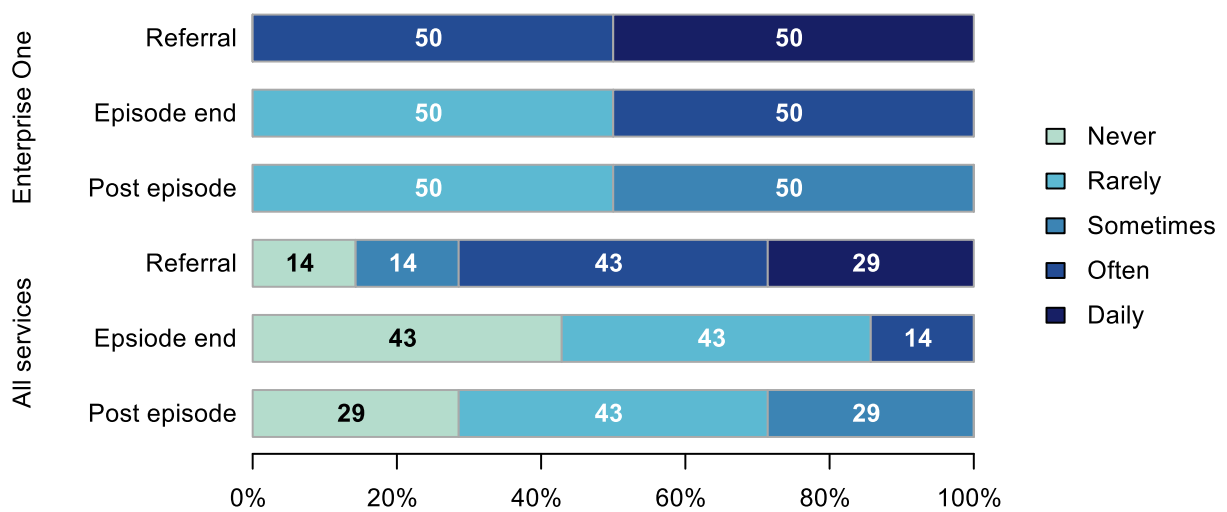


Figure 41 – Anti-inflammatory (prescription) use at referral, episode end and post-episode (%)



Figure 42 – Complementary or alternative medication use at referral, episode end and post-episode (%)

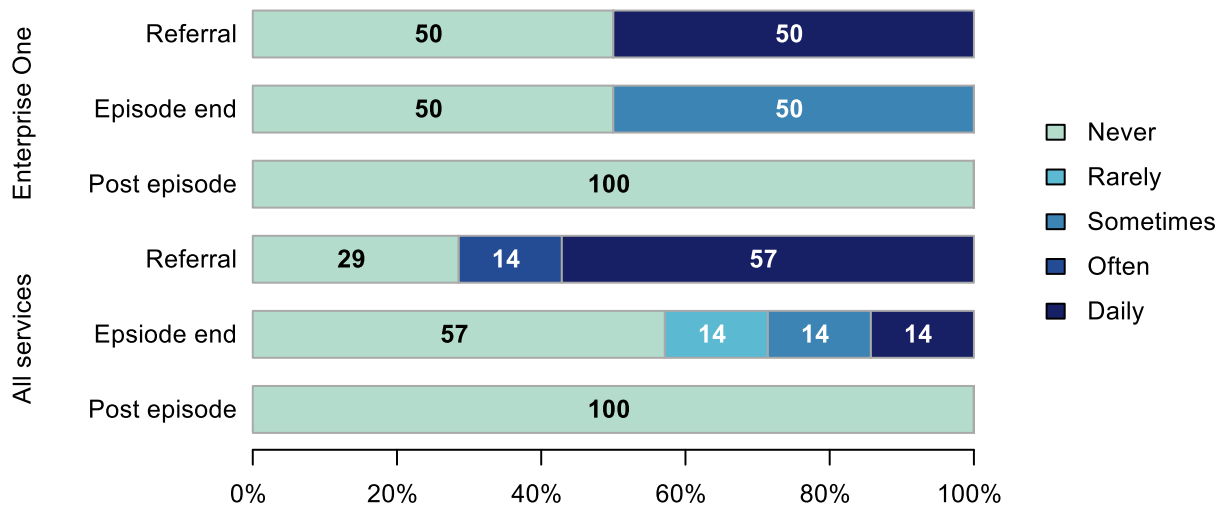


Figure 43 – Opioid medicines containing codeine use at referral, episode end and post-episode (%)

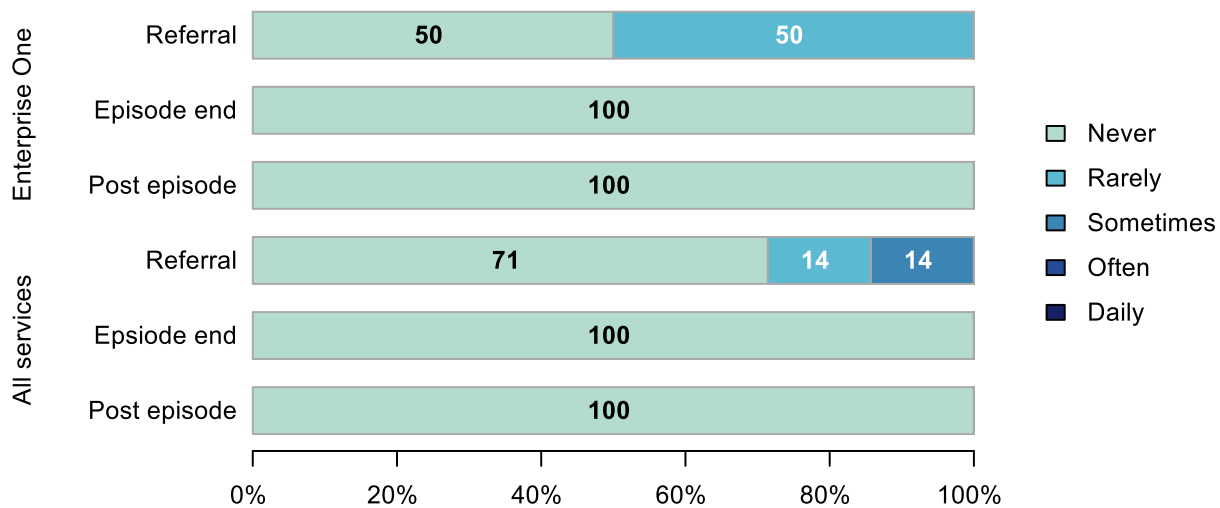


Figure 44 – Opioid medication use (other than codeine) at referral, episode end and post-episode (%)

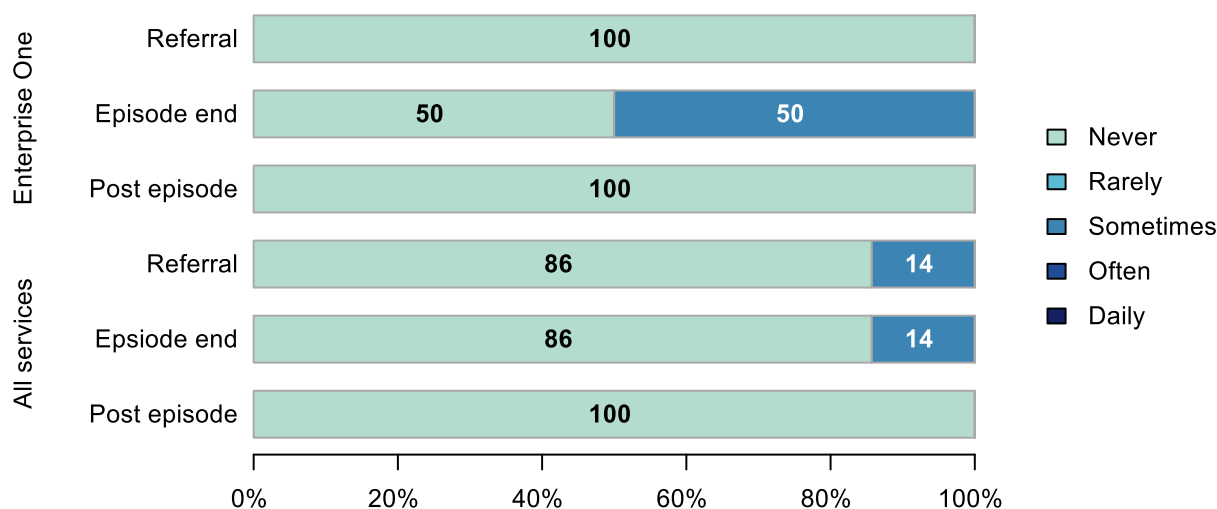
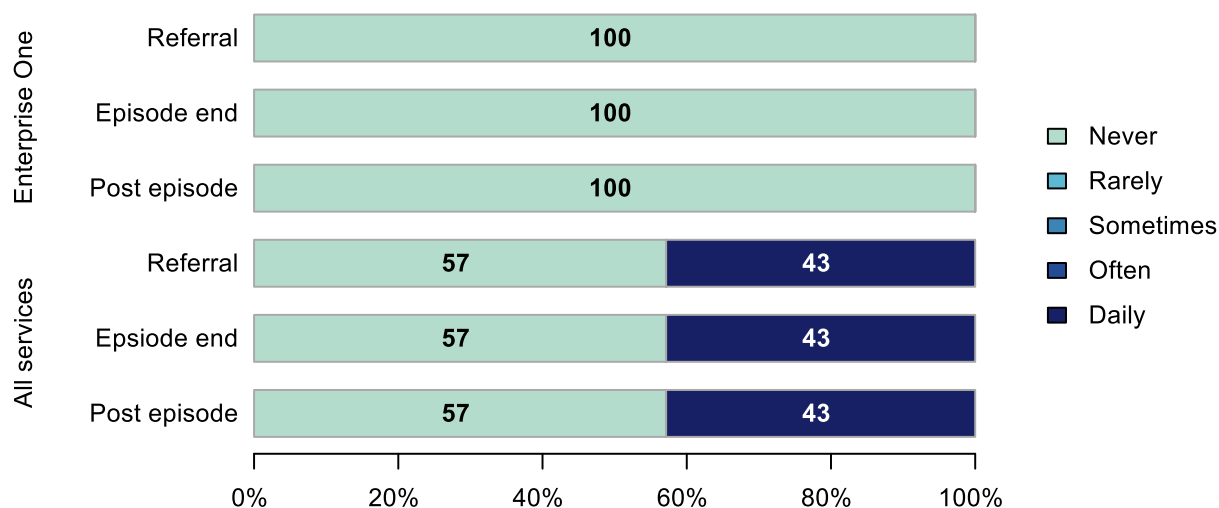


Figure 45 – Use of medications for nerve pain at referral, episode end and post-episode (%)



Health service utilisation

Table 60 reports the average number of times patients used each health service type in the last three months for pain-related reasons.

Table 60 – Pain-related health service use in the past 3 months, reported at referral, episode end and follow-up	Enterprise One			All services		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
General practitioner	4.0	5.0	0.0	2.6	2.0	0.1
Medical specialist	4.0	2.5	0.5	2.9	1.0	0.4
Other health professionals	2.0	1.0	0.0	3.4	2.7	0.6
Other therapists	0.0	0.0	0.0	1.4	0.6	0.0
Emergency department presentations	1.5	1.5	0.0	1.3	0.4	0.0
Hospital admissions	0.0	0.5	0.0	0.3	0.1	0.0
Diagnostic tests	2.0	1.5	0.0	3.3	0.4	0.1

Work status and productivity

The following information is included for carers and adolescent patients who completed an episode and reported work status and/or productivity information at referral, episode end and follow-up.

Table 61 – Patient-reported work status at referral, episode end and follow-up (%)	Enterprise One			All services		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Working full-time	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Working part-time	0 (0.0)	0 (0.0)	0 (0.0)	1 (20.0)	1 (20.0)	1 (20.0)
Unable to work due to pain	0 (0.0)	0 (0.0)	0 (0.0)	1 (20.0)	0 (0.0)	0 (0.0)
Unable to work due to a condition other than pain	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Not working by choice	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (20.0)	1 (20.0)
Seeking employment	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Too young to work	1 (100.0)	1 (100.0)	1 (100.0)	3 (60.0)	3 (60.0)	3 (60.0)
Total	1 (100.0)	1 (100.0)	1 (100.0)	5 (100.0)	5 (100.0)	5 (100.0)

Table 62 – Carer-reported work status at referral, episode end and follow-up (%)	Enterprise One			All services		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Working full-time	0 (0.0)	0 (0.0)	0 (0.0)	2 (33.3)	2 (33.3)	2 (33.3)
Working part-time	2 (100.0)	2 (100.0)	2 (100.0)	4 (66.7)	4 (66.7)	4 (66.7)
Unable to work due to child's pain	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Not working by choice	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Seeking employment	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Total	2 (100.0)	2 (100.0)	2 (100.0)	6 (100.0)	6 (100.0)	6 (100.0)

For the carers and adolescent patients who reported that they were working full or part-time at referral, episode end and post-episode follow-up, additional information relating to work hours missed due to pain and lost productivity while at work was collected (Table 63 and Table 64)

Table 63 – Patient work productivity and impairment (%) for those working full- or part-time	Enterprise One			All services		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Work time missed due to pain	-	-	-	100.0	0.0	0.0
Pain affected work productivity	-	-	-	-	-	-
Overall work impairment	-	-	-	-	-	-

Table 64 – Carer work productivity and impairment (%) for those working full- or part-time	Enterprise One			All services		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Work time missed due to pain	28.5	0.0	0.0	23.4	1.5	2.0
Pain affected work productivity	30.0	0.0	0.0	35.0	15.0	13.3
Overall work impairment	51.4	0.0	0.0	50.4	15.6	13.9

School impact

Table 65 – School days missed in the previous two weeks (average days)	Enterprise One			All services		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Young child	-	-	-	-	-	-
Child	10.0	1.0	0.0	5.3	0.3	0.0
Adolescent	3.0	0.0	0.0	6.7	3.3	0.0

Carer impact

The impact of the child's pain on the carer is measured using the Bath Adolescent Pain Parent Impact Questionnaire. This is completed by carers regardless of the age of the patient. Average scores for each of the sub-scales is shown in Table 66.

Table 66 – Carer impact average scores at referral, episode end and post-episode follow-up	Enterprise One n = 0			All services n = 0		
	Referral	Episode end	Post-episode	Referral	Episode end	Post-episode
Depression	-	-	-	-	-	-
Anxiety	-	-	-	-	-	-
Catastrophising	-	-	-	-	-	-
Self-blame/helplessness	-	-	-	-	-	-
Partner relationship	-	-	-	-	-	-
Leisure functioning	-	-	-	-	-	-
Parental behaviour	-	-	-	-	-	-
Parental strain	-	-	-	-	-	-

Appendix A – Additional patient outcomes

Change from pathway start to pathway end

Measuring change from the beginning to the end of a treatment pathway allows pain services to compare change by pathway type. Services may use this information when reviewing the types of treatments they provide, for example, to determine the relative effectiveness of treatment pathways.

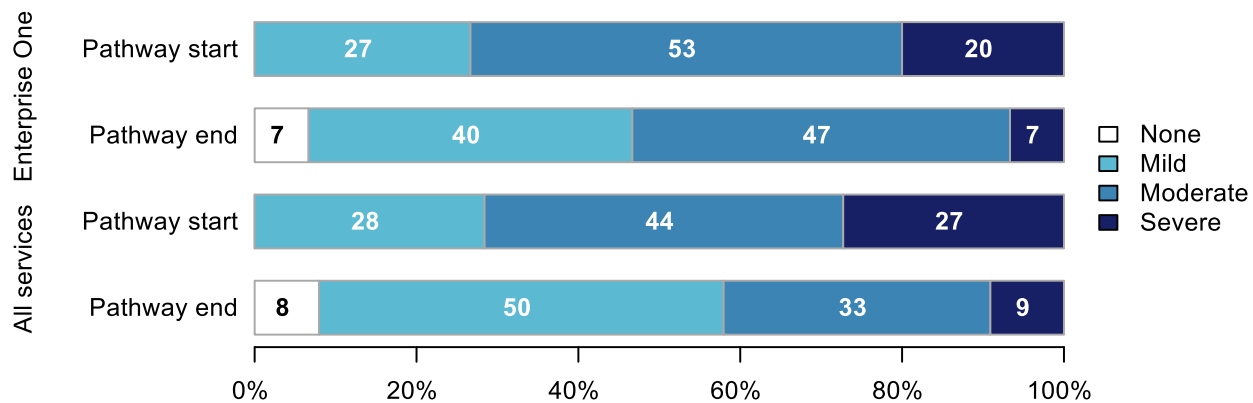
16 patients completed a questionnaire at the end of their treatment pathway at your service during the period 1 July 2023 to 30 June 2024, (all services, n = 100). This section reports change from pathway start to pathway end for these patients.

Pain severity

The severity of pain is measured using either the Faces of Pain Scale (Revised) or the Brief Pain Inventory (BPI), depending on the age of the patient. Average pain scores for patient-reported pain are shown in Table 67, with the proportion in each severity category in Figure 46. Average pain scores reported by the carer are shown in Table 68.

	Enterprise One n = 15		All services n = 88	
	Pathway start	Pathway end	Pathway start	Pathway end
Pain severity	5.3	3.8	5.5	3.6
- Worst pain	7.8	6.4	7.7	5.7
- Least pain	2.8	1.6	3.3	1.7
- Average pain	5.4	3.4	5.5	3.5
- Pain now	4.9	3.8	5.2	3.4

Figure 46 – Pain severity at pathway start and end (patient reported)



	Enterprise One n = 14		All services n = 85	
	Pathway start	Pathway end	Pathway start	Pathway end
Pain severity	5.5	3.1	5.4	3.4
- Worst pain	8.3	5.5	7.6	5.1
- Least pain	3.7	1.4	3.6	2.1
- Average pain	5.4	3.1	5.5	3.4
- Pain now	4.7	2.6	4.9	3.1

Pain frequency

Pain frequency is reported by children and adolescents (i.e. 8-18 year olds) and carers. Table 69 and Figure 47 report the percent of patients reporting the frequency at which pain is experienced, at pathway start and end. Carer reported results are shown in Table 70.

Table 69 – Pain frequency at pathway start and end (%) (patient reported)	Enterprise One n = 15		All services n = 89	
	Pathway start	Pathway end	Pathway start	Pathway end
Always present (same intensity)	13.3	0.0	9.0	5.6
Always present (varying intensity)	46.7	33.3	64.0	37.1
Often present	13.3	13.3	14.6	11.2
Occasionally present	20.0	33.3	10.1	15.7
Rarely present	6.7	13.3	2.2	25.8
Pain no longer present	0.0	6.7	0.0	4.5
Total	100.0	100.0	100.0	100.0

Figure 47 – Pain frequency – distribution at pathway start and end (patient reported)

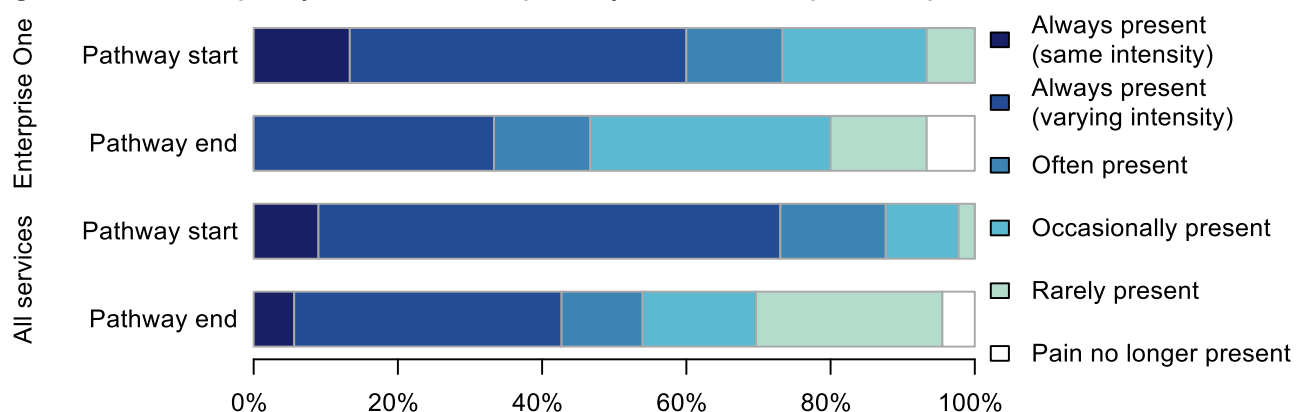


Table 70 – Pain frequency at pathway start and end (%) (carer reported)	Enterprise One n = 14		All services n = 84	
	Pathway start	Pathway end	Pathway start	Pathway end
Always present (same intensity)	7.1	0.0	7.1	1.2
Always present (varying intensity)	50.0	28.6	72.6	42.9
Often present	21.4	21.4	11.9	11.9
Occasionally present	14.3	14.3	6.0	9.5
Rarely present	7.1	28.6	2.4	22.6
Pain no longer present	0.0	7.1	0.0	11.9
Total	100.0	100.0	100.0	100.0

Quality of Life

Quality of life is measured using the Pediatric Quality of Life scale (PedsQL), and is completed by carers and children of all ages. Patient-reported total and sub-scale scores are shown in Table 71, with carer scores in Table 72.

Table 71 – Quality of life score at pathway start and end (patient reported)	Enterprise One n = 16		All services n = 90	
	Pathway start	Pathway end	Pathway start	Pathway end
Sleep	17.2	43.8	28.9	48.9
Physical	43.2	52.8	37.0	56.3
Emotional	50.3	58.4	49.5	64.3
Social	51.3	54.7	61.3	68.1
School	48.1	51.9	45.2	55.4
Psychosocial	49.9	55.0	52.1	62.8
Total score	47.6	54.3	46.9	60.4

Table 72 – Quality of life score at pathway start and end (carer reported)	Enterprise One n = 14		All services n = 86	
	Pathway start	Pathway end	Pathway start	Pathway end
Sleep	25.0	39.3	32.6	48.8
Physical	41.6	57.4	32.8	52.4
Emotional	42.5	51.3	45.2	56.0
Social	44.0	50.8	51.2	61.4
School	51.4	59.6	43.7	57.0
Psychosocial	46.0	54.0	46.6	58.0
Total score	44.8	54.6	41.9	56.0

Table 73 – Patients who experience a clinically meaningful improvement in quality of life ³ following pain management	Enterprise One n (%)	All services n (%)
Patient reported	8 of 16 (50.0%)	58 of 90 (64.4%)
Carer reported	6 of 14 (42.9%)	57 of 86 (66.3%)

Table 74 – Patient 'at risk status' for impaired quality of life at pathway start and end (%)	Enterprise One		All services	
	Pathway start	Pathway end	Pathway start	Pathway end
Patient reported	15 of 16 (93.8%)	14 of 16 (87.5%)	84 of 90 (93.3%)	58 of 90 (64.4%)
Carer reported	13 of 14 (92.9%)	11 of 14 (78.6%)	82 of 86 (95.3%)	62 of 86 (72.1%)

³ Minimal clinically meaningful difference on the PedsQL is measured as a:

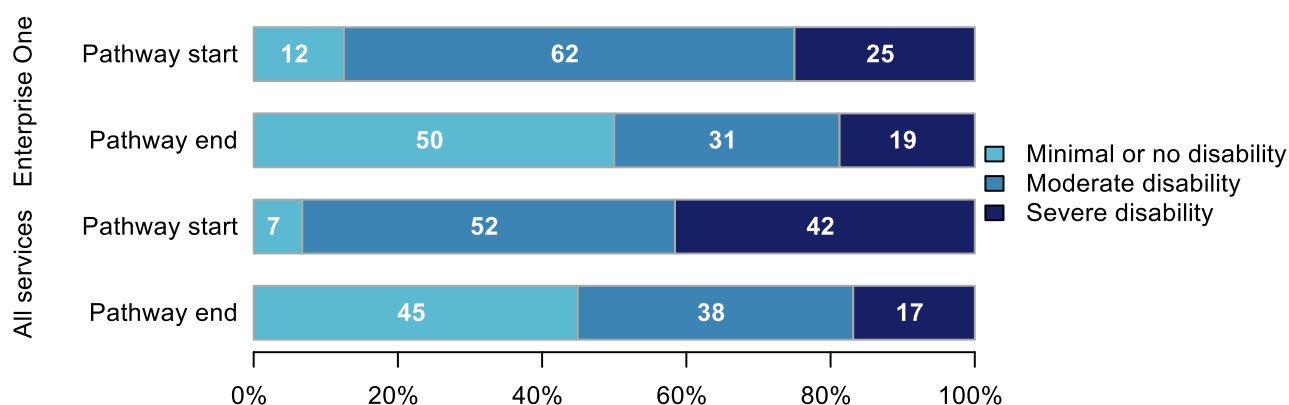
- 4.4 change in the child self-report total score
- 4.5 change in adult proxy-report total score.

Functional disability

Functional disability is measured using the Functional Disability Inventory and is completed by patients aged 8 and over. Average scores at pathway start and end are shown in Table 75. The proportion of patients in each severity category at pathway start and end is shown in Figure 48

Table 75 – Functional disability at pathway start and end	Enterprise One n = 10		All services n = 66	
	Pathway start	Pathway end	Pathway start	Pathway end
Functional disability score	22.7	15.0	27.3	14.4

Figure 48 – Disability severity category at pathway start and end



Pain-related worry

Pain-related worries are measured using Section 5 of the Bath Adolescent Pain Questionnaire. This is completed by patients aged 13 and over.

Table 76 – Average pain-related worry scores at pathway start and end	Enterprise One n = 5		All services n = 37	
	Pathway start	Pathway end	Pathway start	Pathway end
Total score	10.4	8.5	15.0	10.7

Medication use

Figure 49 through to Figure 55 show the change in use of medications by type from pathway start to end.

Figure 49 – Paracetamol only use at pathway start and end

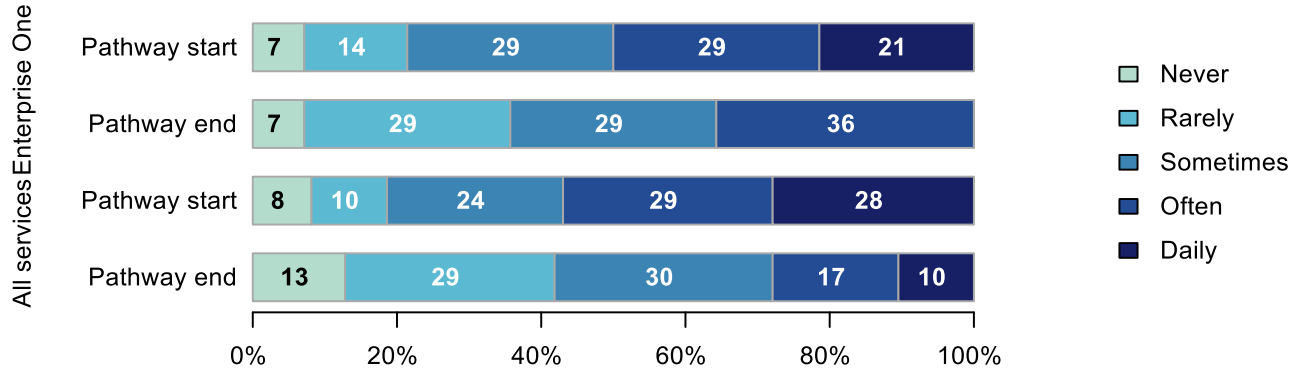


Figure 50 – Anti-inflammatory (non-prescription) use at pathway start and end

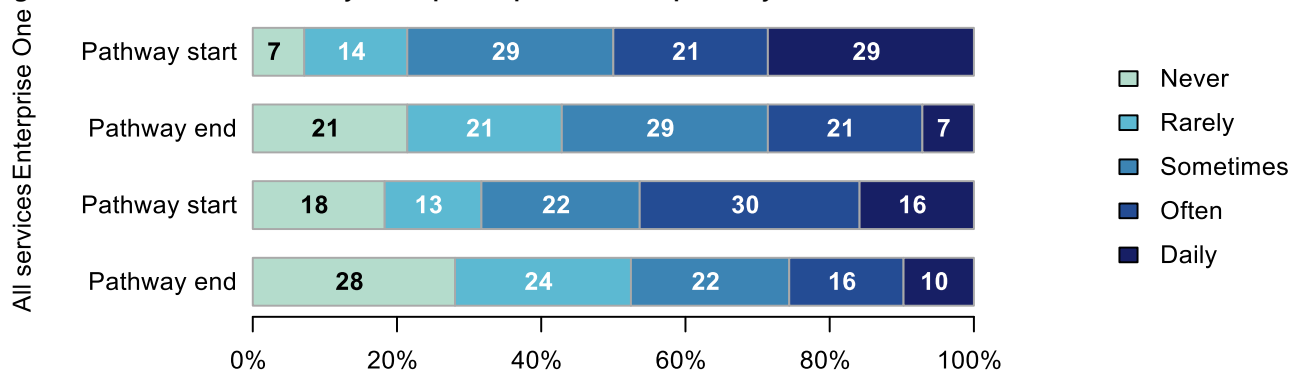


Figure 51 – Anti-inflammatory (prescription) use at pathway start and end

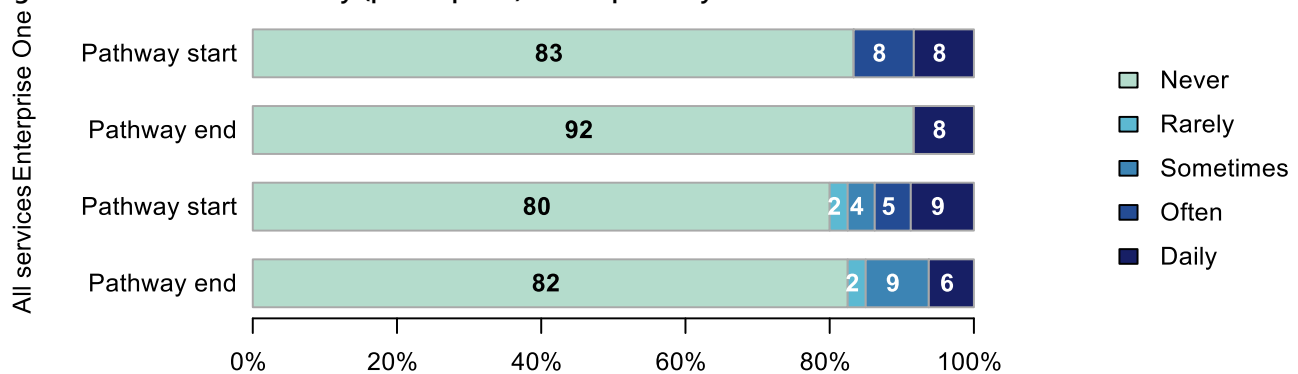


Figure 52 – Complementary or alternative medication use at pathway start and end

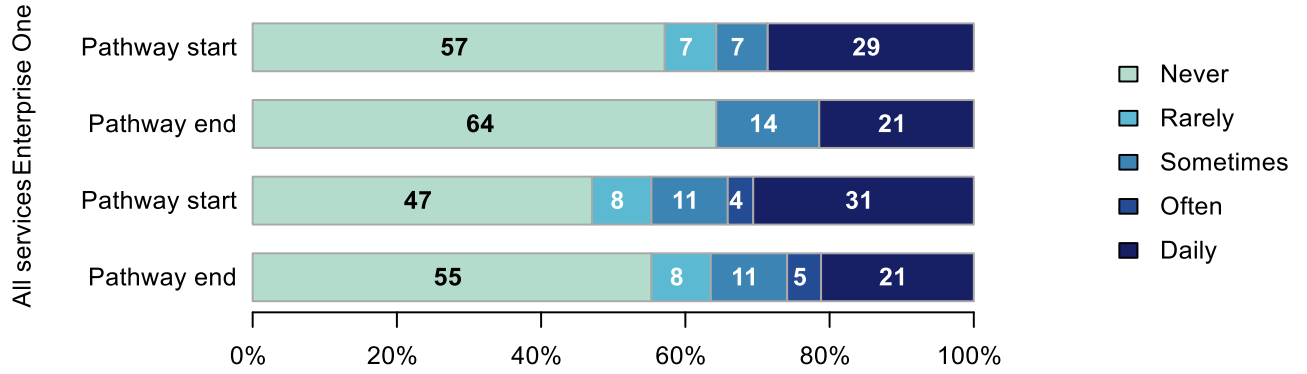


Figure 53 – Opioid medicines containing codeine use at pathway start and end

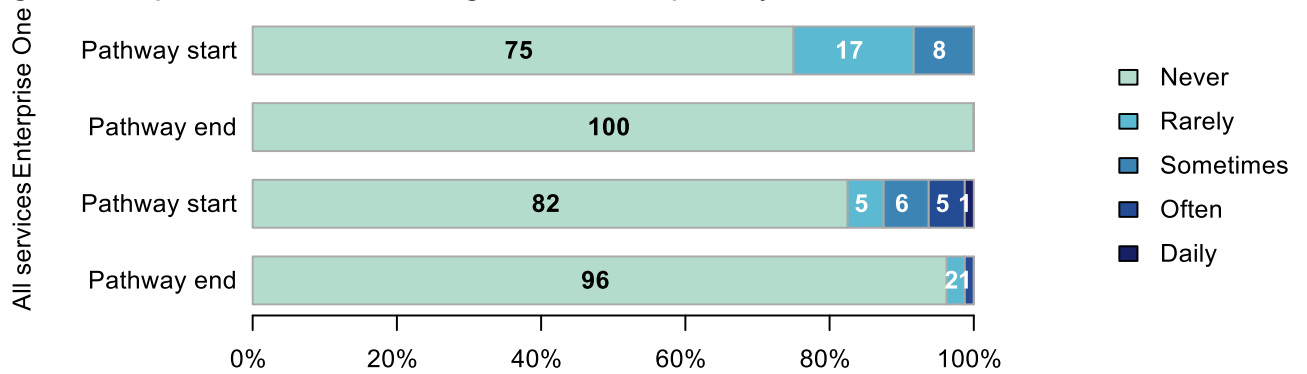


Figure 54 – Opioid medication use (other than codeine) at pathway start and end

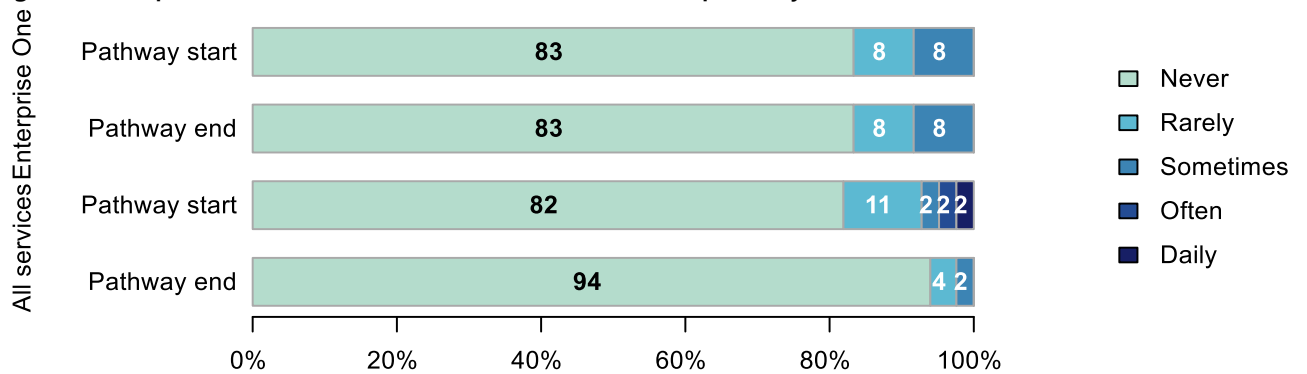
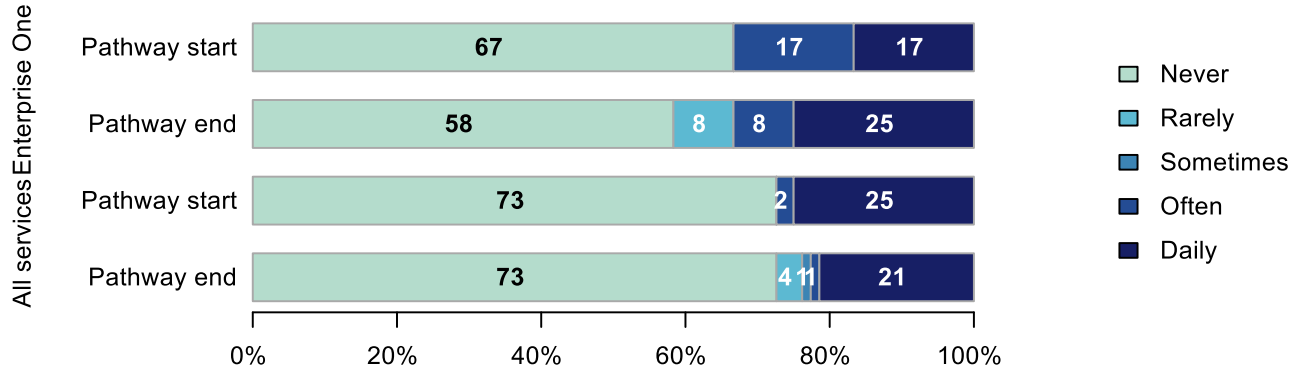


Figure 55 – Use of medications for nerve pain at pathway start and end



Health service utilisation

Table 77 reports the average number of times patients used each health service type in the last three months for pain-related reasons.

	Enterprise One		All services	
	Pathway start	Pathway end	Pathway start	Pathway end
General practitioner	1.6	1.6	2.6	2.6
Medical specialist	1.9	1.9	2.2	2.2
Other health professionals	2.3	2.3	4.2	4.2
Other therapists	1.0	1.0	1.0	1.0
Emergency department presentations	0.3	0.3	0.5	0.5
Hospital admissions	0.2	0.2	0.2	0.2
Diagnostic tests	0.8	0.8	1.8	1.8

Work status and productivity

The following information is included for carers and adolescent patients who completed a pathway and reported work status and/or productivity information at pathway start and end.

Table 78 – Patient work status at pathway start and end, n (%)	Enterprise One		All services	
	Pathway start	Pathway end	Pathway start	Pathway end
Working full-time	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Working part-time	1 (20.0)	1 (20.0)	6 (16.7)	10 (27.8)
Unable to work due to pain	2 (40.0)	2 (40.0)	11 (30.6)	7 (19.4)
Unable to work due to a condition other than pain	0 (0.0)	0 (0.0)	1 (2.8)	0 (0.0)
Not working by choice	1 (20.0)	1 (20.0)	5 (13.9)	6 (16.7)
Seeking employment	0 (0.0)	0 (0.0)	2 (5.6)	6 (16.7)
Too young to work	1 (20.0)	1 (20.0)	11 (30.6)	7 (19.4)
Total	5 (100.0)	5 (100.0)	36 (100.0)	36 (100.0)

Table 79 – Carer work status at pathway start and end, n (%)	Enterprise One		All services	
	Pathway start	Pathway end	Pathway start	Pathway end
Working full-time	6 (42.9)	9 (64.3)	23 (29.5)	28 (35.9)
Working part-time	7 (50.0)	4 (28.6)	35 (44.9)	30 (38.5)
Unable to work due to child's pain	0 (0.0)	0 (0.0)	6 (7.7)	5 (6.4)
Not working by choice	1 (7.1)	1 (7.1)	14 (17.9)	15 (19.2)
Seeking employment	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Total	14 (100.0)	14 (100.0)	78 (100.0)	78 (100.0)

For the carers and adolescent patients who reported that they were working full or part-time at pathway start and end, additional information relating to work hours missed due to pain and lost productivity while at work was collected (Table 80 and Table 81)

Table 80 – Patient work productivity and impairment (%) for those working full- or part-time	Enterprise One		All services	
	Pathway start	Pathway end	Pathway start	Pathway end
Work time missed due to pain	0.0	0.0	45.1	22.6
Pain affected work productivity	30.0	20.0	55.0	45.0
Overall work impairment	30.0	20.0	58.5	55.2

Table 81 – Carer work productivity and impairment (%) for those working full- or part-time	Enterprise One		All services	
	Pathway start	Pathway end	Pathway start	Pathway end
Work time missed due to pain	11.3	3.3	13.9	4.5
Pain affected work productivity	27.7	20.0	34.8	20.7
Overall work impairment	35.5	22.4	42.6	23.5

School impact

Table 82 – School days missed in the previous two weeks (average days)	Enterprise One		All services	
	Pathway start	Pathway end	Pathway start	Pathway end
Young child	-	-	1.7	1.7
Child	4.5	0.3	3.9	0.6
Adolescent	4.4	2.6	4.5	1.0

Carer impact

The impact of the child's pain on the carer is measured using the Bath Adolescent Pain Parent Impact Questionnaire. This is completed by carers regardless of the age of the patient. Average scores for each of the sub-scales is shown in Table 83.

Table 83 – Carer impact average scores at pathway start and end	Enterprise One n = 2		All services n = 19	
	Pathway start	Pathway end	Pathway start	Pathway end
Depression	13.5	12.5	15.0	11.9
Anxiety	8.0	6.0	9.3	6.2
Catastrophising	9.5	5.0	9.2	6.5
Self blame/helplessness	13.5	7.0	13.2	7.5
Partner relationship	11.0	14.0	9.5	9.5
Leisure functioning	18.5	16.5	16.8	13.7
Parental behaviour	23.0	15.5	27.6	21.2
Parental strain	15.0	15.0	8.7	7.7

Appendix B – Data quality and completeness

This section provides information about the number and type of questionnaires returned, questionnaire response rates and individual item completion. Response rate refers to the number of questionnaires returned by the patient as a percent of the number generated.

Table 84 – Number of questionnaires generated and response rate by questionnaire type	Enterprise One		All Services	
	Number generated	Response rate	Number generated	Response rate
Patient questionnaires				
Referral	114	70.2	553	70.0
Pathway start	10	80.0	35	68.6
Group program start (concurrent pathways only)	0	-	1	100.0
Pathway review	2	0.0	17	35.3
Group program end (concurrent pathways only)	0	-	1	100.0
Pathway end	40	42.5	227	40.5
Post episode	10	20.0	67	22.4
Clinical review	7	42.9	28	60.7
Carer questionnaires				
Referral	115	72.2	558	72.2
Pathway start	8	62.5	34	64.7
Group program start (concurrent pathways only)	0	-	1	100.0
Pathway review	2	0.0	18	27.8
Group program end (concurrent pathways only)	0	-	1	100.0
Pathway end	39	38.5	226	37.2
Post episode	10	30.0	67	22.4
Clinical review	6	16.7	26	42.3

Table 85 – Item completion (percent complete)	Enterprise One	All Services
Indigenous status	93.8	93.2
Country of birth	100.0	98.9
Main pain site	87.2	88.4
How main pain began	75.0	72.7
Pain duration	75.0	72.7
Health service use		
- General practitioner	100.0	99.8
- Medical specialist	100.0	99.1
- Other health professionals	97.7	96.7
- Other therapist	95.5	96.7
- Hospital emergency department	97.7	98.8
- Hospital admissions	96.6	97.4
- Diagnostic tests	98.9	98.6

Table 86 – Assessment tool validity and completion	Validity – number of items that must be completed	Enterprise One		All Services	
		Average number of completed items	% of validly completed questionnaires	Average number of completed items	% of validly completed questionnaires
Patient questionnaires					
Brief Pain Inventory					
- Worst pain	1/1	-	99.1	-	99.6
- Least pain	1/1	-	99.1	-	99.1
- Average pain	1/1	-	99.1	-	99.5
- Pain now	1/1	-	99.1	-	99.5
Pain severity	4/4	-	99.1	-	98.8
Functional Disability Inventory	12/15	14.8	98.2	14.9	99.1
Pain-related worries (BAPQ-S5)	6/7	7.0	100.0	7.0	100.0
Paediatric Quality of Life Scale					
- Physical	4/8	7.9	98.3	8.0	99.5
- Emotional	3/5	5.0	99.1	5.0	99.8
- Social	3/5	4.9	97.4	5.0	99.3
- School	3/5	4.9	98.3	5.0	99.3
- Total	12/23	22.8	100.0	22.9	100.0
Carer questionnaires					
Brief Pain Inventory					
- Worst pain	1/1	-	99.1	-	99.3
- Least pain	1/1	-	99.1	-	98.6
- Average pain	1/1	-	98.2	-	98.2
- Pain now	1/1	-	98.2	-	98.6
Pain severity	4/4	-	98.2	-	97.4
Paediatric Quality of Life Scale					
- Physical	4/8	7.9	99.1	7.9	99.5
- Emotional	3/5	4.9	97.3	4.9	99.3
- Social	3/5	4.9	97.3	5.0	99.1
- School	3/5	4.9	97.3	4.9	98.1
- Total	12/23	22.5	99.1	22.7	99.6

Table 87 – Collection of patient outcomes at episode end, by episode end mode	Enterprise One			All services		
	Episodes ending (n)	Outcomes recorded (n)	Data available (%)	Episodes ending (n)	Outcomes recorded (n)	Data available (%)
Treatment complete – self-management/referral to primary care	41	12	29.3	219	71	32.4
Referral to another pain service	4	0	0.0	10	0	0.0
Patient discontinued by choice	4	0	0.0	26	1	3.8
Died	0	0	-	1	0	0.0
Active treatment complete – ongoing review	8	2	25.0	47	21	44.7
Lost to contact/Not to follow-up	6	0	0.0	38	1	2.6
Other	0	0	-	1	1	100.0
Total	63	14	22.2	342	95	27.8

NOTE: The episode end outcomes information included in this table corresponds to episodes ending during the current reporting period. Data available is the number of outcomes recorded, divided by the number of episodes which ended.

Table 88 – Collection of patient outcomes at post-episode follow up, by episode end mode	Enterprise One			All services		
	Episodes ending (n)	Outcomes recorded (n)	Data available (%)	Episodes ending (n)	Outcomes recorded (n)	Data available (%)
Treatment complete – self-management/referral to primary care	57	4	7.0	329	14	4.3
Referral to another pain service	4	0	0.0	18	0	0.0
Patient discontinued by choice	7	0	0.0	41	0	0.0
Died	0	0	-	1	0	0.0
Active treatment complete – ongoing review	12	1	8.3	72	8	11.1
Lost to contact/Not to follow-up	14	0	0.0	61	1	1.6
Other	0	0	-	5	0	0.0
Total	94	5	5.3	527	23	4.4

NOTE: The post-episode follow-up outcomes information included in this table corresponds to a six month longer time-period than the current reporting period; 1 January 2023 – 30 June 2024. This is because it is possible for episodes that have ended in a previous reporting period to have a post-episode follow up questionnaire fall into the current reporting period. Data available is the number of post-episode outcomes recorded, divided by the number of episodes which ended.

Appendix C – Tips for interpreting the report

How information is presented in this report

In this report we have attempted to report information in a way that puts the patient at the centre of care and provides a sense of flow that mirrors the patient journey.

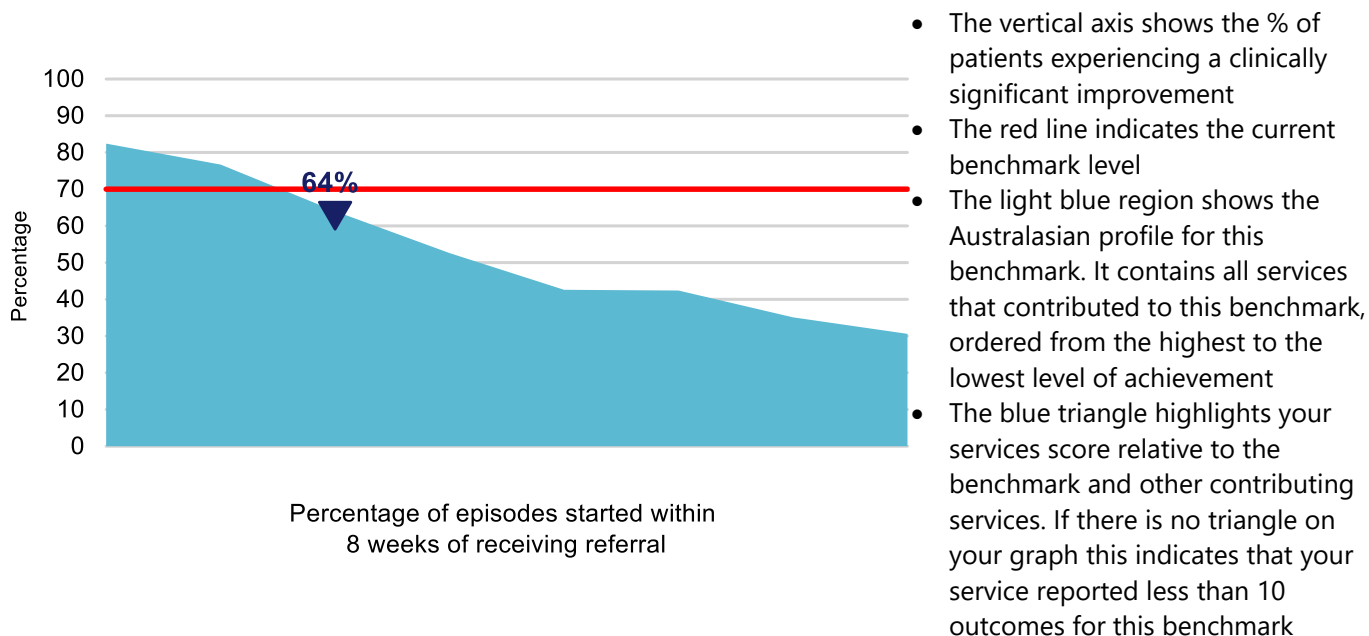
Information describing the people attending pain services is found in the Patient Profile section and includes socio-demographic details and clinical characteristics at referral. A description of typical episodes of care, including wait time, length and services provided are shown in the Episode Details section. Outcomes for the patient, at both the end of the episode and 3-6 months after the episode has ended are shown in the Episode Outcomes and Post-episode Outcomes sections, respectively.

The indicators/benchmarks

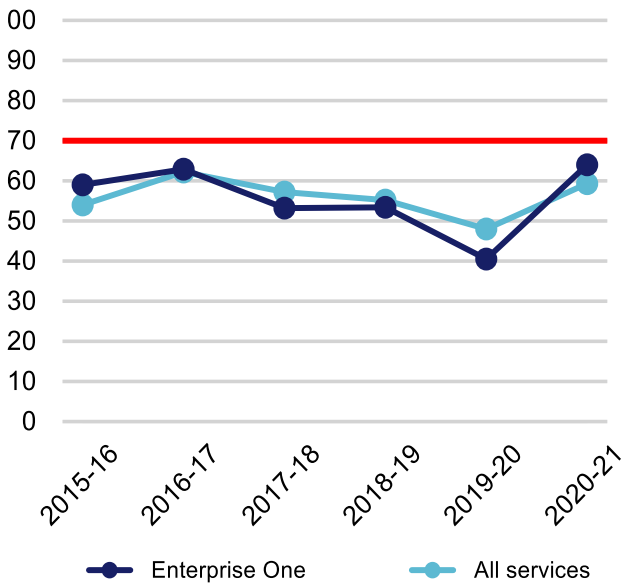
There are currently three clinical indicators and one wait time benchmark. These show the percent of patients experiencing a clinically significant improvement or meeting predetermined conditions (see Appendix E – Assessment tools for more details). This report also includes time series graphs, which show change in performance on each of the benchmarks at 12 month intervals over a five year period for either Mid-Year or Annual reports.

Interpreting the graphs

Benchmarks and Indicators



Time series



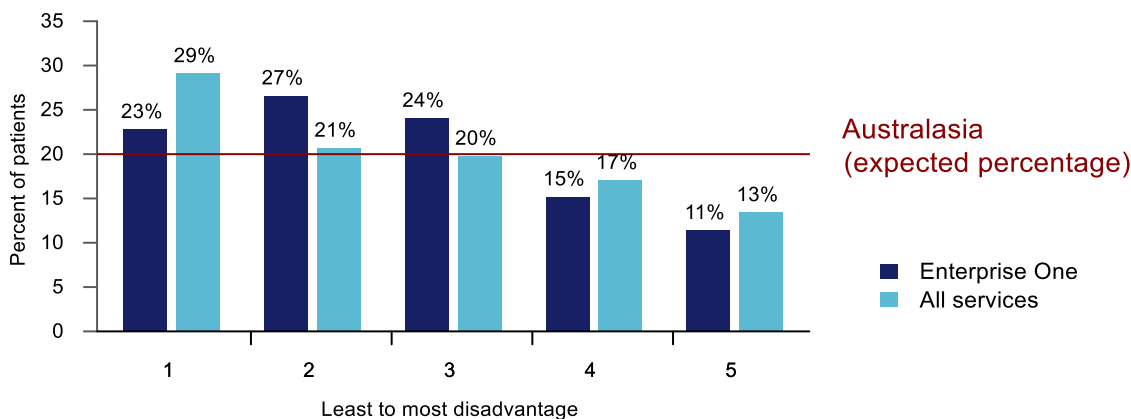
- Results are reported at 12 month intervals over a six year period with either Mid Year (MY) or Annual results, corresponding to the current report
- Results are based on the current benchmark/indicator definition and may not precisely match previously reported results due to a change in definition and/or updated data
- The darker line indicates the result for your service
- The lighter line indicates the average for all services
- The red line indicates the threshold at which the benchmark/indicator is currently set
- If there is no dot for your service for any period, this indicates that your service reported less than 10 outcomes for this benchmark during that period.

Socioeconomic disadvantage

These charts show the relative socioeconomic disadvantage of your patient population based on residential address at referral. The information uses the Socio-Economic Index for Areas – Index of Relative Disadvantage, and the New Zealand Index of Relative Socioeconomic Deprivation. These indices group residential area into five disadvantage quintiles (from least to most disadvantage) such that across the national Australian and New Zealand populations, 20% of people live in each disadvantage quintile. It's important to note that the level of disadvantage relates to the *area* the person lives in rather than the person.

The chart compares the proportion of your patients who live in each disadvantage quintile to the:

- population of all people seeking pain management in Australasia (*All services*)
- expected distribution of disadvantage (*Australasian expected %*)



Appendix D – Pain services that submitted data for this report

The services providing data for this report are:

- The Children's Hospital at Westmead
- Children's Complex Pain Service, John Hunter Children's Hospital
- Queensland Interdisciplinary Persistent Pain Service
- Royal Children's Hospital Melbourne
- Starship Complex Pain service
- SCH-R Complex Pain Service
- Women's and Children's Paediatric Chronic Pain Service
- Sunshine Coast PPMS
- North Qld PPMS

A list of all services participating in ePPOC can be found on the ePPOC web site:

<https://ahsri.uow.edu.au/eppoc>

Appendix E – Assessment tools

The assessment tools used in this report are:

- Modified Brief Pain Inventory (BPI) (Pain severity)
- Faces Pain Scale – Revised (Pain severity)
- Paediatric Quality of Life Inventory (PedsQL)
- Functional Disability Inventory (FDI)
- Bath Adolescent Pain Questionnaire – Pain-related worry section (BAPQ-S5)
- Bath Adolescent Pain – Parent Impact Questionnaire (BAP-PIQ)
- Work Productivity and Impairment (WPAI)
- CARRA Body Chart.

The tool used to capture pain severity is dependent on the patient's age. Patients aged 8 and above use the Modified Brief Pain Inventory, whereas patients aged 5-7 use the Faces Pain Scale. Each of these assessment tools are briefly described below.

Modified Brief Pain Inventory (BPI)⁴

Modified versions of the questions in the standard BPI are used in PaedePPOC to assess pain in patients aged 8 and over, and a parent proxy rating of their child's pain for all ages.

Faces Pain Scale – Revised⁵

Children choose one of six faces showing increasing levels of pain, from 'no pain' to 'very much pain' and corresponding numerically to 0, 2, 4, 6, 8, 10.

For both tools, questions are rated on a scale of 0 ('No pain') to 10 ('Pain as bad as you can imagine'), with patients asked their average, worst and least pain over the last week, and their pain right now. Pain severity is calculated as an average of the four pain items mentioned above.

The IMMPACT group's recommendations for assessing clinical significance for 0-10 numeric pain scales are that a change of:

- ≥ 10% represents minimally important change
- ≥ 30% represents moderate clinically important change (ePPOC uses this category to identify clinically significant improvement on the average pain and worst pain items)
- ≥ 50% represents substantial clinically important change⁶.

Updated BPI severity bands

From the 2022 mid-year report onwards, ePPOC had implemented a modified version of the previously reported severity bands: **0 = none | 1-4 = mild | 5-6 = moderate | 7-10 = severe**

A score of 0 – no pain was previously included in the mild category, but is now reported separately⁷.

The above severity bands can be applied directly to the individual items reported on the integer scales (e.g. the 'average pain' item). When applied to the pain severity score, the mean values is rounded to the closest integer before the severity ranges are applied. The 'none' category should therefore be interpreted as 'no or negligible pain severity'.

⁴ *Modified Brief Pain Inventory*, © 1991. Reproduced with acknowledgement of the Pain Research Group, University of Texas, MD Anderson Cancer Centre, USA. www.mdanderson.org

⁵ Faces Pain Scale – Revised, © 2001, International Association for the Study of Pain. www.iasp-pain.org/RPSR

⁶ Eccleston, C et al 2005, 'The Bath Adolescent Pain Questionnaire (BAPQ-S5): Development and preliminary psychometric evaluation of an instrument to assess the impact of chronic pain on adolescents', *Pain*, vol. 118 num. 1-2, pp 263-270. (Source: Bath Centre for Pain Research www.bath.ac.uk/pain)

⁷ Palos, GR, et al 2006, 'Asking the community about cutpoints used to describe mild, moderate, and severe pain.' *Journal of Pain*, vol. 7, no. 1, pp 49-56

Paediatric Quality of Life Inventory (PedsQL)⁸

PaedePPOC uses the PedsQL Generic Core Scales to measure health-related quality of life. Parents and all patients complete the age-appropriate version. Items are rated on a five point scale where 0='Never' [a problem] and 4='Almost always' [a problem]. For 5-7 year olds the scale is clinician administered and rated on a three point scale where 0='Never' [a problem], 2='Sometimes [a problem] and 4='Almost always' [a problem].

The tool includes four scale scores (physical, emotional, social and school functioning) and two summary scores (psychosocial and physical health), with higher scores indicating better health-related quality of life. If more than 50% of the items in a scale are missing, the scale scores should not be computed and are not reported. Detailed scoring instructions can be found at: www.pedsq.org/score.html

Minimal clinically meaningful difference on the PedsQL is measured as a:

- 4.4 change in the child self-report total score
- 4.5 change in adult proxy-report total score.

This definition is used to represent a clinically significant increase in this report.

"At risk status" for impaired HRQOL is reflected in a:

- Total score below 69.7 for child self-report
- Total score below 65.4 for adult proxy-report.

To assess improvement in sleep, ePPOC reports clinically significant improvement for those who report trouble sleeping at least *sometimes* (sleep item score = 2). The improvement is considered clinically significant if the score for this item decreases by at least 50%.

Functional Disability Inventory (FDI)⁹

The FDI is a 15 item assessment tool which asks patients whether they have had any physical trouble or difficulty doing specified activities. Items are rated on a five point scale where 0='No trouble' and 4='Impossible'.

Severity bands for the FDI are:

- 0-12 = No/minimal disability
- 13-29 = Moderate disability
- >29 = Severe disability

Clinically significant change is indicated where there is a change of 5 or more points coupled with a change to a different severity category.

Bath Adolescent Pain Questionnaire – Pain-related worry section (BAPQ-S5)

Section 5 of the BAPQ-S5 asks patients about specific worries or concerns they have about their pain. There are seven items rated on a five point scale of 'Never' to 'Always'.

⁸ Varni, JW, et al. 2005, 'The PedsQL as a Pediatric Patient-Reported Outcome: Reliability and Validity of the PedsQL Measurement Model in 25,000 Children', *Expert Review of Pharmacoeconomics Outcomes Research*, vol. 5 num. 6, pp 705-718.

⁹ Walker LS and Greene JW 1991, 'The Functional Disability Inventory (FDI): Measuring a neglected dimension of child health status', *Journal of Paediatric Psychology*, vol. 16 num 1, pp 39-58.

Bath Adolescent Pain – Parent Impact Questionnaire (BAP-PIQ)¹⁰

The impact of the child’s pain on the parent is measured over eight subscales: depression, anxiety, child-related catastrophising, self-blame and helplessness, partner relationship, leisure functioning, parental behaviour and parental strain. All items are rated on a 5 point scale, ranging from 0 (never) to 4 (always).

Work Productivity and Impairment (WPAI)¹¹

The work status of all patients is collected using the International Consortium for Health Outcomes Measurement (ICHOM) categories. For patients that are employed, the WPAI items allow calculation of the following outcomes:

- % of time missed from work due to pain (absenteeism)
- % work impairment while working due to pain (lost productivity)
- % overall work impairment due to pain (taking into account absenteeism and lost productivity).

CARRA Body Chart¹²

Patients identify the site/s they feel pain using body maps. For reporting, pain sites are categorised into pain areas as follows:

	Pain areas
Head	head and face
Neck	neck
Chest	chest
Back	upper back, mid back and low back
Leg	left and right thighs, left and right calves, left and right ankles
Arm/shoulder	left and right shoulders, left and right upper arms, left and right elbows, left and right forearms, left and right wrists
Abdomen	abdomen
Hands	left and right hands
Feet	left and right feet
Groin/pubic area	Groin/pubic area
Knee	left and right knees
Hip	left and right hips

¹⁰ Jordan A et al 2008, 'The Bath Adolescent Pain – Parental Impact Questionnaire (BAP-PIQ): development and preliminary psychometric evaluation of an instrument to assess the impact of parenting an adolescent with chronic pain', *Pain*, vol. 137 num. 3, pp 478-487. (Source: Bath Centre for Pain Research www.bath.ac.uk/pain)

¹¹ Reilly MC, Zbrozek AS, Dukes E 1993, 'The validity and reproducibility of a work productivity and activity impairment measure', *Pharmacoeconomics*, vol. 4, num. 5, pp 353-365.

¹² Von Bayer CL, et al. 2011, 'Pain charts (body maps or manikins) in assessment of location of paediatric pain', *Pain Management*, vol. 1 num. 1, pp 61-68. (Source: Childhood Arthritis and Rheumatology Research Alliance, www.carragroup.org)

Appendix F – List of figures

Figure 1 – Location of participating pain services	1
Figure 2 – The information described in each (colour coded) section of the report.....	2
Figure 3 – Age group by sex	3
Figure 4 – Socioeconomic area disadvantage based on patient postcode.....	4
Figure 5 – Distribution of Body Mass Index.....	6
Figure 6 – Pain severity category at referral (%).....	9
Figure 7 – Functional disability severity category at referral (%).....	9
Figure 8 – Sleep severity category at referral (%).....	10
Figure 9 – Paracetamol only medicines (%).....	10
Figure 10 – Anti-inflammatory medicines - non-prescription (%).....	10
Figure 11 – Anti-inflammatory medicines – prescription (%).....	11
Figure 12 – Complementary or alternative medicines (%).....	11
Figure 13 – Opioid medicines containing codeine (%).....	11
Figure 14 – Opioid medications other than codeine (%).....	11
Figure 15 – Medication for nerve pain (%).....	12
Figure 16 – Time from referral to episode start, shown as a percent of people in each time category.....	15
Figure 17 – Wait time (patients seen within 8 weeks), benchmark profile and time series.....	15
Figure 18 – Service events, percentage by type.....	17
Figure 19 – Pain severity category at referral and episode end (patient reported).....	19
Figure 20 – Average pain indicator and time series.....	20
Figure 21 – Pain frequency – distribution at referral and episode end (patient reported).....	21
Figure 22 – Quality of life indicator and time series.....	23
Figure 23 – Patient reported sleep severity at referral and episode end.....	23
Figure 24 – Carer reported sleep severity at referral and episode end.....	23
Figure 25 – Disability severity category at referral and episode end.....	24
Figure 26 – Functional disability indicator and time series.....	24
Figure 27 – Paracetamol only use at referral and episode end (%).....	25
Figure 28 – Anti-inflammatory (non-prescription) use at referral and episode end (%).....	25
Figure 29 – Anti-inflammatory (prescription) use at referral and episode end (%).....	26
Figure 30 – Complementary or alternative medication use at referral and episode end (%).....	26
Figure 31 – Opioid medicines containing codeine use at referral and episode end (%).....	26
Figure 32 – Opioid medication use (other than codeine) at referral and episode end (%).....	27
Figure 33 – Use of medications for nerve pain at referral and episode end (%).....	27
Figure 34 – Pain severity category at referral, episode end and post-episode follow-up (patient reported).....	30
Figure 35 – Patient-reported pain frequency at referral, episode end and post-episode follow-up.....	32
Figure 36 – Patient reported sleep severity at referral, episode end and follow-up (%).....	34
Figure 37 – Carer reported sleep severity at referral, episode end and follow-up (%).....	34
Figure 38 – Disability severity category at referral, episode end and post-episode follow-up (%).....	35
Figure 39 – Paracetamol only use at referral, episode end and post-episode (%).....	36
Figure 40 – Anti-inflammatory (non-prescription) use at referral, episode end and post-episode (%).....	36
Figure 41 – Anti-inflammatory (prescription) use at referral, episode end and post-episode (%).....	37
Figure 42 – Complementary or alternative medication use at referral, episode end and post-episode (%).....	37
Figure 43 – Opioid medicines containing codeine use at referral, episode end and post-episode (%).....	37
Figure 44 – Opioid medication use (other than codeine) at referral, episode end and post-episode (%).....	38
Figure 45 – Use of medications for nerve pain at referral, episode end and post-episode (%).....	38
Figure 46 – Pain severity at pathway start and end (patient reported).....	41
Figure 47 – Pain frequency – distribution at pathway start and end (patient reported).....	42
Figure 48 – Disability severity category at pathway start and end.....	44
Figure 49 – Paracetamol only use at pathway start and end.....	45

Figure 50 – Anti-inflammatory (non-prescription) use at pathway start and end45
Figure 51 – Anti-inflammatory (prescription) use at pathway start and end45
Figure 52 – Complementary or alternative medication use at pathway start and end46
Figure 53 – Opioid medicines containing codeine use at pathway start and end46
Figure 54 – Opioid medication use (other than codeine) at pathway start and end46
Figure 55 – Use of medications for nerve pain at pathway start and end47

Appendix G – List of tables

Table 1 – Sex.....	3
Table 2 – Age (years).....	3
Table 3 – Indigenous status.....	4
Table 4 – Country of birth.....	4
Table 5 – Referral source.....	5
Table 6 – Has your child previously attended a specialist pain service at a children’s hospital?	5
Table 7 – School level	5
Table 8 – Pain-related health service use in the past 3 months (average number of times used).....	6
Table 9 – Comorbidities and disabilities.....	6
Table 10 – How the main pain began (the precipitating event).....	7
Table 11 – Pain duration – how long the main pain has been present	7
Table 12 – Main pain area.....	7
Table 13 – Number of pain areas.....	7
Table 14 – Assessment tools collected	8
Table 15 – Assessment tool scores, average (std. deviation).....	8
Table 16 – Patient ‘at risk status’ for impaired health-related quality of life.....	9
Table 17 – Employment status (adolescents).....	13
Table 18 – Work productivity and impairment (%) for adolescents working full- or part-time.....	13
Table 19 – Employment status (carer).....	13
Table 20 – Work productivity and impairment (%) for carers working full- or part-time	13
Table 21 – School days missed in the previous two weeks (average days).....	14
Table 22 – Scores on the Bath Parent Impact Questionnaire, average (std. deviation).....	14
Table 23 – Waiting time.....	15
Table 24 – How the episode started	16
Table 25 – Service events provided at your service (total hours).....	16
Table 26 – Treatment pathways.....	17
Table 27 – Pathway delivery mode.....	17
Table 28 – How the episode ended	17
Table 29 – Length of the episode (lapsed days).....	18
Table 30 – Length of the episode (lapsed days) - distribution.....	18
Table 31 – Service duration (average hours)	18
Table 32 – Pain at referral and episode end (patient reported).....	19
Table 33 – Pain at referral and episode end (carer reported).....	19
Table 34 – Pain frequency at referral and episode end (%) (patient reported)	21
Table 35 – Pain frequency at referral and episode end (%) (carer reported).....	21
Table 36 – Quality of life score at referral and episode end	22
Table 37 – Quality of life score at referral and episode end	22
Table 38 – Patient ‘at risk status’ for impaired quality of life at referral and episode end (%).....	22
Table 39 – Functional disability at referral and episode end	24
Table 40 – Average pain-related worry scores at referral and episode end.....	25
Table 41 – Pain-related health service use in the past 3 months, reported at referral and episode end	27
Table 42 – Patient work status at referral and episode end.....	28
Table 43 – Carer work status at referral and episode end	28
Table 44 – Patient work productivity and impairment (%) for those working full- or part-time.....	28
Table 45 – Carer work productivity and impairment (%) for those working full- or part-time	28
Table 46 – School days missed in the previous two weeks	29
Table 47 – Carer impact average scores at referral and episode end	29
Table 48 – Pain severity at referral, episode end and post-episode follow-up (patient reported).....	30

Table 49 – Pain severity at referral, episode end and post-episode follow-up (carer reported)	31
Table 50 – Proportion of patients making clinically significant improvement in Average pain	31
Table 51 – Pain frequency at referral, episode end and post-episode follow-up (patient reported)	32
Table 52 – Pain frequency at referral, episode end and post-episode follow-up	32
Table 53 – Quality of life scores at referral, episode end and post-episode follow-up (patient reported)	33
Table 54 – Quality of life scores at referral, episode end and post-episode follow-up (carer reported)	33
Table 55 – Patient ‘at risk status’ for impaired quality of life at referral, episode end and post-episode follow-up, (%).....	33
Table 56 – Patients experiencing clinically meaningful improvement in quality of life	33
Table 57 – Functional disability at referral, episode end and post-episode follow-up.....	35
Table 58 – Proportion of patients making clinically significant improvement in functional disability	35
Table 59 – Pain-related worry at referral, episode end and post-episode follow-up.....	35
Table 60 – Pain-related health service use in the past 3 months, reported at referral, episode end and follow-up	38
Table 61 – Patient-reported work status at referral, episode end and follow-up (%)	39
Table 62 – Carer-reported work status at referral, episode end and follow-up (%)	39
Table 63 – Patient work productivity and impairment (%) for those working full- or part-time	39
Table 64 – Carer work productivity and impairment (%) for those working full- or part-time	39
Table 65 – School days missed in the previous two weeks.....	40
Table 66 – Carer impact average scores at referral, episode end and post-episode follow-up.....	40
Table 67 – Pain severity at pathway start and end	41
Table 68 – Pain severity at pathway start and end	41
Table 69 – Pain frequency at pathway start and end (%).....	42
Table 70 – Pain frequency at pathway start and end (%).....	42
Table 71 – Quality of life score at pathway start and end	43
Table 72 – Quality of life score at pathway start and end	43
Table 73 – Patients who experience a clinically meaningful improvement in quality of life following pain management.....	43
Table 74 – Patient ‘at risk status’ for impaired quality of life at pathway start and end (%)	43
Table 75 – Functional disability at pathway start and end	44
Table 76 – Average pain-related worry scores at pathway start and end.....	44
Table 77 – Pain-related health service use in the past 3 months, reported at pathway start and end	47
Table 78 – Patient work status at pathway start and end, n (%)	48
Table 79 – Carer work status at pathway start and end, n (%)	48
Table 80 – Patient work productivity and impairment (%) for those working full- or part-time	48
Table 81 – Carer work productivity and impairment (%) for those working full- or part-time	48
Table 82 – School days missed in the previous two weeks.....	49
Table 83 – Carer impact average scores at pathway start and end	49
Table 84 – Number of questionnaires generated and response rate by questionnaire type.....	50
Table 85 – Item completion (percent complete).....	51
Table 86 – Assessment tool validity and completion	52
Table 87 – Collection of patient outcomes at episode end, by episode end mode	53
Table 88 – Collection of patient outcomes at post-episode follow up, by episode end mode	53