



electronic persistent pain  
outcomes collaboration

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# Annual Data Report

## 2017

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#### 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. We would advise readers to use their professional judgement in considering the information contained in this report.

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#### SUGGESTED CITATION

Blanchard M, Tardif H, Bryce M, White J and Eagar K (2018) *Electronic Persistent Pain Outcomes Collaboration Annual Data Report 2017*. 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. Deidentified information is sent to ePPOC for analysis, and results are fed back to participating services every six months. The information collected by services is also used 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 carers.

## This report

This report presents data collected by participating pain management units during 2017. Sixty-three adult and seven paediatric pain management services contributed data for this report. These services are listed at Appendix A.

Information on over 20,000 patients is included in this report. Demographic and clinical characteristics of the patients, along with information about the care they received are described. The outcomes for adult patients who completed an episode of treatment are also described. Although small in comparison, the outcomes for paediatric patients who completed an episode of treatment are included.

Data for the adult and paediatric patients are described in separate sections of the report.

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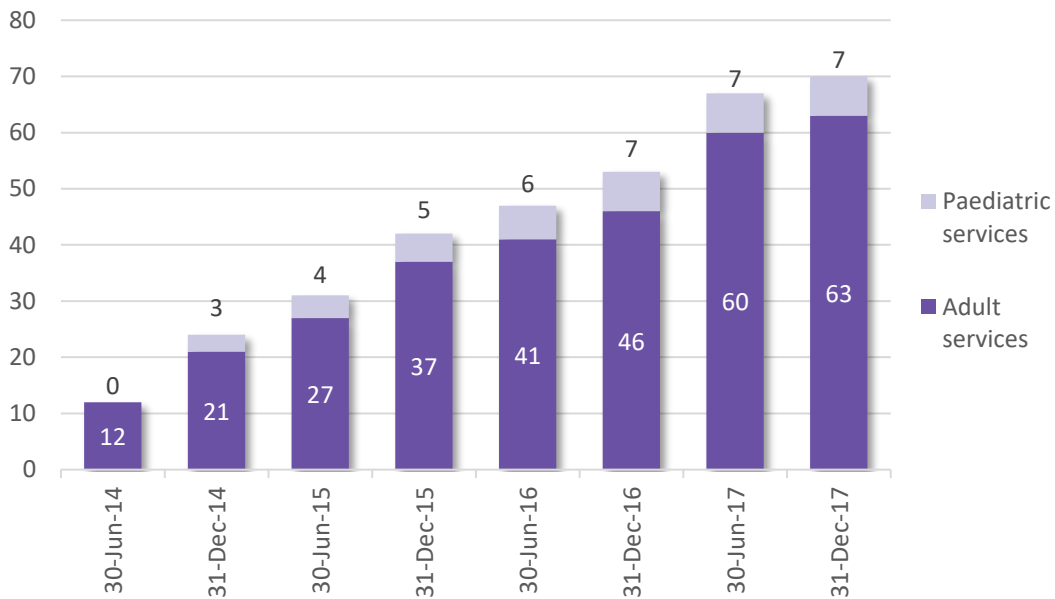
## Pain management services

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

- New South Wales (17 adult and 3 paediatric services)
- Victoria (17 adult and 2 paediatric services)
- Queensland (6 adult and 2 paediatric)
- Western Australia (3 adult services)
- New Zealand (20 adult services).

Since the first ePPOC report in June 2014, the number of data-submitting services has increased from 12 to 70.

Figure 1 – Number of data submitting services, 2014-2017



An episode of care at a pain management service is defined as the period from the first clinical contact to discharge from the service, or to the end of the active treatment of the patient. 19,932 adult and 704 paediatric episodes of care were reported during 2017.

The median time from receiving a patient referral to the start of the episode was 61 days for adult services. This a reduction from the previous year (70 days), however the average time decreased substantially from 102 days in 2016 to 88 in 2017.

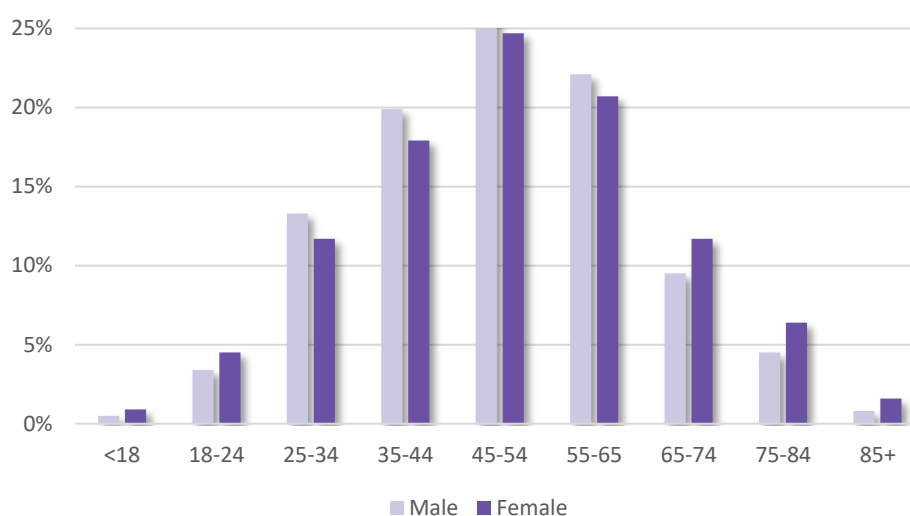
The median time from referral to the start of the episode for patients at paediatric services was lower (21 days), as was the average time (46 days).

# Adult Patients

## Patient demographics

Participating adult pain management services contributed data for 26,103 patients during 2017. Of these patients, 57% were female, with an average age of 50.7 years at the time of referral. Males were slightly younger on average at 49.5 years. The distribution by gender and age is shown in Figure 2.

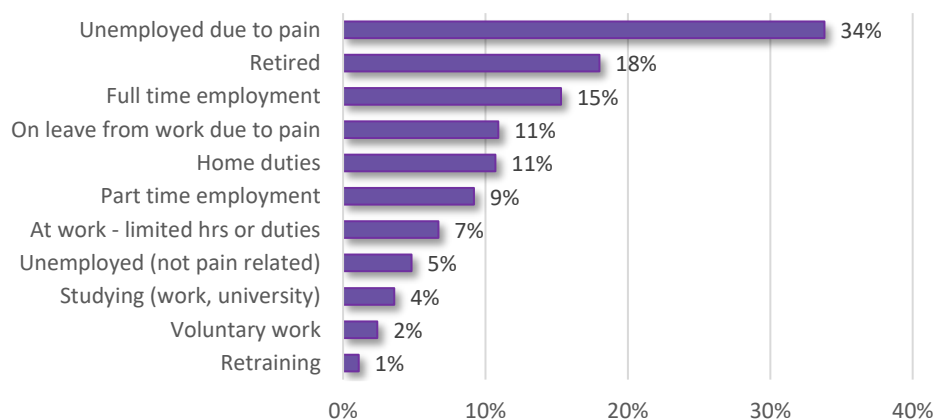
Figure 2 – Age at referral and gender distribution of patients



Most patients were born in Australia (54%) or New Zealand (20%) and 4% identified as being of Aboriginal and/or Torres Strait Islander origin. 5% of patients required an interpreter and 9% required assistance with written or spoken communication. Most patients were referred to the pain management service by a general practitioner or nurse practitioner (52%).

The majority of patients stated that their pain affected the number of hours they were able to work or study (87%) and the type of work they were able to do (92%). 20% of episodes involved a compensation claim. Figure 3 shows the work status of patients at referral to the pain management service. One in three (34%) patients were unemployed due to their pain condition.

Figure 3 – Work status of patients at referral



## Clinical characteristics of patients 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.

18,263 of these initial questionnaires were completed, providing a picture of the health and clinical characteristics of patients following their referral to a specialist pain management service. All information in this section is based on patient self-report.

### Pain

39% of patients had experienced their pain for more than five years, and most (86%) described their pain as ‘always present’. The events considered responsible for triggering the pain are shown in Table 1.

The region of patients’ main pain are shown in Figure 4, with the back being the most common (43%). 17% of patients had pain in one region only, with the remainder identifying multiple regions, as shown in Figure 5.

Table 1 – Event precipitating the patient’s pain

Triggering event	%
Injury at work/school	26.1
No obvious cause	14.4
Injury at home	10.2
Motor vehicle crash	9.9
After surgery	9.4
Related to another illness	9.0
Injury in another setting	8.8
Related to cancer	1.1
Other	11.0

Figure 4 – Site of patient’s main pain

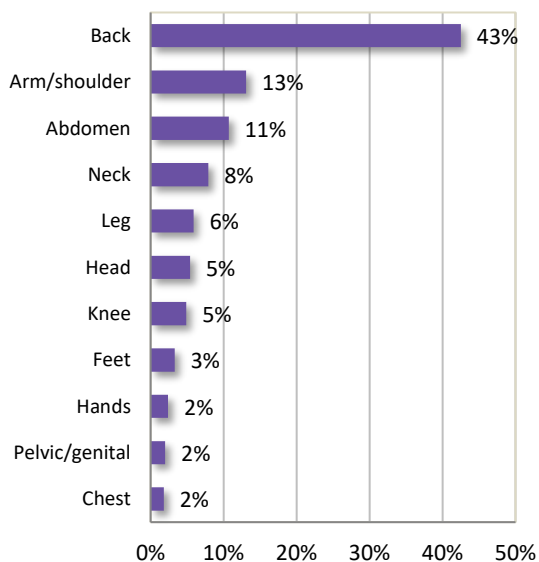


Figure 5 – Number of pain sites

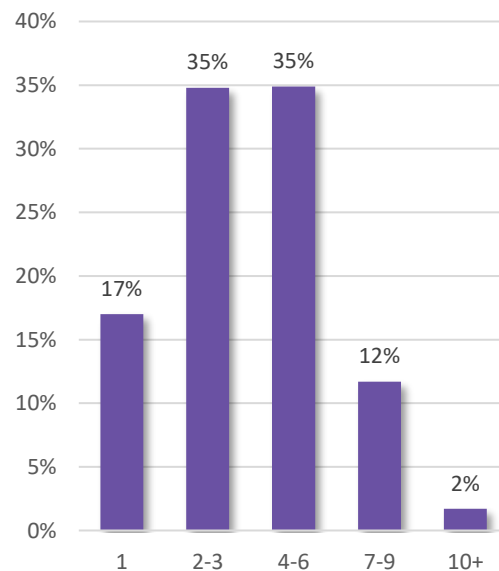


Table 2 – BPI scores for intensity and interference subscales

BPI	Mean	SD	Interpretation
Pain Intensity	6.1	1.8	Mod/Severe
- Worst pain	7.9	1.7	
- Least pain	4.5	2.5	
- Average pain	6.2	1.9	
- Pain now	6.0	2.3	
Pain Interference	6.9	2.0	Mod/Severe

The Brief Pain Inventory (BPI) was used to assess the intensity of the patient’s pain and its interference in activities of daily living over the past week. Average scores for the pain intensity and interference scale are shown in Table 2.

### Comorbid conditions

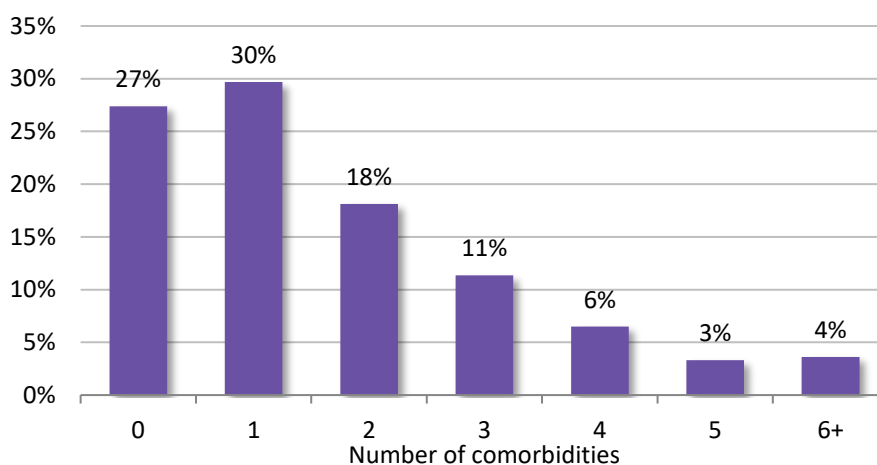
The patient questionnaires included a list of 12 medical conditions, and asked patients to indicate which (if any) they experienced in addition to their pain. 38% of patients reported that they experienced depression and/or anxiety. The percent of patients with each of these conditions is shown in Table 3.

The clinical complexity of patients referred to pain management services is further illustrated in Figure 6, which shows the proportion of people experiencing one or more of the 12 listed medical conditions.

Table 3 – Patient comorbidities

Medical condition	Percentage
Depression/Anxiety	38.2
Osteoarthritis, degenerative arthritis	22.8
High blood pressure	20.9
Diabetes	10.2
Heart disease	6.5
Rheumatoid arthritis	5.8
Ulcer or stomach disease	5.6
Lung disease	4.1
Stroke or neurological condition	3.9
Anaemia or other blood disease	3.9
Cancer	3.2
Kidney disease	2.4
Other medical problems	25.7

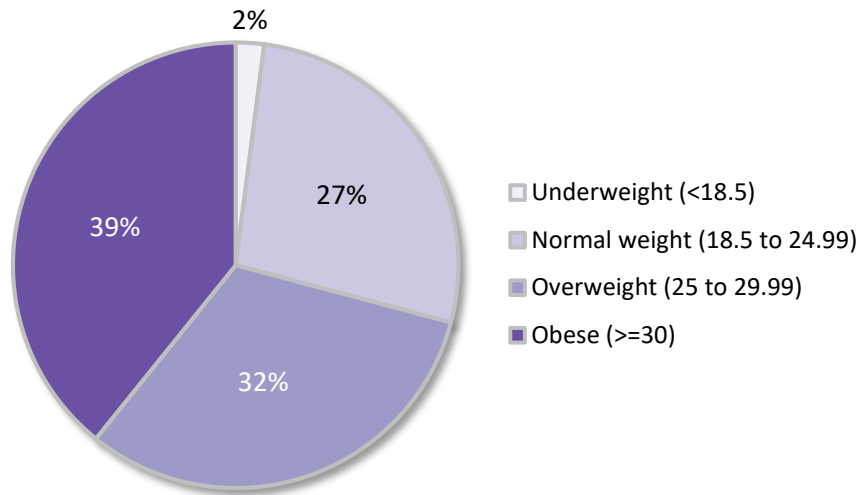
Figure 6 – Distribution of patients by number of comorbidities



## Body Mass Index

The average Body Mass Index (BMI) of patients was 29.4 (SD=7.6) which lies in the Overweight category, but bordering on Obese. The percentage of patients in each BMI category is show in Figure 7.

Figure 7 – Patient BMI



## Mood

Table 4 shows patients’ average scores on the depression, anxiety and stress scales of the DASS21 following referral to the pain services. The interpretation of the severity of the average score is also shown.

Table 4 – DASS scores

DASS subscale	Mean	SD	Interpretation
Depression	19.0	12.8	Moderate
Anxiety	13.3	10.8	Moderate
Stress	20.5	11.4	Moderate

## Cognition

Self-efficacy refers to a person’s beliefs about their ability to accomplish outcomes, activities or goals. The self-efficacy of patients referred to pain management services was assessed using the Pain Self-Efficacy Questionnaire (PSEQ). This tool assesses a patient’s belief that he or she can perform a range of activities despite their pain, with scores shown to predict treatment outcome and long term disability.

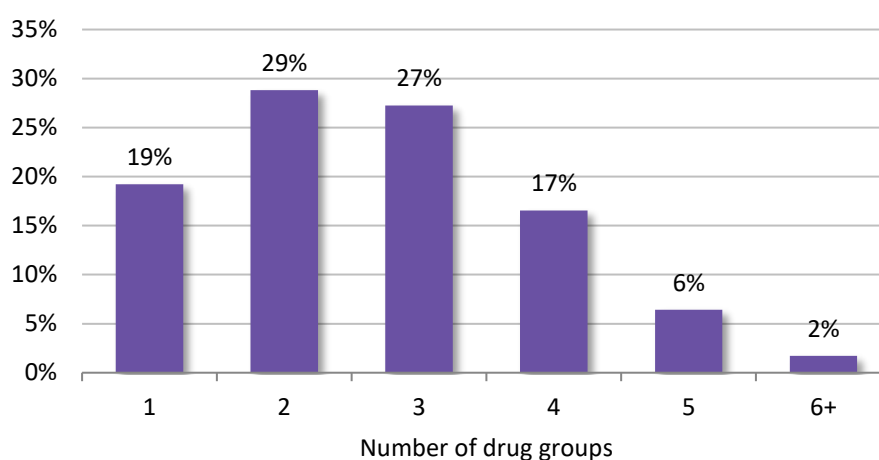
The average score on the PSEQ following referral to the pain services was 21.5 (SD=13.1), a score classified as ‘Moderate’ but bordering on severe impairment (identified by scores less than 20).

Patients also completed the Pain Catastrophising Scale (PCS), which measures thoughts and feelings related to pain. The average score on the PCS at referral to the pain services was 27.6 (SD=14.1), a score classified as ‘Moderate’.

## Medication use

At referral to the service, 56% 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 67.2 mg. On average, patients were using medications from two of the six major drug groups, identified by the Faculty of Pain Medicine as of particular interest in pain management. These are opioids, paracetamol, NSAIDs, antidepressants, anticonvulsants and benzodiazepines. Figure 8 shows the proportion of patients using one or more of these drug types.

Figure 8 – Proportion of patients using one or more of the six drug groups



## 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 (see Table 5). These equate to, on average, one visit every week for pain-related reasons.

Table 5 – Patient use of health services

Health service	Mean
General practitioner	4.7
Medical specialist	1.5
Health professionals other than doctors	4.8
Hospital emergency department	0.5
Hospital admission	0.3
Diagnostic tests	1.4

## Patient outcomes

Pain management units provided information on the outcomes of 3,851 patients who completed an episode of treatment during 2017. Information on the treatment received in these episodes of care is described in a later section.

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.

### ***Benchmarking***

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The first of the ePPOC benchmarks were introduced in 2016, with services benchmarked based on the proportion of patients who made a clinically significant improvement from referral to the end of their episode. This proportion was compared to a target, the value of which was determined following collaboration and involvement with the pain management services and major stakeholders.

It is important to note that the benchmark targets were chosen to reflect **best practice** rather than average practice. The benchmarks are considered aspirational and it is therefore not expected that all services will meet the benchmark.

Interpreting the benchmark graphs:

In the graphs that follow, the vertical axes show the percentage of patients who made a clinically significant improvement. The purple region shows the Australasian profile for the benchmark. It represents all services that contributed to the benchmark, ordered from the highest to the lowest score. The red line indicates the level at which the benchmark target is set.

To be included in the benchmark graphs, a service needed to have at least ten patients of moderate or worse severity. Not all services had this volume of patients, therefore the number of services included in each benchmark varies.

## Pain

	Average pain	Pain interference
Services included (n)	45	45
Services meeting the benchmark	21	40
Overall % of patients making clinically significant improvement	28%	62%

Figure 9 – Benchmark 1 – Average pain

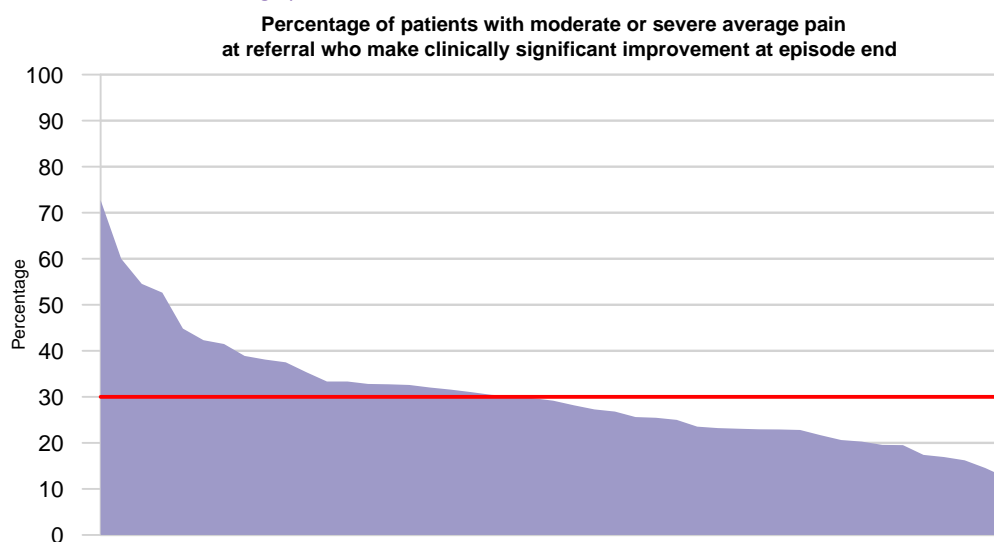
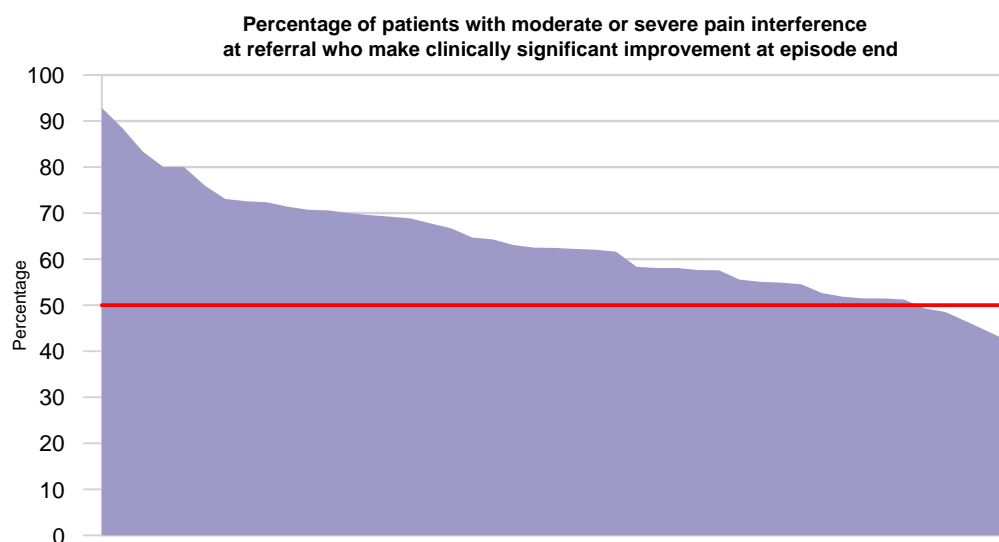


Figure 10 – Benchmark 2 – Pain interference



## Mood

	Depression	Anxiety	Stress
Services included (n)	39	39	37
Services meeting the benchmark	17	12	12
Overall % of patients making clinically significant improvement	57%	43%	57%

Figure 11 – Benchmark 3 - Depression

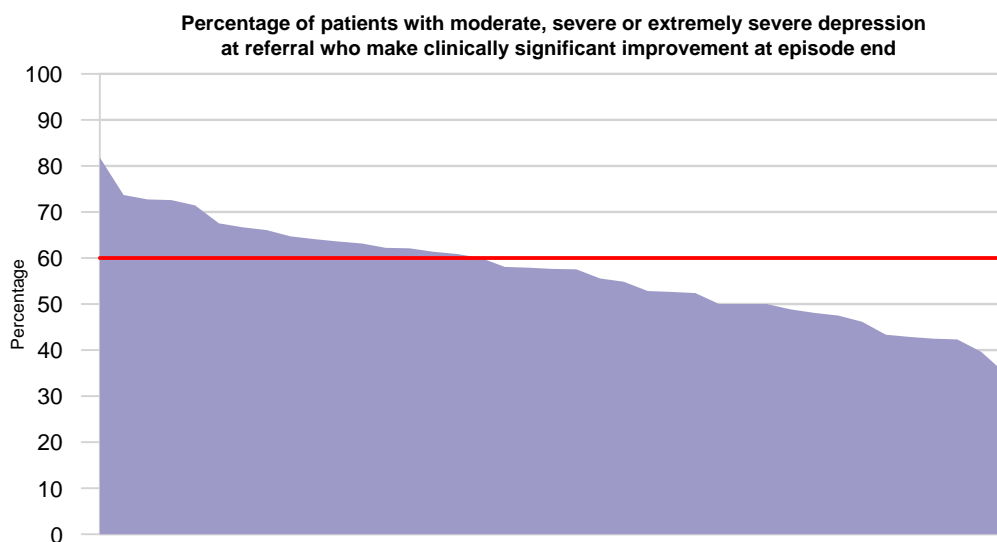


Figure 12 – Benchmark 4 – Anxiety

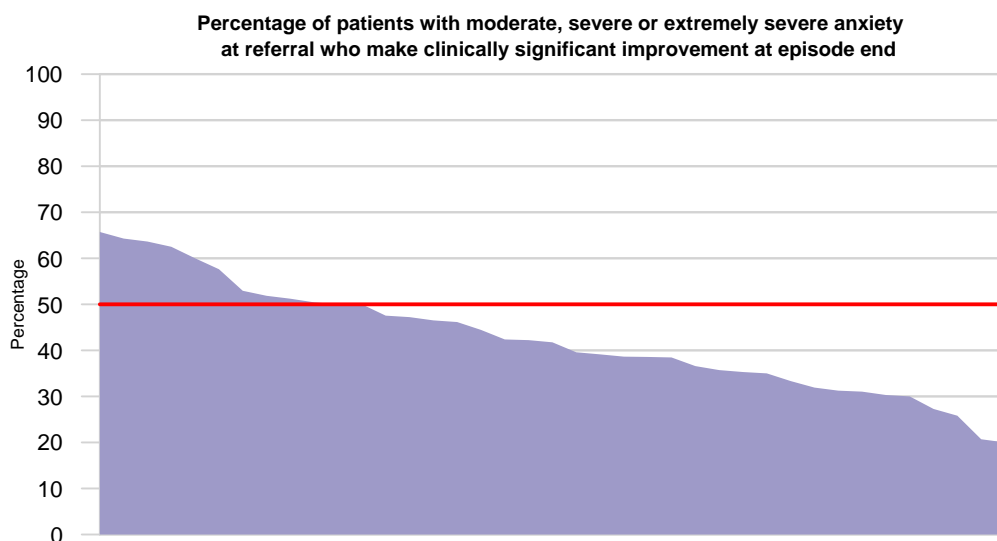
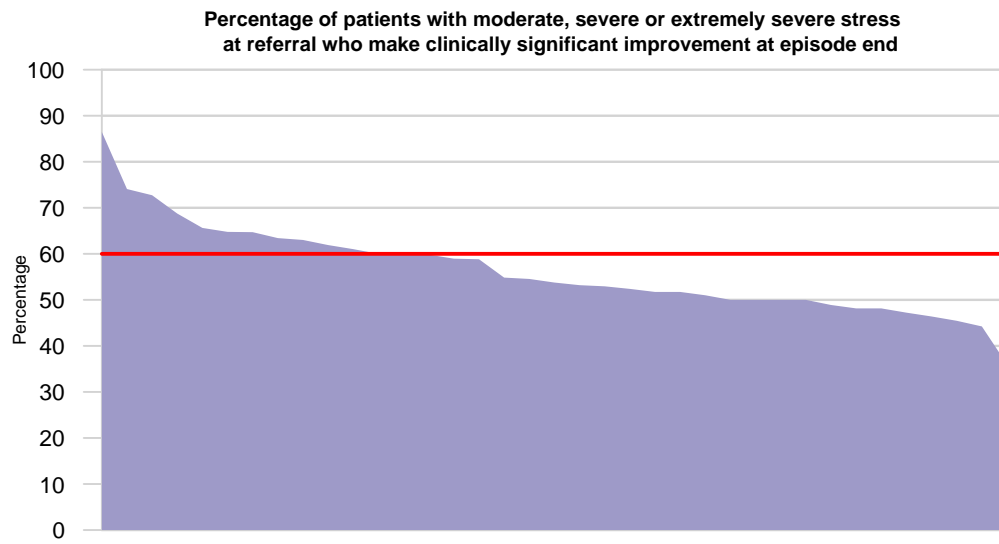


Figure 13 – Benchmark 5 – Stress



## Cognition

	Pain catastrophising	Pain self-efficacy
Services included (n)	42	43
Services meeting the benchmark	18	11
Overall patients making clinically significant improvement	54%	51%

Figure 14 – Benchmark 6 – Pain catastrophising

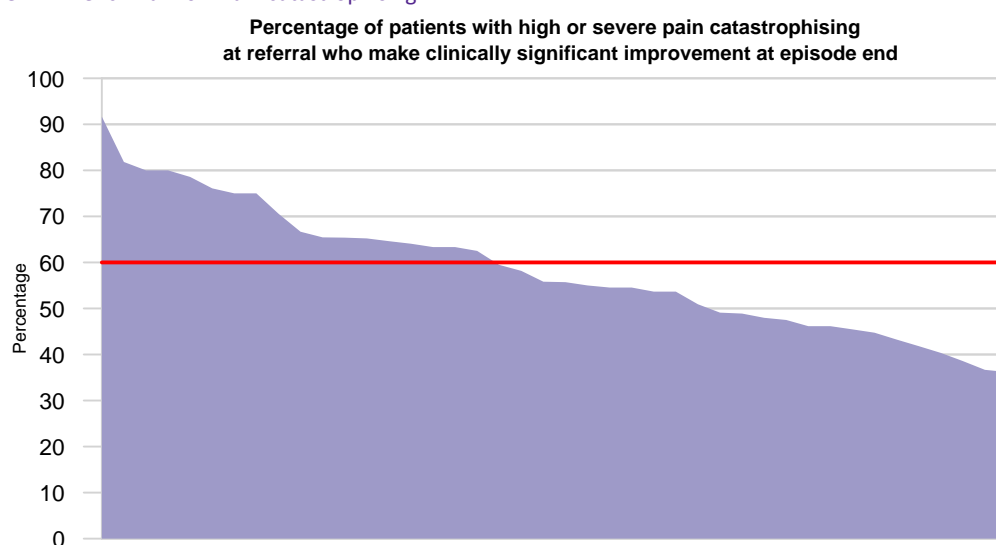
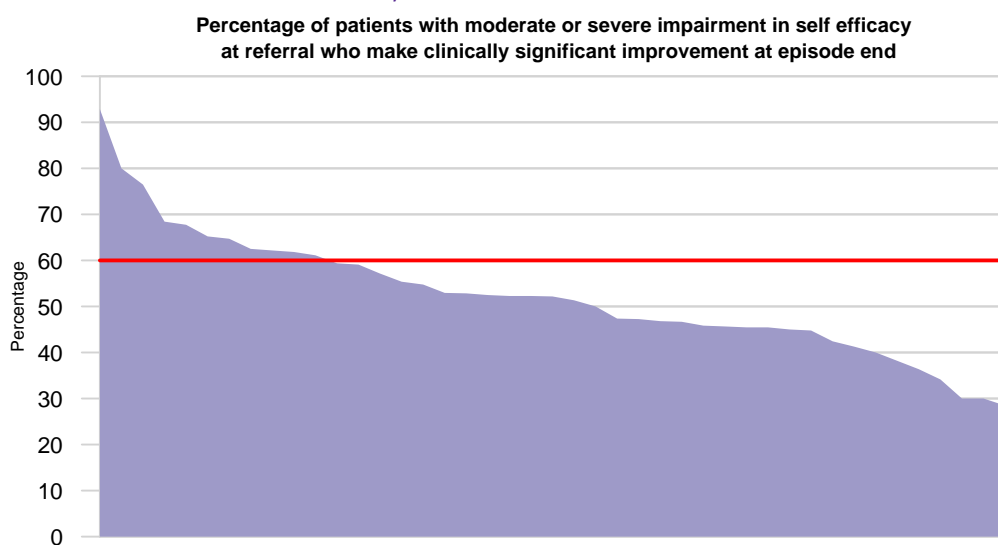


Figure 15 – Benchmark 7 – Pain self-efficacy

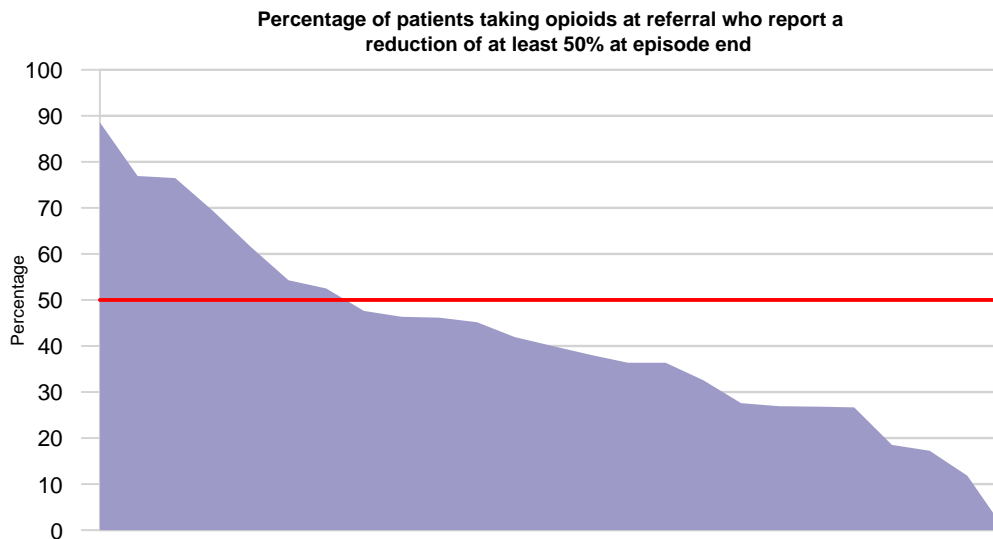


## Medication use

A number of patients were using opioid medication on a regular basis at entry to the pain service. For patients who completed an episode of treatment, the average oral morphine equivalent daily dose was 58 mg at referral, and 45 mg at the end of the episode. Many patients were able to take their opioid medication less frequently, with 34% no longer taking opioid medication on more than two days per week. 44% of patients also reduced the number of drug types they used.

In 2017, an additional benchmark assessing opioid reduction was introduced. This benchmark measured the proportion of patients who were able to reduce the dose of opioid medication they were taking by half by the end of the episode of care. The target that was set at 50%, that is, by the end of the episode, 50% of patients have reduced the opioids they are taking by half.

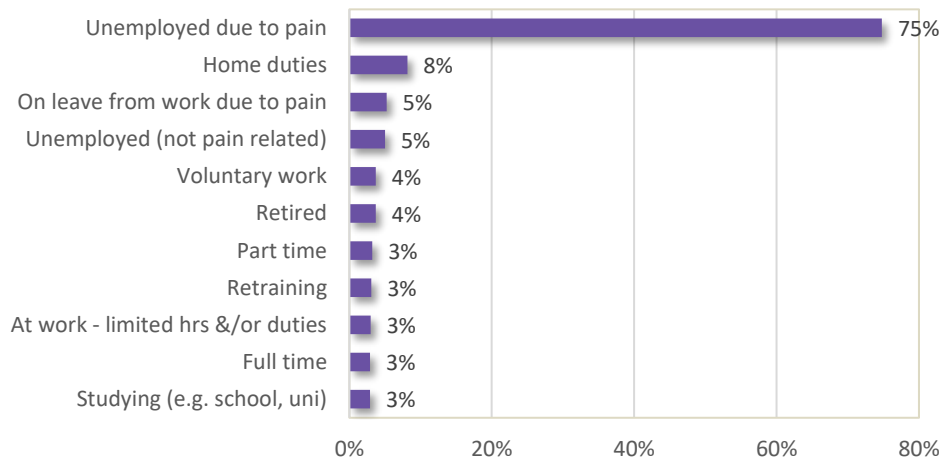
Figure 16 – Benchmark 8 – Opioid use



## Work status

People with chronic pain are often unable to work due to their pain. Of the patients who completed outcome measures at both referral and the end of their episode of care at the pain management unit, 35% were initially unemployed due to pain. At the end of the episode, 75% reported that they remained unemployed due to their pain. However, the remainder (1 in 4 people) no longer classified themselves in this way – they were either employed (full time, part time, retraining, or on limited hours), studying, or otherwise occupied (retired or on home duties).

Figure 17 – Work status at episode end for patients ‘unemployed due to pain’ at referral

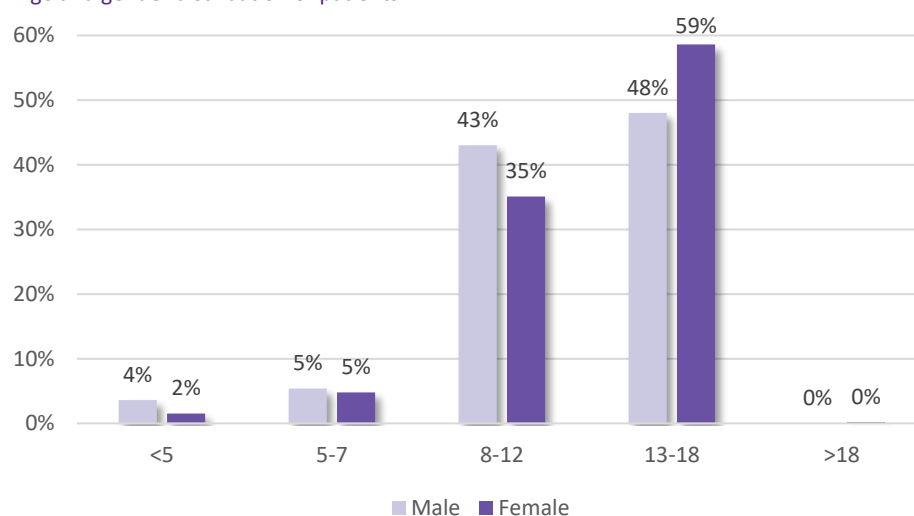


# Paediatric patients

## Patient demographics

Participating paediatric pain management services contributed data for 693 patients during 2017. Of these patients, 68% were female, with an average age of 12.6 years at the time of referral. Males were younger on average at 11.8 years. The distribution by gender and age is shown in Figure 18.

Figure 18 – Age and gender distribution of patients



Most patients were born in Australia (95%) and 6% identified as being of Aboriginal and/or Torres Strait Islander origin. Patients were generally referred to the pain management service by a specialist practitioner (59%).

## Clinical characteristics of patients at referral

Most children and their carers completed a questionnaire prior to their first appointment with the service. These questionnaires asked children and carers about pain, medication and health care utilisation, 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.

708 of these initial questionnaires were completed (346 completed by the child, 362 by the carer), 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 carer report.

## Pain

Parents were asked how long their child’s pain had been present, and 58% responded that their child had experienced the pain for more than 12 months. Most (71%) described the pain as ‘always present’. The events considered responsible for triggering the pain are shown in Table 6.

Regions where the main pain was experienced are shown in Figure 19, with the abdomen the most common (23%). Just over one in four patients had pain in one region only, with the remainder identifying multiple regions (see Figure 20).

Table 6 – Event precipitating the patient’s pain

Triggering event	%
No known cause	39.4
Injury	21.4
Illness	14.7
After surgery	7.1
Other	17.2

Figure 19 – Site of patient’s main pain

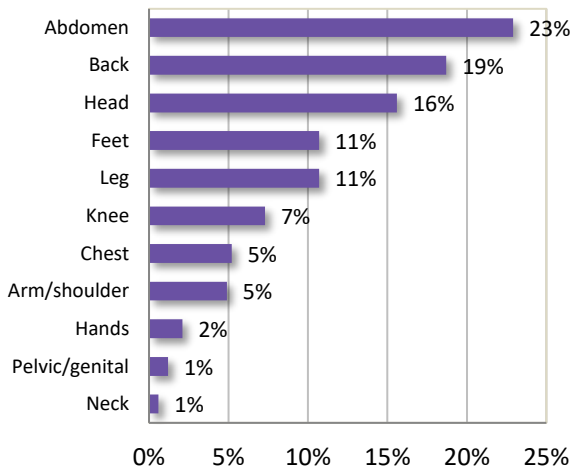
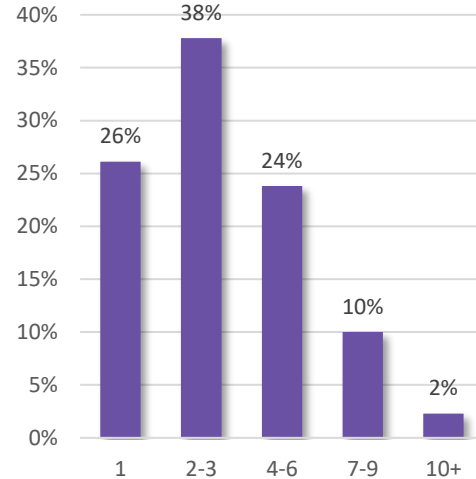
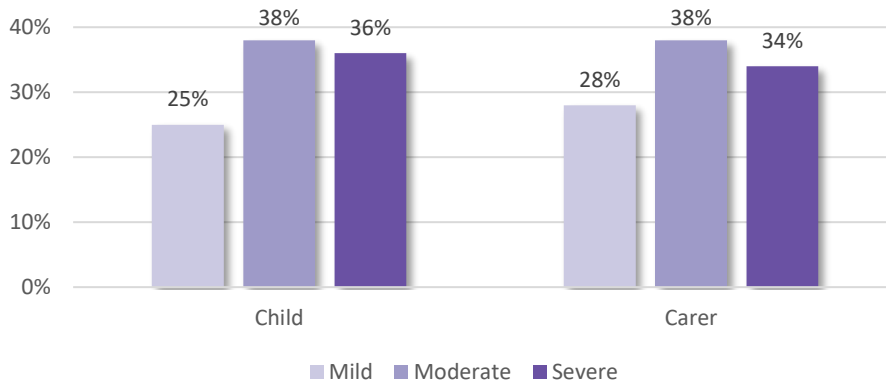


Figure 20 – Number of pain sites



Pain severity was assessed using a modified Brief Pain Inventory (BPI) in children aged eight years and above. Young children aged 5-7 completed the Faces Pain Scale – Revised. Carers also rated their child’s pain using the BPI. The average pain rating reported by child and carer at referral was 5.6 and 5.5 (moderate severity) respectively.

Figure 21 – Patient and carer ratings of pain severity



## Comorbid conditions

Carers were asked whether their child had a disability and/or other medical condition in addition to their pain. The responses are shown in Table 7 below.

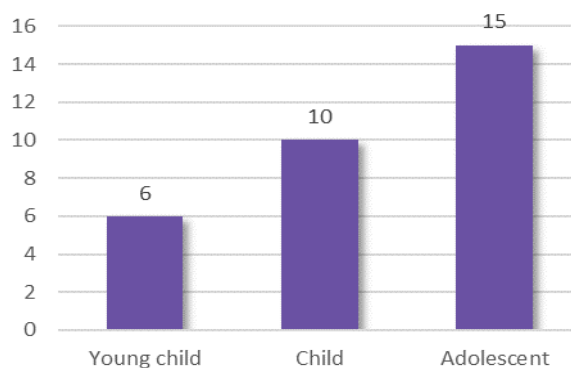
Table 7 – Percentage of patient with disabilities and comorbid conditions

Disability	% of patients	Comorbid condition	% of patients
Sight impairment	6.1	Chronic disease	17.6
Hearing impairment	1.8	Mental health condition	19.3
Intellectual disability	2.4	Cancer	1.7
Physical disability	7.0	Other	21.0
Other disability	3.4		

## Role functioning

The number of school days children missed in the previous school term as a result of their pain increases with age, as shown in Figure 22. The number of school days missed has increased compared to the ePPOC 2016 annual report for adolescents (from 11 to 15) and young children (from 3 to 6), but has remained stable at 10 for children. While 13% of adolescents were in paid employment, pain affected the number of hours that almost half (41%) were able to work.

Figure 22 – Days of school missed by age group



## Quality of Life

Quality of life was assessed using the Paediatric Quality of Life Inventory (PedsQL) with both children and carers rating the child's quality of life. Total and subscale average scores at referral are shown in Table 8, with higher scores reflecting greater quality of life. Total scores below 69.7 and 65.4 for the child and carer, respectively, indicate 'at risk' status for impaired quality of life. Over 80% of both carers and children rated the child's quality of life in this 'at risk' range.

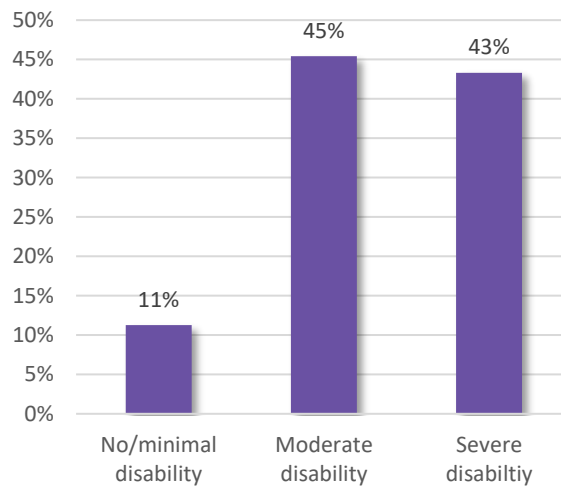
Table 8 – Patient and carer quality of life scores

Domain	Child	Carer
Psychosocial	53.4	50.1
Physical	37.3	35.4
Total score	47.8	45.0

## Disability

Children aged eight and older completed the Functional Disability Inventory (FDI) to assess the impact of pain on the ability to complete 15 physical activities. The average score for children was 27.2, reflecting moderate disability. The distribution of scores by severity category is shown in Figure 23, indicating that over 4 in 5 children rated their functional disability as either moderate or severe.

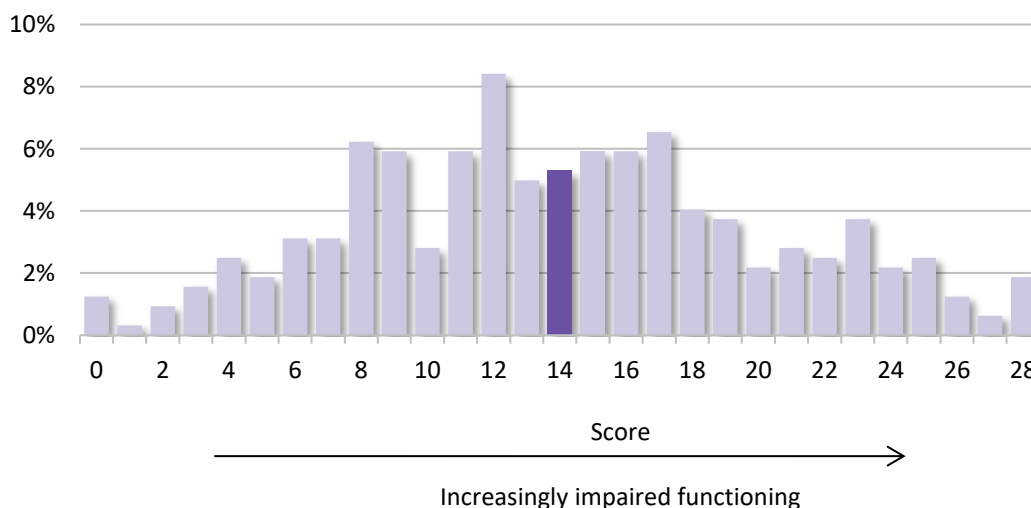
Figure 23 – Disability at referral by severity category



## 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. The distribution of scores on this tool is shown below in Figure 24 with the average score highlighted.

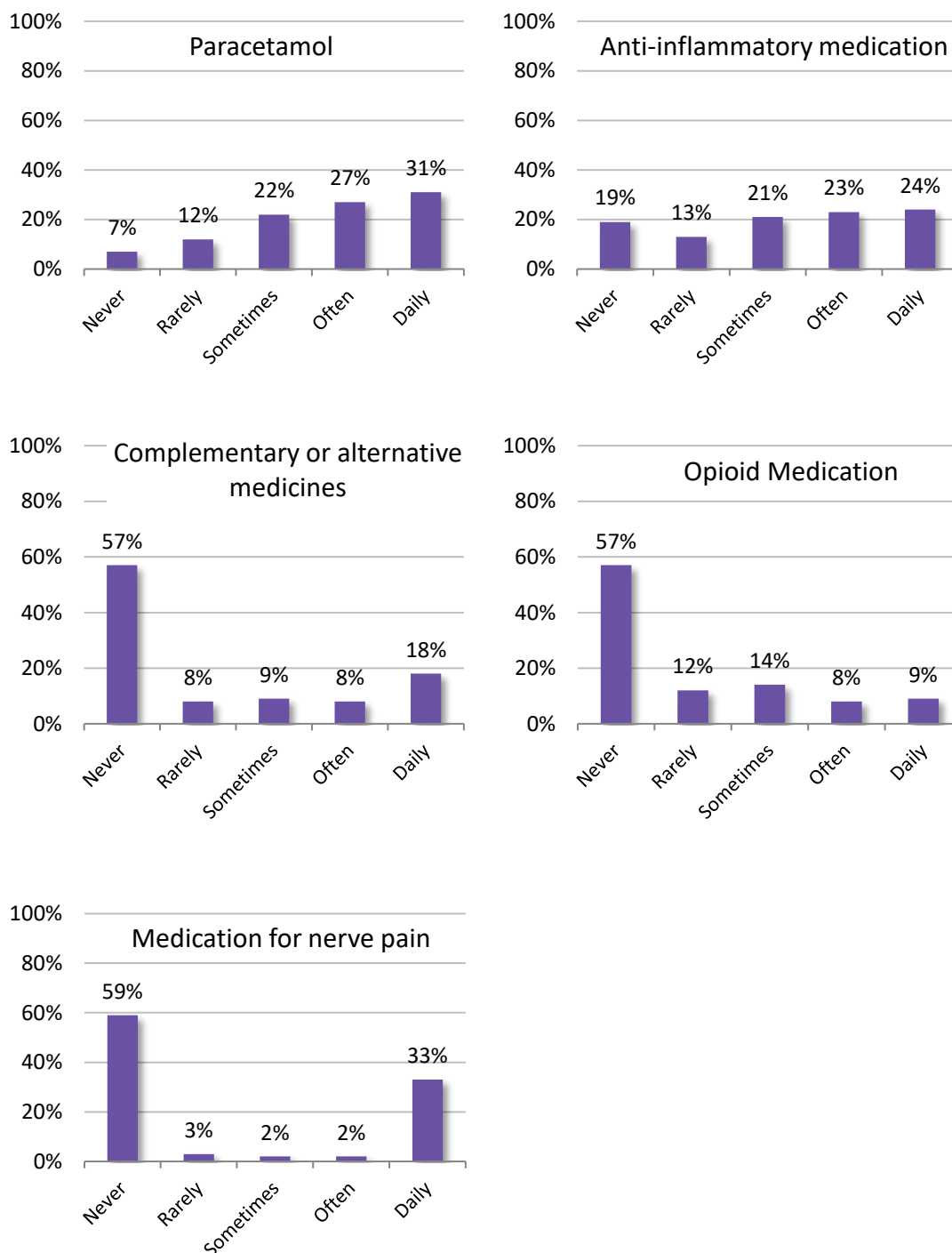
Figure 24 – Distribution of pain-related worry scores



## Medication use

Carers provided information regarding the medication their child was taking for pain and how frequently each was used. Use and frequency are shown in the figures below.

Figure 25 – Percentage of patients using medication by frequency of use



## Health service utilisation

Carers 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 9 below.

Table 9 – Paediatric patient use of health services

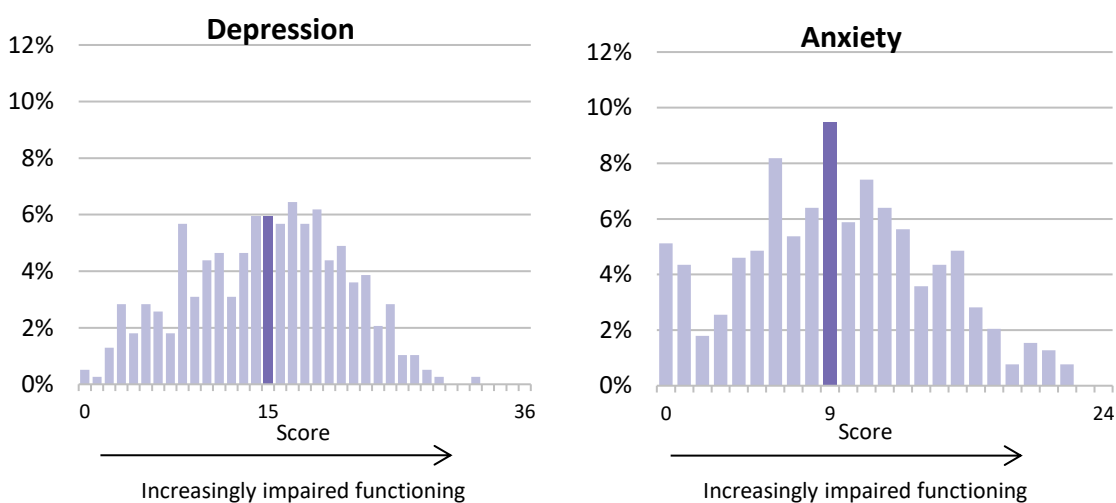
Health service	Mean
General practitioner	3.5
Medical specialist	2.7
Allied health professionals	3.5
Other therapist	1.2
Hospital emergency department	1.2
Hospital admission	0.3
Diagnostic tests	1.9

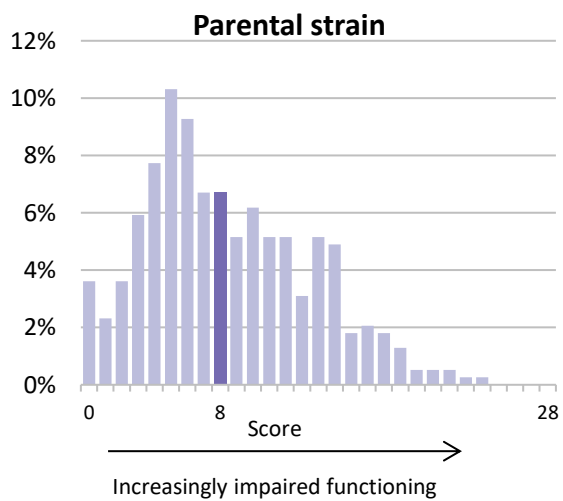
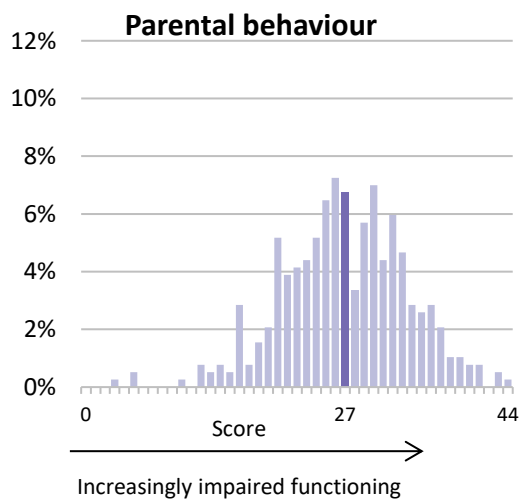
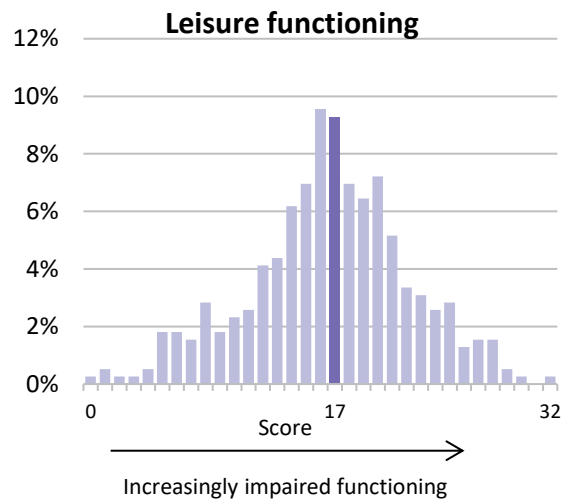
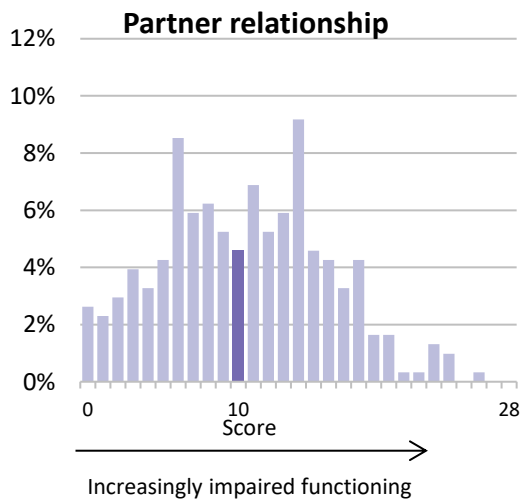
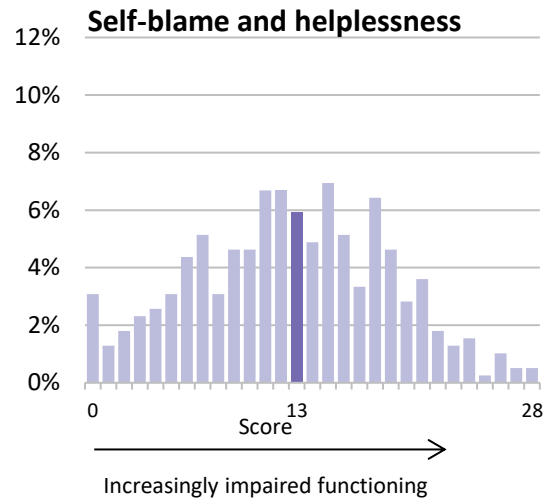
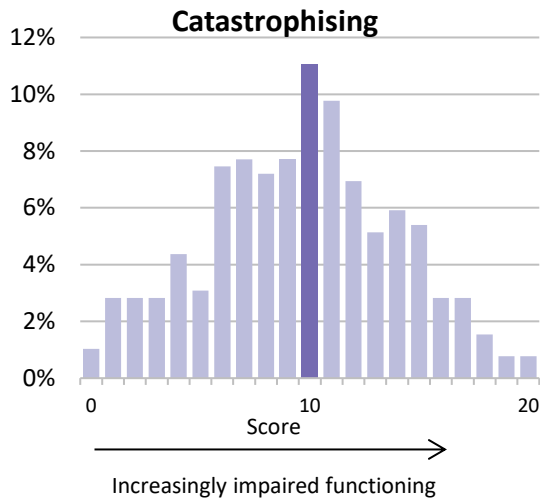
## Impact of pain on the carer

At referral to the pain service, parents or carers of the child completed a Bath Adolescent Pain Parent Impact Questionnaire, to assess the impact of parenting a child with persistent pain. This questionnaire asks a series of questions over a number of subscales: depression, anxiety, child-related catastrophising, self-blame and helplessness, relationship with partner, social and leisure time, parental behaviour in relation to the child’s pain and parental strain.

The distribution of scores on each of these domains is shown in the figures below, with the average score highlighted.

Figure 26 – Distribution of scores on the Bath Parent Impact subscales





## Patient outcomes

Pain management units provided information on outcomes reported by 72 patients and 73 carers for episodes ending during 2017. The guidelines for determining whether change from referral to episode end is clinically significant are detailed in Appendix C.

### *Pain and quality of life*

Although the volume of outcomes is small, clinically significant improvements were made by many children. Average and worst pain improved in almost 1 in 2 children, as did functional ability. An even higher proportion reported clinically significant improvement in their overall health-related quality of life, as measured by the PedsQL.

The percentage of patients making a clinically significant improvement in each domain is shown in the table below.

Table 10 – Paediatric patient outcomes

Percent of patients experiencing a clinically significant improvement	Patient rated	Carer rated
Pain Severity		
Usual pain	45%	48%
Worst pain	31%	26%
Health-related quality of life		
Sleep	37%	24%
Overall	72%	65%
Functional disability	52%	na

The PedsQL also revealed a reduction in the percentage of children whose quality of life was impaired: at referral 93% of children were classified as having impaired quality of life, however at the end of the episode of care this proportion was 71%.

On average, there was improvement in all patient and parent/carer reported average scores.

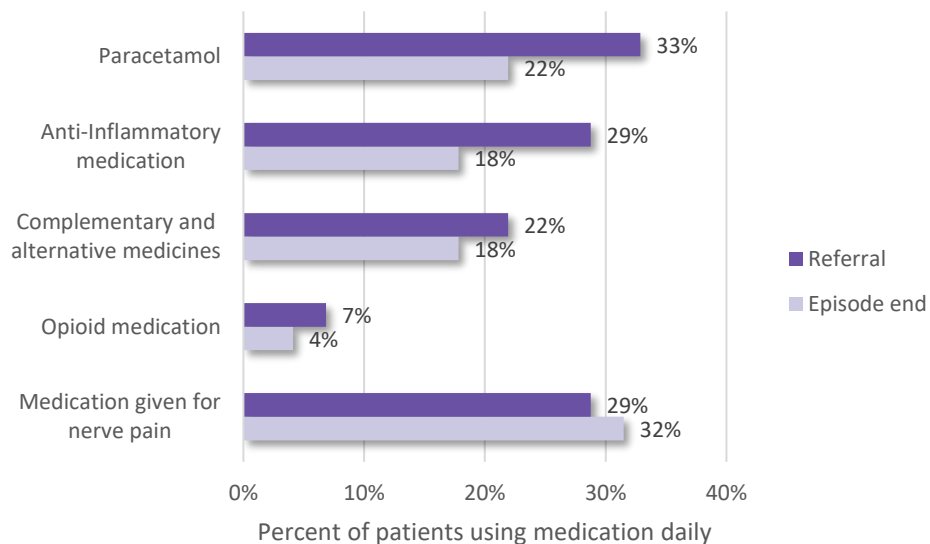
Table 11 – Change in patient reported outcome measures from referral to episode end

Assessment tool	Score at referral	Average change
Pain Severity – Worst pain	7.9	-1.8
– Least pain	3.5	-1.3
– Usual pain	5.5	-1.5
– Pain now	5.3	-1.9
PedsQL – Sleep	32.0	17.3
– Physical	34.5	18.8
– Emotional	48.6	15.2
– Social	64.4	7.4
– School	43.4	9.8
– Total	45.9	13.5
Functional Disability (FDI)	27.2	-8.6
Pain-related anxiety (BAP)	15.1	-4.4

## Medication use

The change in medication use from referral to episode end is shown in Figure 27.

Figure 27 – Medications used daily at referral and episode end



## School and work impact

Parents and carers reported a reduction in the average number of school days their child missed in the previous school term, from 16.5 days at referral to 14.7 days at episode end. Similarly, the number of work days the parent/carer missed during the previous school term reduced from 7.3 days at referral to 5.1 days at episode end.

## Future directions

This 2017 ePPOC report presents data from over 20,000 individuals, providing a picture of patients seeking pain management in Australia and New Zealand, the treatment they receive and their outcomes as a result of attending a pain management service.

ePPOC is expecting continued growth in 2018, with services in South Australia and Tasmania expected to join the collaboration.

An updated version of the dataset will be introduced in 2018, allowing improved assessment of the impact of pain on employment and productivity, and a global rating of change following treatment. The new dataset will also allow us to identify persistent pain and treatment outcomes in serving members and veterans of the Australian Defence Force.

We look forward to continued collaboration with participating services and stakeholders in the coming year, and welcoming new services to ePPOC.

# Appendix A – Data submitting services

## Adult pain management services

### ***New South Wales***

Central Coast Integrated Pain Service  
 Concord Repatriation Hospital Pain Clinic  
 Greenwich Hospital Pain Management Service  
 Hunter Integrated Pain Service  
 Illawarra-Shoalhaven Chronic Pain Service  
 Lismore Hospital Pain Management Clinic  
 Liverpool Hospital Chronic Pain Service  
 Nepean Hospital Pain Management Unit  
 Orange Base Hospital Chronic Pain Clinic  
 Port Macquarie Chronic Pain Service  
 Prince of Wales Pain Management Department  
 Royal North Shore Hospital Pain Service  
 Royal Prince Alfred Pain Management Service  
 St George Pain Management Unit  
 St Vincent's Hospital Pain Clinic  
 Tamworth Integrated Pain Service  
 Westmead Hospital Pain Service

### ***Queensland***

Interventus Pain Specialists  
 North Queensland Persistent Pain Management  
 Service (Townsville Hospital)  
 Princess Alexandra Hospital – Metro South Health  
 Persistent Pain Management Service  
 St Vincent's Private Hospital Brisbane  
 Sunshine Coast Persistent Pain Management  
 Service (Nambour Hospital)  
 The Wesley Hospital Brisbane

### ***Western Australia***

Fiona Stanley Hospital  
 PainCare  
 Sir Charles Gairdner Hospital

### ***Victoria***

Advance Healthcare  
 Austin Health  
 Barbara Walker Centre for Pain Management  
 Caulfield Pain Management and Research Centre  
 Dorset Rehabilitation Centre  
 Eastern Health Pain Management Service  
 Empower Rehab  
 Epworth Hospital  
 Goulburn Valley Chronic Pain Service  
 Latrobe Regional Hospital  
 Melbourne Health – Pain Management Services  
 Monash Health Pain Management  
 Northern Health Pain Assessment & Management  
 Service  
 Peninsula Health Chronic Pain Management Service  
 Precision Ascend Rehabilitation Centre  
 The Victorian Rehabilitation Centre  
 Western Health Pain Management

### ***New Zealand***

Active Plus  
 Advantage South  
 APM Workcare  
 Body in Motion  
 Canterbury DHB (Burwood Hospital)  
 Capital and Coast DHB (Wellington)  
 EnableWorks Limited  
 Fit For Work  
 Futureproof Rehab  
 Habit Group  
 Hutt Valley DHB  
 Integrative Pain Care  
 Nelson Nursing Service  
 Occupational Health Canterbury  
 Pain Management and Rehabilitation Services Ltd  
 Pain Rehabilitation Christchurch Ltd  
 Proactive Health  
 QE Health  
 Southern Rehab  
 TBI Health

## Paediatric pain management services

### ***New South Wales***

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

### ***Queensland***

Lady Cilento Children's Hospital  
St Vincent's Private Hospital Brisbane

### ***Victoria***

Monash Children's Hospital  
Royal Children's Hospital Melbourne

## Appendix B – ePPOC assessment tools

Four standardised assessment tools have been chosen to measure patient outcomes – these are the:

- Brief Pain Inventory (BPI)
- Depression, Anxiety, Stress Scale (DASS21)
- Pain Self-Efficacy Questionnaire (PSEQ)
- Pain Catastrophising Scale (PCS)

### Brief Pain Inventory

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.

Pain severity questions are rated on a scale of 0 to 10, where 0 = ‘No pain’ and 10 = ‘Pain as bad as you can imagine’, with patients asked to rate 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

Clinically significant change is reported as follows:

- ≥ 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 of moderate or worse severity at referral is clinically significant, the improvement must be at least moderately clinically important, i.e. at least a 30% improvement.

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.

Clinically significant change is considered to be a change of 1 point over the average of the 7 items. ePPOC reports clinically significant improvement for patients whose symptoms are of moderate or worse severity at referral.

### Depression Anxiety Stress Scales

The DASS measures the negative emotional states of depression, anxiety and stress. The DASS21 comprises 21 questions 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. The following table shows the range of scores associated with severity categories for each subscale.

	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 requires a change of 5 or more points coupled with a move to a different severity category for patients whose symptoms are of moderate or worse severity at referral.

### ***Pain Self-Efficacy Questionnaire***

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'. Increases in score represent an improvement in self-efficacy.

Severity bands for the PSEQ are:

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

Clinically significant change requires a change in score of 7 or more points, combined with movement to a different severity category for patients whose symptoms are of moderate or worse severity at referral.

### ***Pain Catastrophising Scale***

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'.

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 category for patients whose symptoms are of moderate or worse severity at referral.

## 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/carer:

- Modified Brief Pain Inventory - Pain severity
- Faces Pain Scale – Revised
- Paediatric Quality of Life Inventory (PedsQL)
- Functional Disability Inventory (FDI)
- Bath Adolescent Pain – Pain-related worry section (BAP-Q5)
- Bath Adolescent Pain – Parent Impact Questionnaire (BAP-PIQ)

### *Pain Severity*

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.

MODIFIED BRIEF PAIN INVENTORY (BPI) - 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 – REVISED - 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.

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 of moderate or worse severity at referral is clinically significant, the improvement must be at least moderately clinically important, i.e. at least a 30% improvement.

### ***Paediatric Quality of Life Inventory (PedsQL)***

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)***

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 for patients whose symptoms are of moderate or worse severity at referral.

### ***Bath Adolescent Pain Questionnaire – Pain-related worry section (BAPQ5)***

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 Questionnaire (BAPPIQ)***

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).