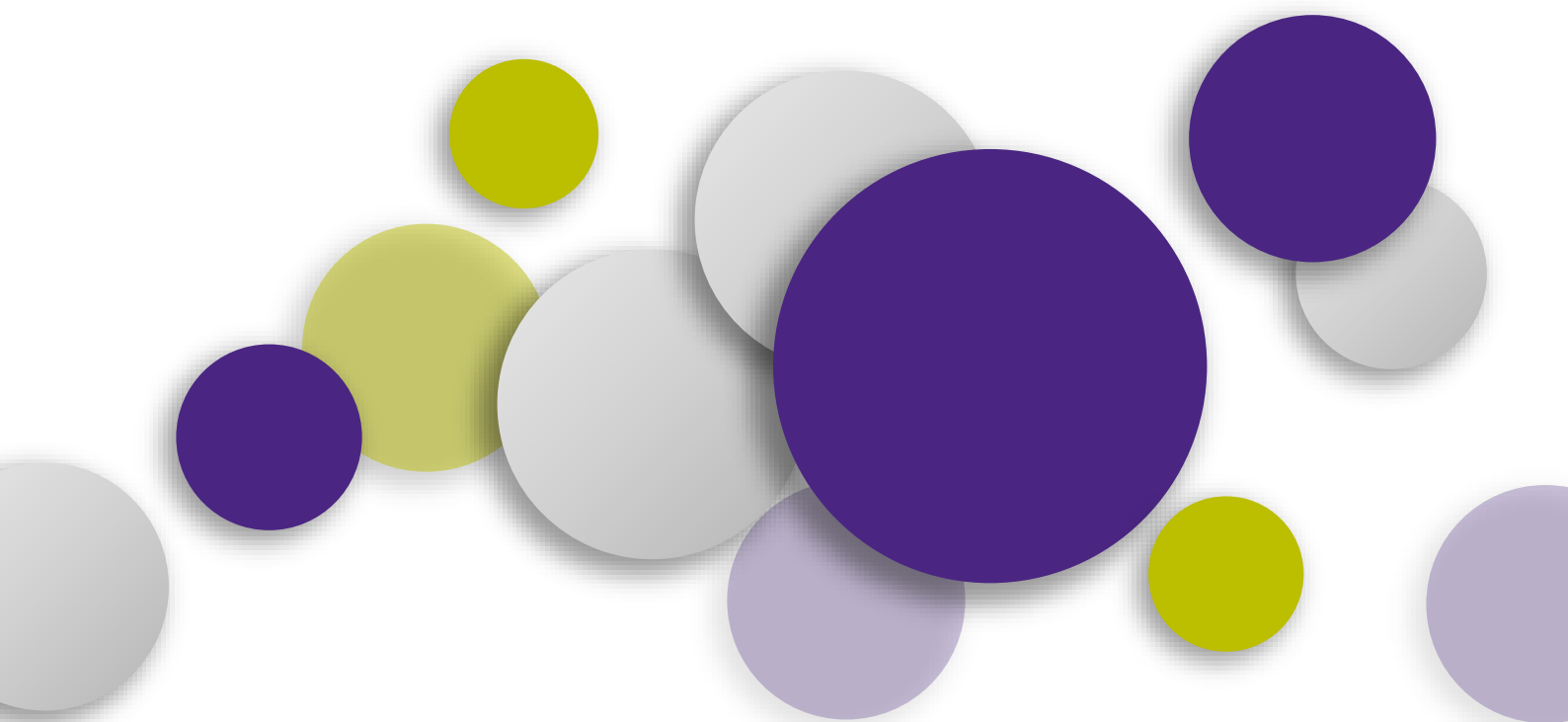




electronic persistent pain
outcomes collaboration

Annual Data Report

2020



ACKNOWLEDGEMENTS

ePPOC wishes to acknowledge the NSW Ministry of Health for funding the establishment of this initiative, and the many staff from pain management services who have spent considerable time collecting, collating and correcting the data.

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 asked to resubmit information where relevant.

COPYRIGHT

This work is copyright. It may be produced in whole or in part for study or training purposes subject to the inclusion of an acknowledgement of the source. It is not for commercial use or sale. Reproduction for purposes other than those above requires the written permission of ePPOC.

SUGGESTED CITATION

Shebeshi D, Allingham S, Tardif H, Bryce M, Cameron K, White J, Damm S and Eagar K (2021) *Electronic Persistent Pain Outcomes Collaboration Annual Data Report 2020*. Australian Health Services Research Institute, University of Wollongong.

The electronic Persistent Pain Outcomes Collaboration (ePPOC)

ePPOC is a program that aims to improve services and outcomes for people experiencing persistent pain. It involves specialist pain services collecting a standard set of information to measure outcomes for their patients as a result of treatment. Pain services use the information to triage, monitor and plan treatment for individual clients, and also send non-identifiable information to ePPOC for analysis. The results of these analyses are fed back to participating services every six months, allowing pain management services to assess their results, and compare their patients, services and outcomes to other pain management services. ePPOC also uses the information collected by services for national benchmarking and to develop a coordinated approach to research into the management of chronic pain in Australasia.

ePPOC is an initiative of the Faculty of Pain Medicine, established with funding from the New South Wales Ministry of Health, and supported by key stakeholder bodies. It was launched in 2013 with a small number of pain management services trialling the measures and processes. All other pain management services throughout Australia and New Zealand are now able to participate.

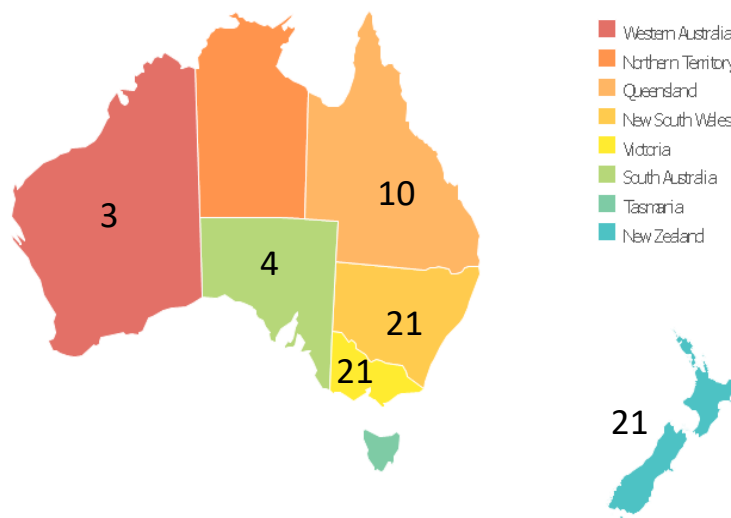
PaedePPOC addresses the differing needs of the paediatric pain management sector. This program allows collection of data items and assessment tools specific to the needs of children, adolescents and their parents.

This report

This report presents data collected by participating pain management units during 2020. Seventy-two adult and eight paediatric pain management services contributed data for this report (see Appendix A). The map below shows the locations of these services.

This report includes:

- Information on over 20,000 patients
- Information on patients' demographic and clinical characteristics and the care they received
- Outcomes for adult and paediatric patients who completed an episode of treatment



Contents

Pain management services participating in ePPOC.....	3
Adults referred for pain management	4
Demographic profile	4
Clinical characteristics at referral.....	5
Pain	5
Comorbid conditions	6
Body Mass Index.....	7
Mood	7
Cognition.....	7
Medication use	8
Health service utilisation	9
The episode of care.....	9
Patient outcomes	9
Pain, mood and cognitions	10
Medication use	11
Employment and work productivity	11
Children and adolescents referred for pain management.....	12
Demographic profile	12
Clinical characteristics at referral.....	12
Pain	13
Comorbid conditions	14
Role functioning.....	14
Quality of Life.....	14
Disability	15
Pain-related anxiety.....	15
Medication use	16
Health service utilisation	16
The episode of care.....	17
Patient outcomes	17
Pain and quality of life	17
Medication use	18
Appendix A – Data submitting services.....	19
Appendix B – ePPOC assessment tools	21
Appendix C – PaedePPOC assessment tools	25

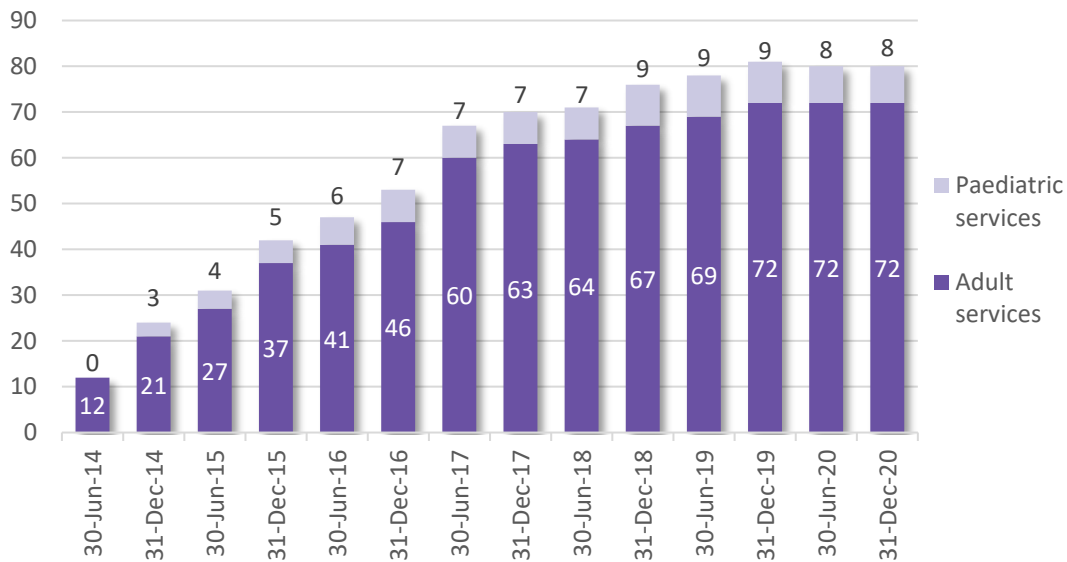
Pain management services participating in ePPOC

The services submitting data for this report were both public and private services located in:

- New South Wales (18 adult and 3 paediatric services)
- Victoria (19 adult and 2 paediatric services)
- Queensland (8 adult and 2 paediatric services)
- Western Australia (3 adult services)
- South Australia (3 adult and 1 paediatric services)
- New Zealand (21 adult).

Since the first ePPOC report in 2014, the number of data-submitting services has increased from 12 to 80.

Figure 1 – Number of data submitting services, 2014-2020

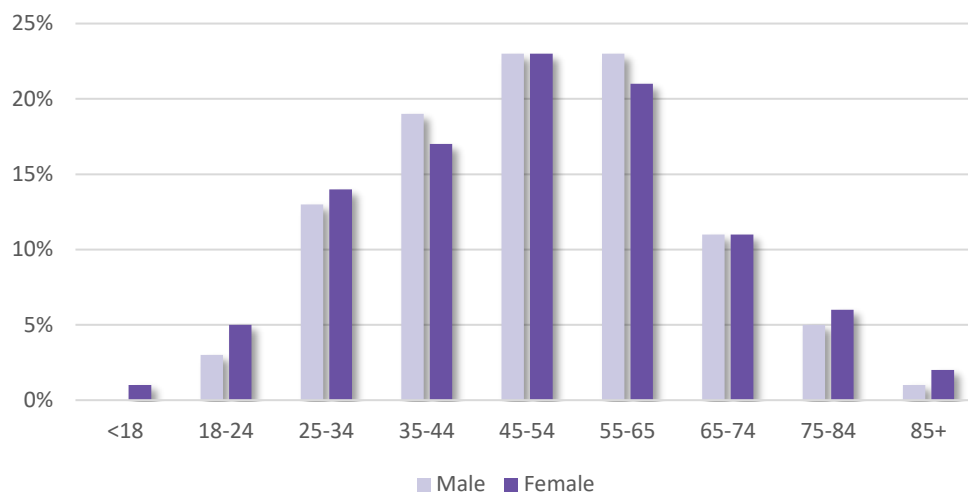


Adults referred for pain management

Demographic profile

Adult pain management services contributed data for 19505 patients during 2020. Of these patients, 58.2% were female, with an average age of 50.3 years at the time of referral. Males were slightly older on average at 50.4 years. The distribution by gender and age is shown in Figure 2.

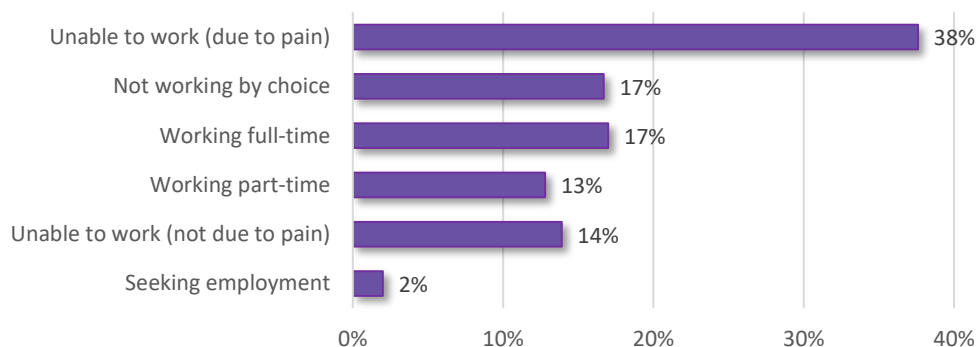
Figure 2 – Age at referral and gender distribution of patients



Most patients were born in Australia (50.9%) or New Zealand (24.1%) and 4.7% identified as being of Aboriginal and/or Torres Strait Islander origin. A relatively small proportion (3.9%) required an interpreter and 8.0% required assistance with written or spoken communication. Most patients were referred to the pain management service by a general practitioner or nurse practitioner (55.3%).

Figure 3 shows the work status of patients at referral to the pain management service. Almost two in five patients were unable to work, either due to pain (38%) or another condition (14%). 17.3% of episodes involved a compensation claim.

Figure 3 – Work status of patients at referral



Clinical characteristics at referral

Most patients referred to pain management services completed a questionnaire prior to their first appointment with the service. These questionnaires asked patients about their pain, medication and health care utilisation, and included standard assessment tools which examined mood, cognition, physical function and pain interference. More detailed information regarding these tools is provided in Appendix B. 19,505 of these initial questionnaires were completed, providing a picture of the health and clinical characteristics of patients referred for specialist pain management.

Pain

42.1% of patients had experienced their pain for more than five years, and most (81.3%) described their pain as 'always present'. The events that led to the patients' pain are shown in Table 1.

The regions where pain was at its worst are shown in Figure 4, with the back being the most common (42% of patients identified this as the most painful site). 12% of patients had pain in one region only, with the remainder identifying multiple regions, as shown in Figure 5.

Table 1 – Patient-reported cause of pain

Precipitating event	%
Injury at work/school	25.0
No obvious cause	14.2
Related to another illness	11.5
Injury at home	10.8
Motor vehicle crash	10.2
Injury in another setting	9.3
After surgery	8.1
Related to cancer	1.2
Other	9.8

Figure 4 – Site of patient's main pain

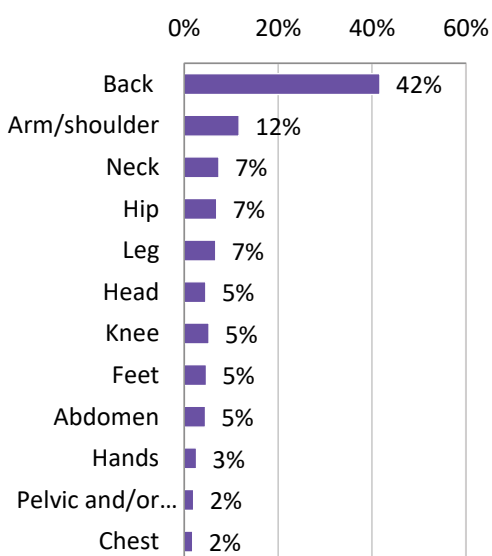
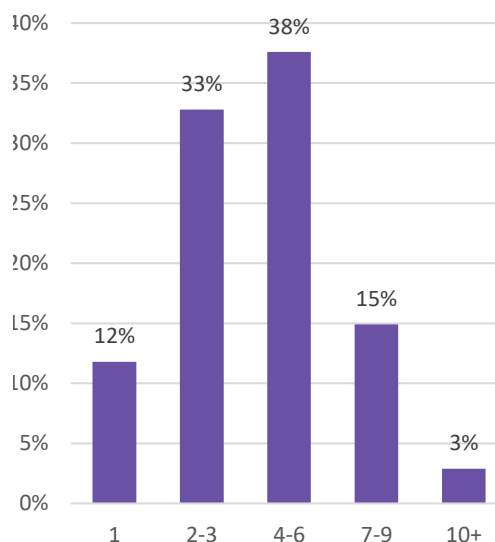
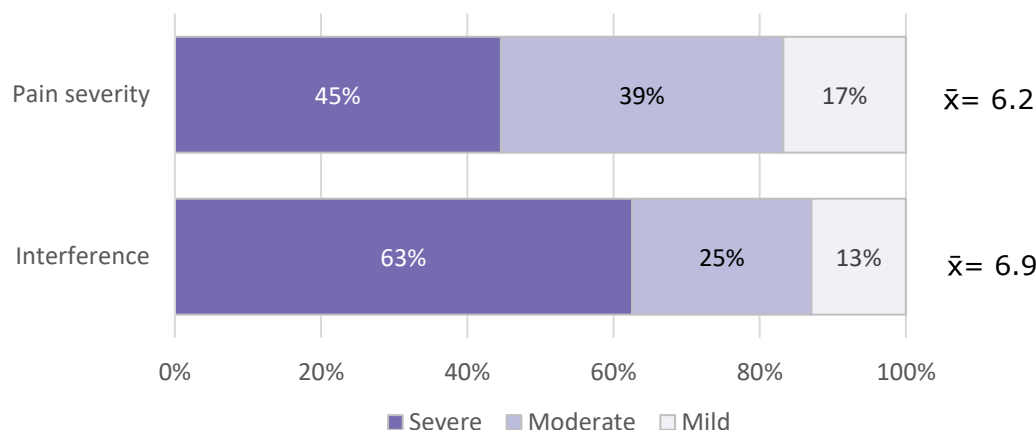


Figure 5 – Number of pain sites



The Brief Pain Inventory (BPI) was used to assess the intensity of pain and its interference in activities of daily living over the past week. Figure 6 shows that at referral, nearly 1 in 2 people rated their pain as severe, and over 60% reported that it severely interfered with daily activities.

Figure 6 - Proportion of people with severe, moderate and mild pain and pain interference



Comorbid conditions

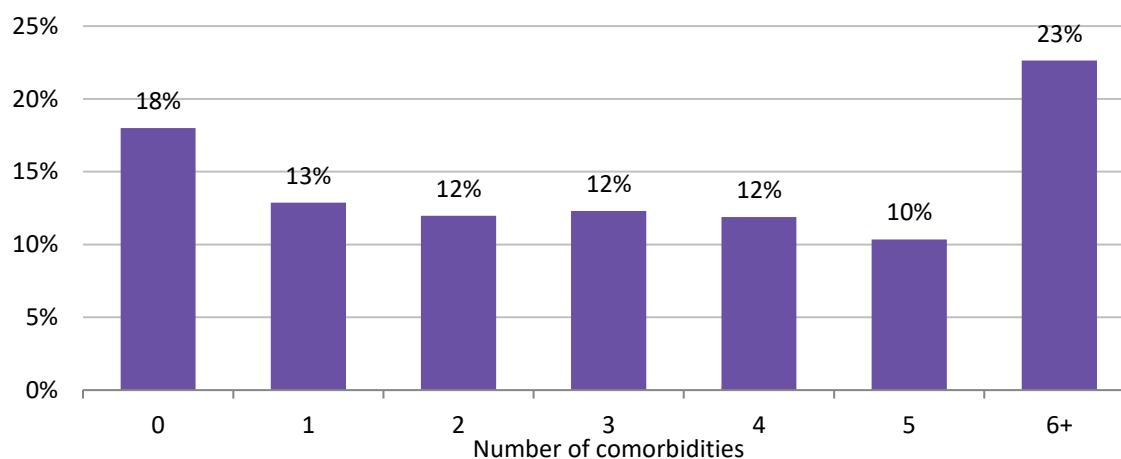
The patient questionnaires included a list of medical conditions, and asked patients to indicate which (if any) they experienced in addition to their pain. The percent of patients with each of these conditions is shown in Table 2. 43% of patients reported that they had a mental health condition, with the majority of these people experiencing depression.

The clinical complexity of people referred to pain management services is further illustrated in Figure 7, which shows that most people experience at least one other condition in addition to their pain.

Table 2 - Comorbid conditions

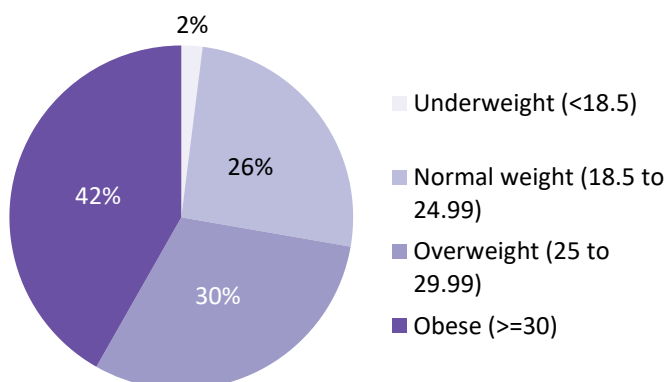
Medical condition	Percentage
Mental health condition	43.0
PTSD	12.2
Anxiety	30.2
Depression	33.2
Arthritis	35.6
Muscle, bone and joint problems other than arthritis	33.5
Heart and circulation problems	21.7
High Blood Pressure	13.0
High Cholesterol	7.6
Diabetes	11.7
Digestive problems	26.8
Respiratory problems	25.0
Neurological problems	8.0
Thyroid problems	8.6
Liver, kidney and pancreas problems	7.3
Cancer	4.2
Other medical conditions	22.0

Figure 7 – Distribution of patients by number of comorbidities



Body Mass Index

Figure 8 – Patient BMI

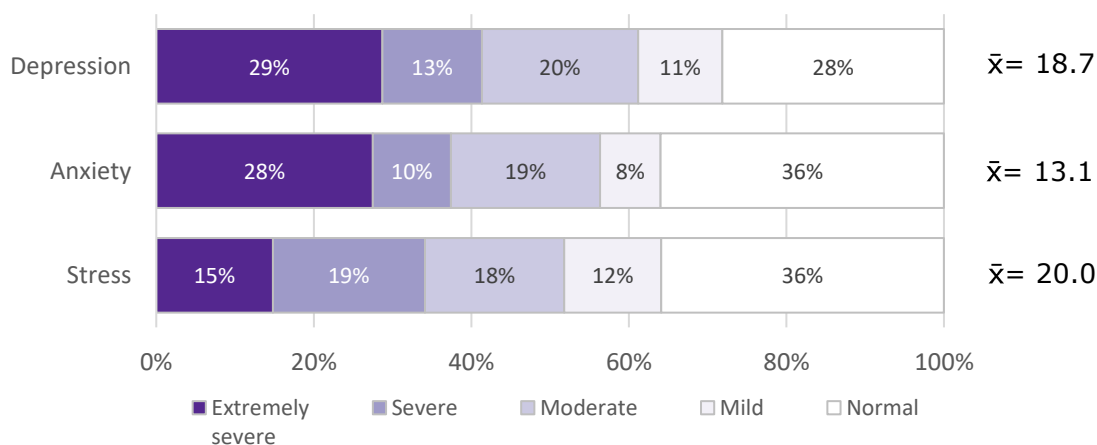


The average Body Mass Index (BMI) of patients at referral was 30.0 (SD=7.8) which lies in the obese category. The percentage of patients in each BMI category is shown in Figure 8.

Mood

The Depression Anxiety and Stress Subscale (short form) was used to assess the mental health of people referred for specialist pain management. Figure 9 shows that 40% of people were experiencing extremely severe or severe depression, and over one third reported severe or extremely severe anxiety and/or stress.

Figure 9 - The proportion of people reporting depression, anxiety and stress at referral

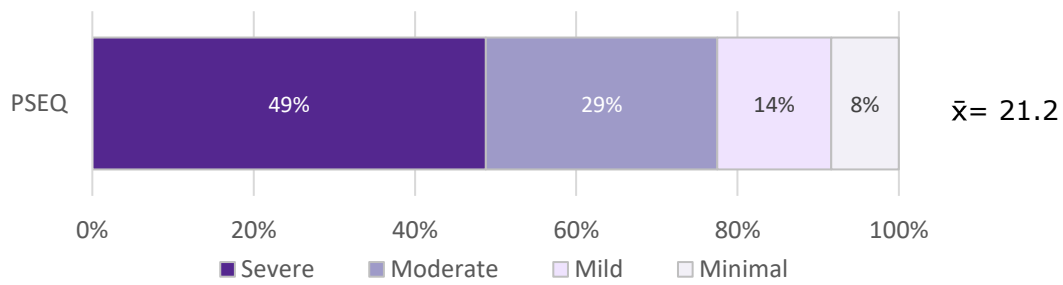


Cognition

The Pain Self-Efficacy Questionnaire (PSEQ) assesses a patient's belief that he or she can perform a range of activities despite their pain.

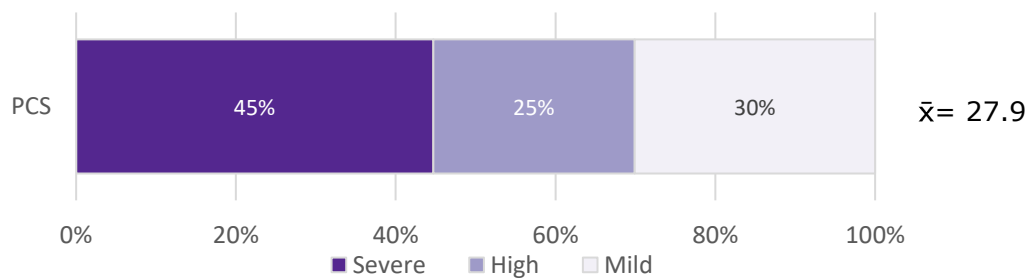
The average score on the PSEQ following referral to the pain services was 21.2 (SD=12.8), a score classified as 'Moderate' but bordering on severe impairment (identified by scores less than 20). Figure 10 shows that almost one in two people reported that pain severely impaired their belief that they could perform these daily activities.

Figure 10 - The proportion of people reporting severe, moderate and mildly impaired pain self-efficacy at referral



Patients also completed the Pain Catastrophising Scale (PCS), which measures thoughts and feelings related to pain. The average score on the PCS at referral was 27.9 (SD=13.8), a score classified as ‘High’. However, 45% of people reported severe pain catastrophising (Figure 11).

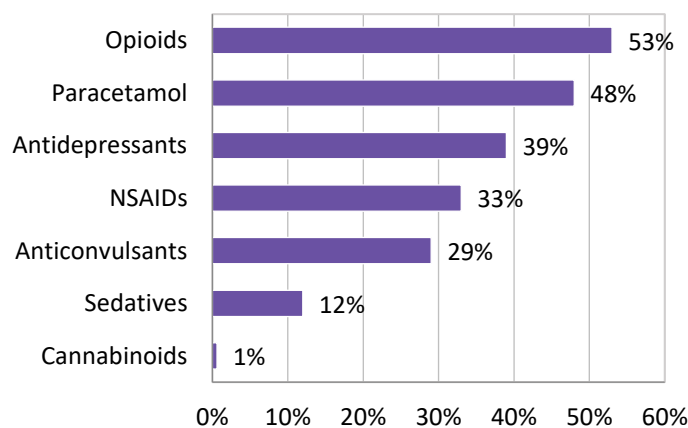
Figure 11 - The proportion of people reporting severe and high levels of pain catastrophising at referral



Medication use

At referral to the service, 51% of patients were taking opioid medication on more than two days per week. The average daily oral morphine equivalent for patients using opioid medication was 54.2mg. On average, patients were using medications from two of the seven major drug groups, identified by the Faculty of Pain Medicine as of particular interest in pain management¹. The percentage of patients using each of the drug groups is show in Figure 12.

Figure 12 – Percent of patients using each drug group at referral



¹ These are opioids, paracetamol, NSAIDs, antidepressants, anticonvulsants, benzodiazepines and medicinal cannabinoids.

Health service utilisation

Patients reported how many times in the past three months they used various health services and had diagnostic tests performed because of their pain (Table 3).

Table 3 – Patient use of health services

Health service	Mean
Health professionals other than doctors	5.7
General practitioner	2.4
Medical specialist	0.9
Diagnostic tests	0.6
Hospital emergency department	0.2
Hospital admission	0.1

The episode of care

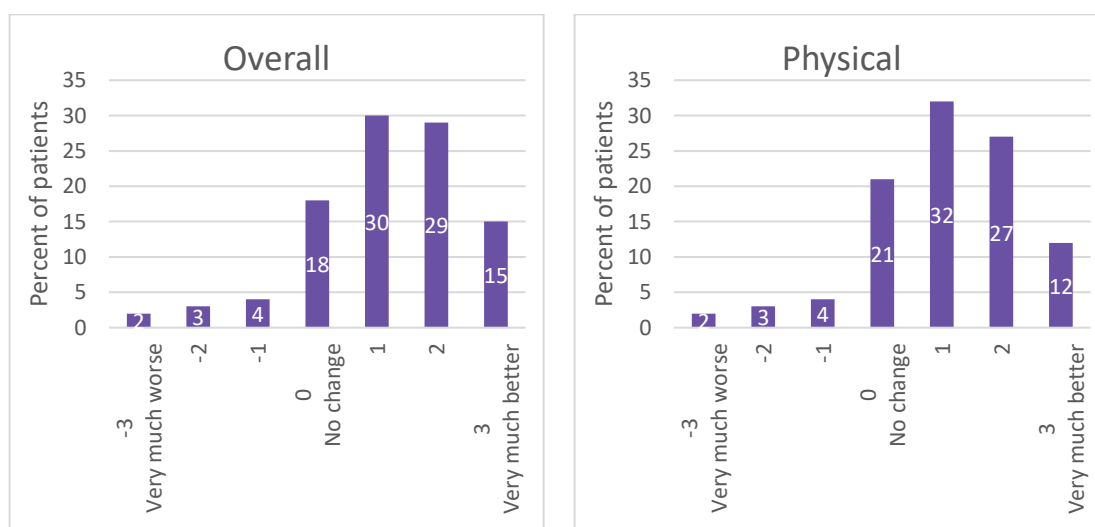
The median wait time for a patient to start an episode of care at a pain management service was 61 days (average = 107.4 days). This reflects the time from when the pain service receives a referral, to the patient's first clinical contact. Almost two thirds of people were seen within 3 months of the service receiving the referral (63%).

One in two patients' care extended from between 1 to 6 months (median = 176.0 lapsed days) and patients typically received an average of 20.8 hours of treatment during that period.

Patient outcomes

During 2020, 4564 patients reported outcomes at the end of their episode of care. Patients were asked to compare how they would describe themselves now (overall and physical abilities) compared to before receiving treatment. Patients responded using a Likert scale which ranged from -3 (very much worse) to +3 (very much better). Responses are shown in Figure 13, with almost 3 in 4 patients reporting that they had improved following pain management. Approximately 1 in 5 reported no change, and 9% rated themselves as worse.

Figure 13 – Global rating of change at episode end – overall and physical



Pain, mood and cognitions

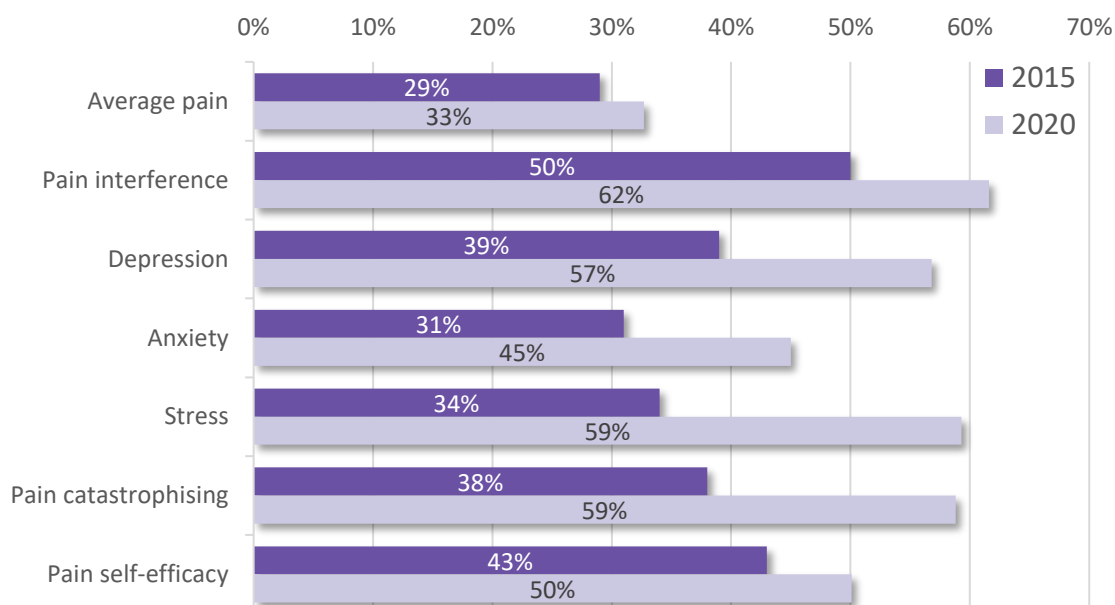
After receiving pain management, a large proportion of people reported clinically significant improvement² in the severity of their pain and its interference in their daily activities, as well as improved mood and pain-related cognitions (see Table 4).

Table 4 - Proportion of people who made clinically significant improvement (CSI) from referral to episode end

Domain	People who report CSI
Pain	
- Average pain	32.7%
- Pain interference	61.6%
Mood	
- Depression	56.8%
- Anxiety	45.8%
- Stress	59.3%
Cognitions	
- Pain catastrophising	58.8%
- Pain self-efficacy	50.1%

Over time, the proportion of people who report clinically significant improvement has increased across all domains. This is shown in Figure 14, which displays improvement in 2020 compared to 2015.

Figure 14 – Percentage of patients reporting clinically significant improvement, 2015 vs. 2020



² In assessing outcomes using the standard assessment tools, ePPOC has adopted guidelines for determining whether a change is **clinically significant**, that is, what change in score represents a meaningful difference to the patient. These guidelines are detailed in Appendix B.

Medication use

Following treatment at a pain management service, many people made improvements in their use of medications. In particular, of the people who were using opioid medication at referral:

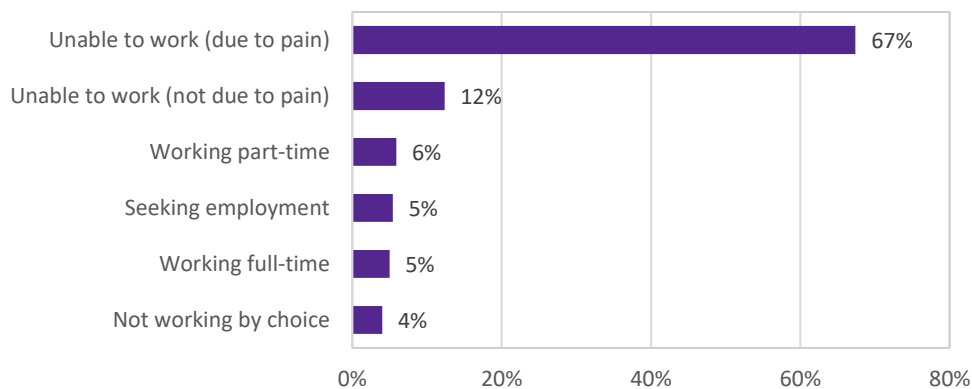
- The average daily morphine equivalent reduced from 41.4mg to 26.8mg per day
- 55.7% of people were able to at least halve their opioid dose
- 50.5% of people who were using high doses of opioid at referral (>40mg per day) were able to reduce their dose by at least half following pain management.

Employment and work productivity

Almost two out of every five patients (38.6%) who completed an episode of care were unemployed due to pain at referral. While the majority were still unemployed due to pain at the end of the episode, 1 in 3 people no longer classified themselves in this way – they were either employed (full time or part time), seeking employment, not working by choice or unable to work for a reason other than pain (see

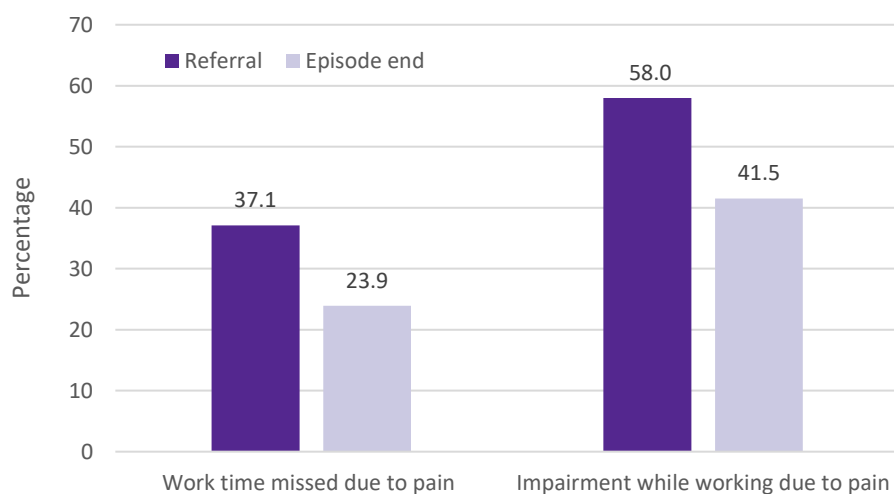
Figure 15).

Figure 15 – Work status at episode end for patients who were ‘unemployed due to pain’ at referral



For those people who were working at referral, absenteeism and productivity improved following pain management. Figure 16 shows that at referral, workers missed 37% of their usual hours because of pain, and rated impairment while working at 58%. After treatment this decreased to 24% missed hours and 42% impairment.

Figure 16 - Absenteeism and productivity at referral compared to episode end



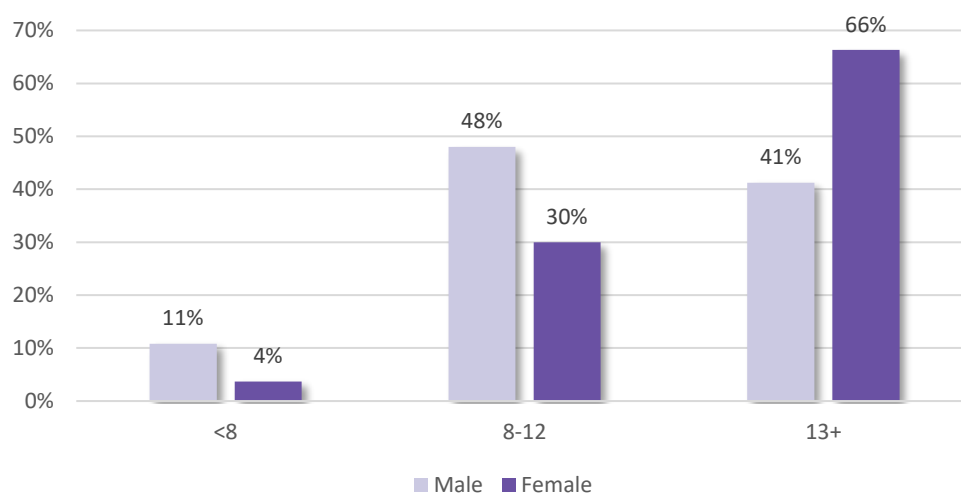
Overall work impairment, taking into account absenteeism and impairment while at work, decreased from 66% at referral to 48% following treatment at a pain management service.

Children and adolescents referred for pain management

Demographic profile

Participating paediatric pain management services contributed data for 781 patients during 2020. Of these patients, 68.2% were female, with an average age of 13.0 years at the time of referral. Males were younger on average at 11.5 years. The distribution by gender and age group is shown in Figure 17.

Figure 17 – Age and gender distribution of patients



Most patients were born in Australia (91.9%) and 3.8% identified as being of Aboriginal and/or Torres Strait Islander origin. Patients were generally referred to the pain management service by a specialist practitioner (61.3%).

Clinical characteristics at referral

Most children and their parents completed a questionnaire prior to their first appointment with the service. These questionnaires asked children and parents about pain, medication and use of health care services, and included standard assessment tools which examined pain severity, quality of life, disability, pain-related worries and the impact of the child's pain on the parent. More detailed information regarding these tools is provided in Appendix C.

747 of these initial questionnaires were completed (374 completed by the child, 373 by the parent), providing a picture of the health and clinical characteristics of patients following their referral to a specialist paediatric pain management service. All information in this section is based on patient and/or parent report.

Pain

Parents were asked how long their child's pain had been present, and 63.3% responded that their child had experienced the pain for more than 12 months. Most (63%) described the pain as 'always present'. The events thought to have caused the child's pain are shown in Table 5. 37.7% of parent's reported that the cause of their child's pain was unknown.

Regions where the main pain was experienced are shown in Figure 18, with the back and head the most common (20% and 15% respectively) followed by the abdomen (13%). One in four patients had pain in one region only, with the remainder identifying multiple regions (see Figure 19).

Table 5 – Event precipitating the patient's pain

Precipitating event	%
No known cause	37.7
Injury	18.7
Illness	17.6
After surgery	6.9
Other	19.0

Figure 18 – Site of patient's main pain

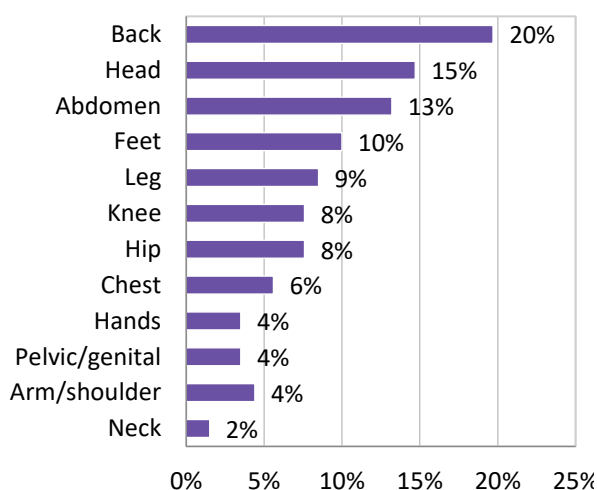
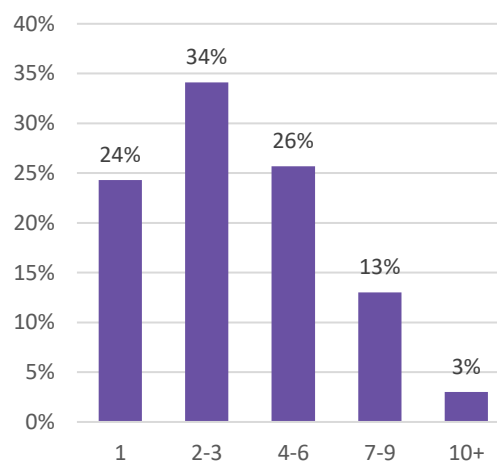
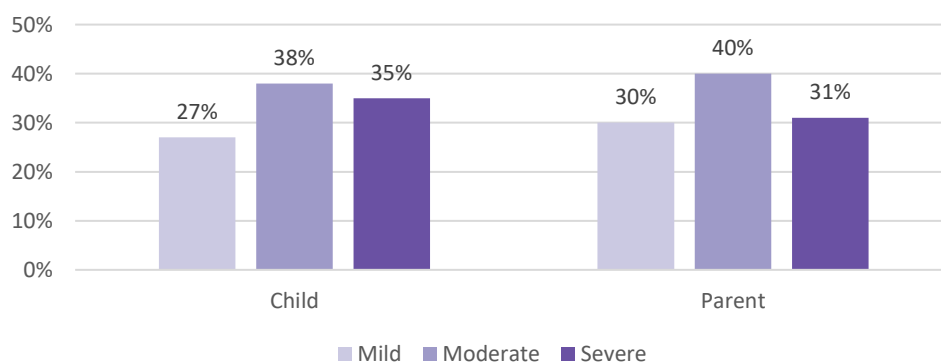


Figure 19 – Number of pain sites



Pain severity was assessed using the Brief Pain Inventory (BPI) in children aged eight years and above. Young children aged 5-7 completed the Faces Pain Scale – Revised. Parents also rated their child's pain using the BPI. The average pain rating reported by child and parent at referral was 5.6 and 5.5 (moderate severity), respectively, with more than one in three children and almost one in three parents rating the pain as severe.

Figure 20 – Patient and parent ratings of pain severity



Comorbid conditions

Parents were asked whether their child had a disability and/or other medical condition in addition to their pain. The responses are shown in Table 6 below.

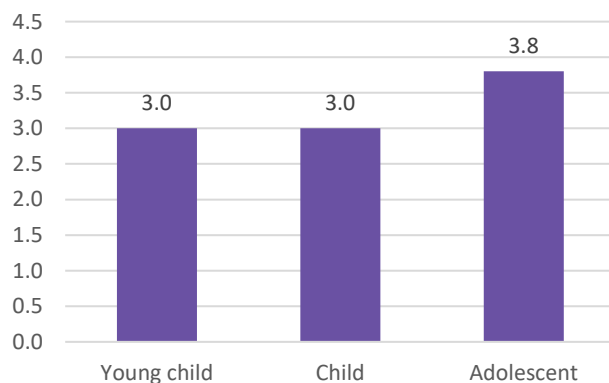
Table 6 - Percent of parents reporting disabilities and comorbidities

Disabilities and comorbid conditions	% of patients
Disabilities	
Physical disability	10.2
Sight impairment	7.0
Intellectual disability	4.3
Hearing impairment	2.5
Comorbid conditions	
Mental health condition	28.2
Chronic disease	23.9
Cancer	2.0

Role functioning

The median number of days of school missed in the fortnight prior to completion of the referral questionnaire ranges from 3.0 for both young children and children to 3.8 days for adolescents (Figure 21).

Figure 21 – Median number of days of school missed over the previous fortnight (10 days)



Quality of Life

Quality of life was assessed using the Paediatric Quality of Life Inventory (PedsQL) with both children and parents rating the child's quality of life. Total and subscale average scores at referral are shown in Table 7, with higher scores reflecting better quality of life. Total scores below 69.7 and 65.4 for the child and parent, respectively, indicate 'at risk' status for impaired quality of life.

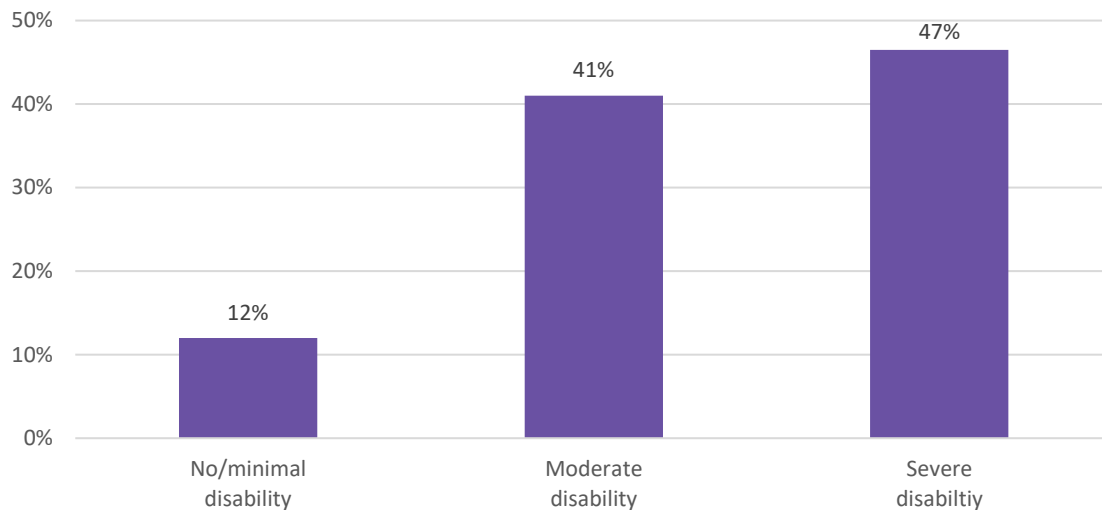
Table 7 – Patient and parent quality of life scores

Domain	Child	Parent
Psychosocial	51.1	47.7
Physical	36.8	34.9
Total score	46.1	43.2

Disability

Children aged eight and older completed the Functional Disability Inventory (FDI) to assess the impact of pain on the ability to complete 15 regular physical activities (such as walking, going to school, getting to sleep). The average score for children was 27.5, reflecting moderate disability. The distribution of scores by severity category is shown in Figure 22, indicating that over 4 in 5 children rated their functional disability as either moderate or severe.

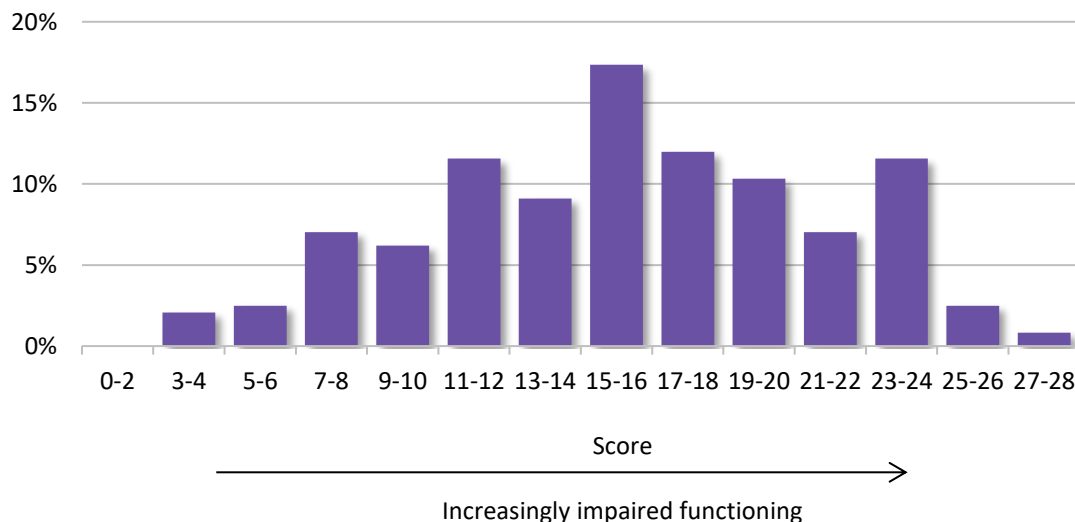
Figure 22 – Disability at referral by severity category



Pain-related anxiety

Children aged 13 and older completed the pain-specific anxiety section of the Bath Adolescent Pain Questionnaire. This asks questions assessing pain-related worries, such as “I avoid activities that cause pain” and “When I have pain, I think something harmful is happening”. Responses range from Never to Always, with higher scores indicating greater severity. Children scored an average of 15.8 in pain-specific anxiety. The distribution of scores on this tool is shown below in Figure 23.

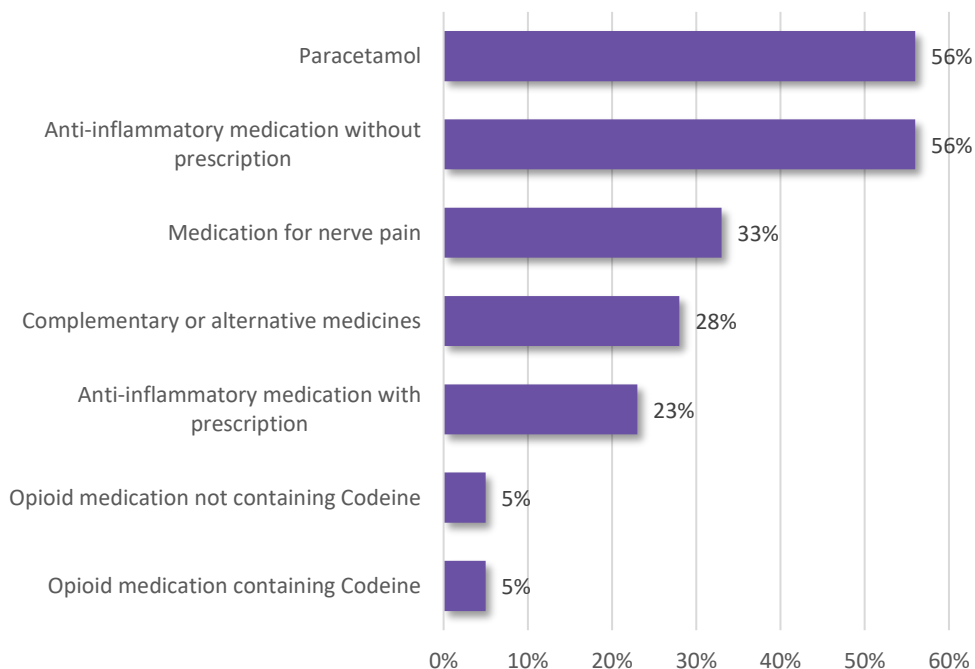
Figure 23 – Distribution of pain-related worry scores



Medication use

Parents provided information regarding the medication their child was taking for pain and how frequently each was used. The percent of patients taking each medication type daily or often is shown in Figure 23 below.

Figure 23 – Percentage of patients using medication daily or often by medication type



Health service utilisation

Parents reported how many times in the past three months their child had used various health services and had diagnostic tests performed because of their pain, shown in Table 8. These equate to, on average, more than one visit every week for pain-related reasons.

Table 8 – Paediatric patient use of health services

Health service	Mean
Allied health professionals	4.4
General practitioner	3.3
Medical specialist	2.8
Diagnostic tests	2.0
Other therapist	1.3
Hospital emergency department	1.0
Hospital admission	0.5

The episode of care

In paediatric services, the median wait time was 46 days (average = 76.7 days). This reflects the time from when the pain service receives a referral, to the first clinical contact. 74.4% of people were seen within 3 months of the service receiving the referral.

Episodes of care tended to be longer in paediatric services (compared to adult pain services), with a median episode length of 184.0 days.

Patient outcomes

Pain management units provided information on outcomes reported by 127 patients and 125 parents for episodes that ended during 2020.

Pain and quality of life

Although the volume of outcomes is relatively small, a large proportion of children and adolescents (and their parents) reported clinically significant improvement³ after receiving pain management at specialist services (see Table 9).

Table 9 – Paediatric patient outcomes

Percent of patients reporting a clinically significant improvement	Patient rated	Parent rated
Pain Severity		
Average pain	41.3	59.8
Worst pain	33.0	46.1
Health-related quality of life		
Sleep	35.2	37.2
Overall	72.9	73.0
Functional disability	59.4	-

Average pain improved in almost 2 in 3 children, as did functional ability. An even higher proportion of patients and parents reported clinically significant improvement in overall health-related quality of life, with almost 3 in 4 children improving.

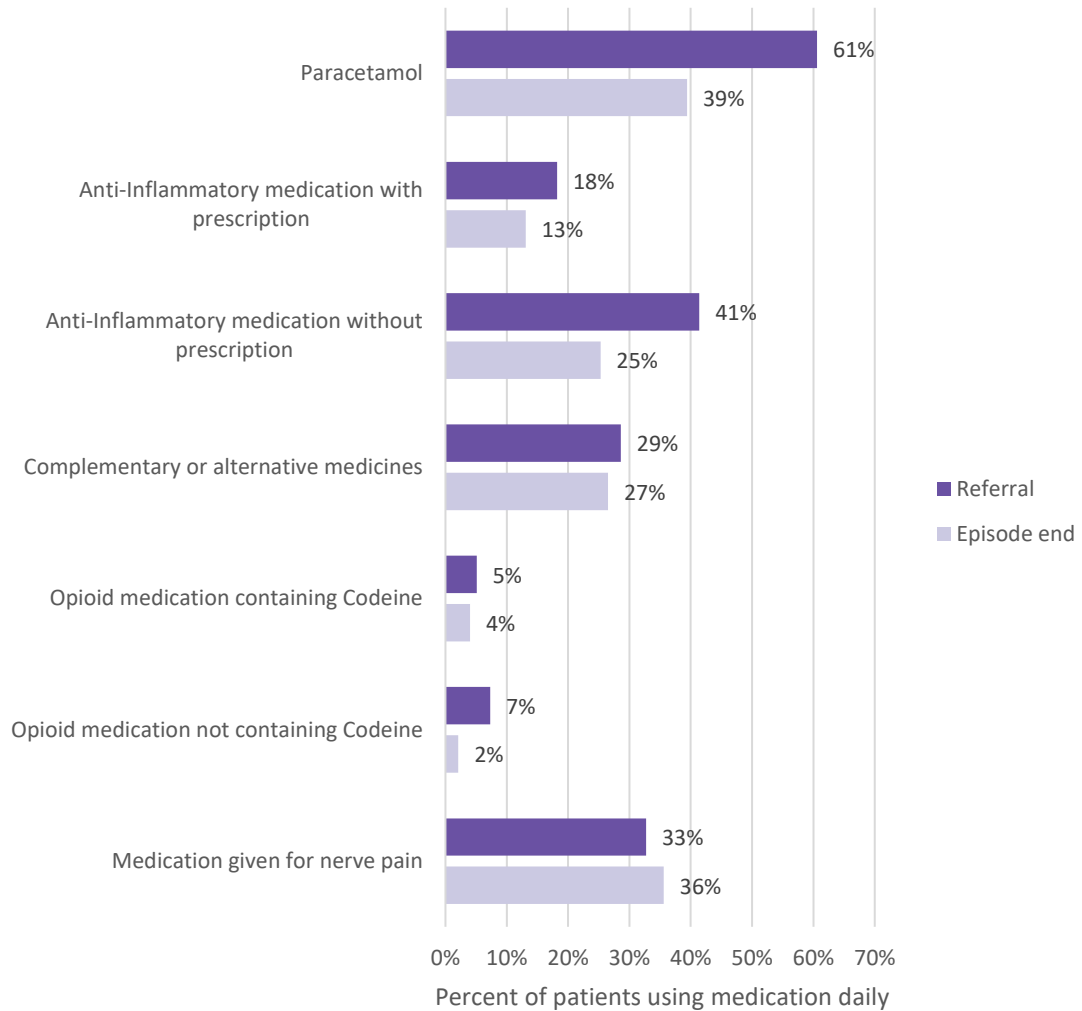
There was also a reduction in the percentage of children whose scores on the PedsQL indicated impaired quality of life: at referral 85% of children were classified as having impaired quality of life, however at the end of the episode of care this proportion was 71.1%.

³ In assessing outcomes using the standard assessment tools, ePPOC has adopted guidelines for determining whether a change is **clinically significant**, that is, what change in score represents a meaningful difference to the patient. These guidelines are detailed in Appendix C.

Medication use

The change in frequent use of medications from referral to episode end is shown in Figure 24. With the exception of medication given for nerve pain, there was a reduction in the use of medications used daily or often.

Figure 24 – Medications used daily or often at referral compared to episode end



Appendix A – Data submitting services

Adult pain management services

New South Wales

Central Coast Integrated Pain Service
Coffs Harbour Chronic Pain Service
Concord Repatriation General Hospital
(Multidisciplinary Pain Clinic)
Department of Pain Management, Prince of
Wales Hospital
Hunter Integrated Pain Service
Illawarra Shoalhaven Chronic Pain Service
Innervate Pain Management
Lismore Hospital Pain Clinic
Liverpool Hospital Chronic Pain Services
Nepean Pain Unit
Orange Health Service Chronic Pain Clinic
Royal North Shore Hospital Pain Management
and Research
Royal Prince Alfred PMC
St George Hospital Pain Management Unit
SVH Pain Service, Sydney
Sydney Spine and Pain Rehab
Tamworth Integrated Pain Service (TIPS)
Westmead Hospital Pain Management Centre

Queensland

Gold Coast Interdisciplinary Persistent Pain
Centre
Metro South Health Persistent Pain
Management Service
North Queensland Persistent Pain Management
Service
St Vincent's Private Hospital Brisbane
Sunshine Coast Persistent Pain Management
Service
Tess Cramond Pain and Research Centre
Wesley Pain and Spine Centre
Interventus Pain Specialists

South Australia

CALHN Pain Management Unit
Flinders Pain Management Unit
Northern Adelaide Pain
Rehabilitation Service

Western Australia

Fiona Stanley Hospital
King Edward Memorial Hospital Pelvic Pain Clinic
Sir Charles Gairdner Hospital

Victoria

Advance Healthcare
Austin Health Pain Service
Barbara Walker Centre for Pain Management
Caulfield Pain Management and Research Centre, Alfre
Health
Dorset Rehabilitation Centre
Eastern Health Ambulatory Pain Management Service
Empower Rehab
Epworth Hospital
Goulburn Valley Health Chronic
Pain Clinic
Latrobe Regional Hospital
Monash Health
Northern Health Service
Outpatient Rehabilitation Services, Bendigo Health
Peninsula Health Integrated Pain Service (Persistent Pa
Management Service)
Precision Ascend
Royal Melbourne Hospital
Royal Women's Hospital - Chronic Pelvic Pain Clinic
Victorian Rehabilitation Centre
Western Health

New Zealand

Active+ Pain Management Service
Advantage South
APM NZ
Body in Motion
Canterbury
DHB - Pain Management Centre
Capital and Coast DHB (Wellington Hospital)
Futureproof Rehab Ltd
Habit Rehabilitation
Hutt Valley DHB - ACC Pain Team
Integrative Pain Care
Nelson Nursing Services
Occupational Health Canterbury
Pain Management and Rehabilitation Services
Limited
Pain Rehabilitation Christchurch Ltd
Proactive Rehab
Proactive Southern Ltd
QE Health
Southern Rehab
Taranaki DHB
Persistent Pain Service
TBI Health Group Ltd
The Auckland Regional Pain Service

Paediatric pain management services

New South Wales

Children's Hospital at Westmead
John Hunter Children's Hospital
Sydney Children's Hospital Randwick

Victoria

Monash Children's Hospital
Royal Children's Hospital Melbourne

Queensland

Queensland Children's Hospital
St Vincent's Private Hospital Brisbane

South Australia

Women's and Children's Hospital Adelaide

Appendix B – ePPOC assessment tools

The assessment tools used in ePPOC are:

- Brief Pain Inventory (BPI)
- Depression, Anxiety, Stress Scale (DASS)
- Pain Catastrophising Scale (PCS)
- Pain Self-Efficacy Questionnaire (PSEQ)
- Global Rating of Change (GRC)
- Work Productivity and Impairment (WPAI)
- CARRA Body Chart.

Each of these assessment tools are briefly described below.

Brief Pain Inventory⁴

The BPI items used in the ePPOC dataset measure the severity of pain and the degree to which the pain interferes with common activities of daily living. There are four pain severity questions, rated on a scale of 0 to 10, where 0 = 'No pain' and 10 = 'Pain as bad as you can imagine'. Patients are asked to rate their average, worst and least pain over the last week, and their pain right now. Pain severity is calculated as an average of these four items.

Severity bands for these items are:

- 0-4 = mild pain
- 5-6 = moderate pain
- 7-10 = severe pain

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 for average and worst pain)

≥ 50% represents substantial clinically important change.

The interference questions are rated on a scale of 0 to 10, where 0 = 'Does not interfere' and 10 = 'Completely interferes'. The interference subscale is an average of the seven interference questions. At least 4 of 7 questions must be completed for this subscale to be valid. The IMMPACT recommendation for assessment of clinically significant change on the BPI interference scale is a change of 1 point over the average of the 7 items⁵.

⁴ Modified Brief Pain Inventory, reproduced with acknowledgement of the Pain Research Group, University of Texas, MD Anderson Cancer Centre, USA

⁵ Dworkin, RH, et al 2008, 'Interpreting the Clinical Importance of Treatment Outcomes in Chronic Pain Clinical Trials: IMMPACT Recommendations.' *The Journal of Pain*, vol. 9, no. 2, pp 105-121.

Depression Anxiety Stress Scales (DASS)⁶

The DASS measures the negative emotional states of depression, anxiety and stress. Due to the large number of questions in the full DASS (42 questions), the DASS21 is administered. This comprises 21 questions which are rated on a scale of 0 to 3, where 0 = 'did not apply to me at all', 1 = 'applied to me to some degree, or some of the time', 2 = 'applied to me to a considerable degree, or a good part of the time', or 3 = 'applied to me very much, or most of the time'. Scores are multiplied by 2 to enable comparison with the full-scale DASS42 for which norms exist.

For each subscale (Depression, Anxiety and Stress), the 7 items are summed and then multiplied by 2. The test developers suggest that at least 6 of 7 items should be complete for each subscale to be considered valid. Table 10 shows the range of scores associated with severity categories for each subscale.

Table 10 DASS severity categories

	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely Severe	28+	20+	34+

Clinical significance on each of the DASS subscales is defined as a change of 5 or more points coupled with a move to a different severity category.

Pain Catastrophising Scale (PCS)⁷

The PCS measures a patient's thoughts and feelings related to their pain. This includes three subscales measuring the dimensions of Rumination, Magnification and Helplessness. The PCS comprises 13 questions (Rumination – 4 items, Magnification – 3 items, Helplessness – 6 items) which are rated on a scale of 0 to 4, where 0 = 'not at all', 1 = 'to a slight degree', 2 = 'to a moderate degree', 3 = 'to a great degree' and 4 = 'all the time'. For each subscale, all items must be completed to be valid. For the total to be valid, at least 12 of 13 items must be completed.

Severity bands for the PCS are:

- <20 = mild
- 20 to 30 = high
- >30 = severe.

Clinically significant change requires a change in score of 6 or more points, combined with movement to a different severity category⁸.

⁶ Lovibond, SH and Lovibond, PF 1995, *Manual for the Depression Anxiety Stress Scales*, Psychology Foundation Monograph, Sydney, Australia.

⁷ Sullivan, MJL, et al 1995, 'The Pain Catastrophizing Scale: Development and Validation', *Psychological Assessment*, vol. 7, num. 4, pp 524-532.

⁸ Sullivan, MJL, personal communication with Nicholas, MK July 2014.

Pain Self-Efficacy Questionnaire (PSEQ)⁹

The PSEQ measures how confident a patient is that he or she can do a range of activities despite their pain. The PSEQ Total is a sum of scores from 10 questions which are rated on a scale from 0 = 'Not confident at all' to 6 = 'Completely confident'. At least 9 of 10 items must be complete for the PSEQ Total to be valid. Higher scores represent greater pain self-efficacy.

Severity bands for the PSEQ are:

- <20 = severe
- 20 to 30 = moderate
- 31 to 40 = mild
- >40 = minimal impairment.

Clinically significant change is defined as a change in score of 7 or more points, combined with movement to a different severity category¹⁰.

Global Rating of Change¹¹

The Global Rating of Change questions were included as part of the ePPOC dataset in 2018. They are asked in follow-up questionnaires only. The two questions are "Compared with before receiving treatment at this pain management service, how would you describe yourself now overall?" and "Compared with before receiving treatment at this pain management service, how would you describe your physical abilities now?" Participants answer by indicating their response on a Likert scale from -3 (very much worse) to +3 (very much better).

Work Productivity and Impairment (WPAI)¹²

WPAI outcomes are expressed as impairment percentages, with higher numbers indicating greater impairment and less productivity. The work status of all patients is collected, based on the International Consortium for Health Outcomes Measurement (ICHOM) categories. For patients who 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).

For more information on the calculations used please see the ePPOC Australian and New Zealand Data Dictionaries on the ePPOC website <https://ahsri.uow.edu.au/eppoc/forms>.

⁹ Nicholas, MK 1989, 'Self-efficacy and chronic pain', *British Psychological Society*, St. Andrews, Scotland.

¹⁰ Nicholas, MK, personal communication, July 2014.

¹¹ Bartlett, A, Flett, P, Tardif, H and Hush, J 2017, *Introducing a global measure of function and change in NSW pain services*, 37th ASM of the Australian Pain Society, Adelaide, Australia.

¹² 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.

CARRA Body Chart¹³

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

Pain sites	
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
Pelvic	groin
Knee	left and right knees
Hip	left and right hips

¹³ 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 C – PaedePPOC assessment tools

Six standardised assessment tools have been chosen to measure patient outcomes and the impact of the child's pain on the parent/parent:

- Modified Brief Pain Inventory - Pain severity questions
- Faces of Pain Scale – Revised
- Paediatric Quality of Life Inventory (PedsQL)
- Functional Disability Inventory (FDI)
- Bath Adolescent Pain – Pain-specific anxiety
- Bath Adolescent Pain – Parent Impact Questionnaire (BAP-PIQ)

Pain Severity

The tool used to capture pain severity is dependent on the patient's age. Children aged eight and above use the Modified Brief Pain Inventory¹⁴, whereas those aged 5-7 use the Faces of Pain Scale-Revised¹⁵.

MODIFIED BRIEF PAIN INVENTORY (BPI) - Modified versions of the questions in the standard BPI are used to assess pain in children aged eight and over, and obtain a parent proxy rating of the child's pain for all age groups.

FACES PAIN SCALE – REVISED - Children choose one of six faces showing increasing levels of pain, from 'no pain' to 'very much pain' which correspond 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.

Severity bands for these items are:

- 0-4 = mild pain
- 5-6 = moderate pain
- 7-10 = severe pain

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

≥ 50% represents substantial clinically important change.

To determine whether the change experienced by patients at referral is clinically significant, the improvement must be at least moderately clinically important, i.e. at least a 30% improvement.

¹⁴ Modified Brief Pain Inventory, reproduced with acknowledgement of the Pain Research Group, University of Texas, MD Anderson Cancer Centre, USA

¹⁵ Hicks CL, von Baeyer CL, Spafford P, van Korlaar I, Goodenough B. The Faces Pain Scale—Revised: toward a common metric in pediatric pain measurement. PAIN, 2001;93:173–83.

Paediatric Quality of Life Inventory (PedsQL)¹⁶

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].

Results are reported as 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.

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.

For the PedsQL 'Sleep' item, clinically significant improvement is reported for patients with trouble sleeping at least sometimes (sleep item score = 2). The improvement is classed as clinically significant if the score for sleep is reduced by at least 50%.

Functional Disability Inventory (FDI)¹⁷

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 defined as a change of 5 or more points coupled with a change to a different severity category.

¹⁶ Varni JW, Burwinkle TM, Seid M. The PedsQL as a pediatric patient-reported outcome: reliability and validity of the PedsQL measurement model in 25,000 children. *Expert Rev Pharmacoecon Outcomes Res* 2005;5:705–18.

¹⁷ Walker LS, Greene JW. The Functional Disability Inventory (FDI): measuring a neglected dimension of child health status. *J Paediatric Psychol* 1991;16:39–58.

Bath Adolescent Pain Questionnaire – Pain-specific anxiety¹⁸

Section 5 of the BAPQ 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’.

Bath Adolescent Pain – Parent Impact Questionnaire¹⁹

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).

¹⁸ Eccleston C, Jordan A, McCracken LM, Slead M, Connell H, Clinch J. The Bath Adolescent Pain Questionnaire (BAPQ): development and preliminary psychometric evaluation of an instrument to assess the impact of chronic pain on adolescents. *PAIN* 2005;118:263–70.

¹⁹ Jordan A, Eccleston C, McCracken LM, Connell H, Clinch J. 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*, 2008;137:478–87.