



electronic persistent pain
outcomes collaboration

Annual Data Report

2015



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

Tardif H, Blanchard M, Fenwick N, Blissett C and Eagar K (2016) *Electronic Persistent Pain Outcomes Collaboration Annual Data Report 2015*. 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 chronic 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 is the second ePPOC Annual Report, presenting the data collected by participating pain management units during 2015. Thirty-seven adult pain management services contributed data for this report. These services were located in New South Wales (16), New Zealand (1), Queensland (1), Victoria (17) and Western Australia (2) and included public (30) and privately (7) funded services. Five specialist paediatric pain management services also contributed data. These services were located in New South Wales (3) and Victoria (2). A list of all services participating in ePPOC during 2015 is provided at Appendix A.

Information on over 11,000 patients is included in this report, describing demographic and clinical characteristics of the patients, along with information about the care they received. The outcomes for adult patients who completed a treatment pathway are also described. The number of outcomes for paediatric patients is limited at this stage due to the relatively recent introduction of PaedePPOC, combined with often long episodes of care. As a result, this report will focus on the characteristics of the patients referred to specialist paediatric pain management services and the care they received.

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

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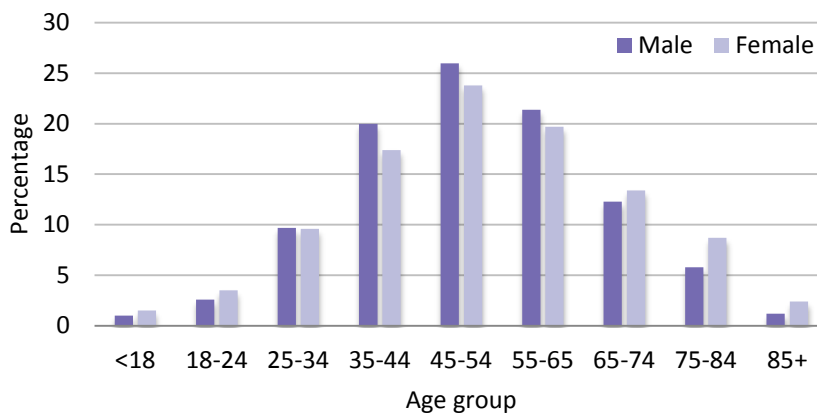
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Adult Patients

Patient demographics

Participating adult pain management services contributed data for 10727 patients during 2015. Of these patients, 59% were female, with an average age of 52.4 years at the time of referral. Males were younger on average at 51.2 years. The distribution by gender and age is shown in Figure 1.

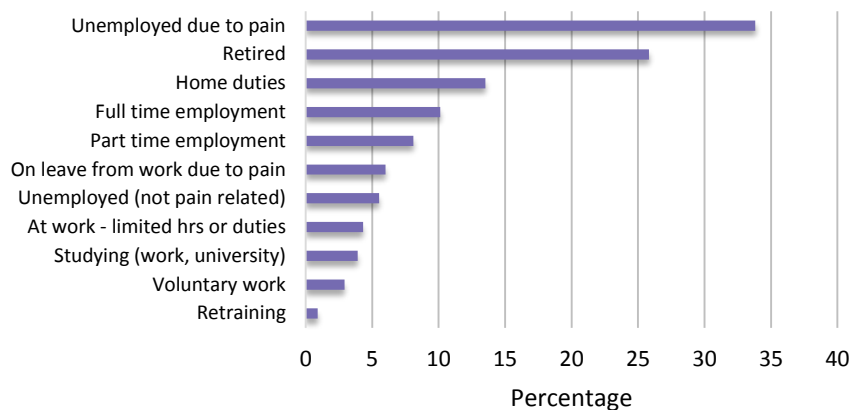
Figure 1: Age and gender distribution of patients



Most patients were born in Australia (69.3%) and 4.5% identified as being of Aboriginal and/or Torres Strait Islander origin. Nearly 6% required an interpreter and 9.5% required assistance with written or spoken communication. Most patients were referred to the pain management service by a general practitioner or nurse practitioner (71.6%).

The majority of patients stated that their pain affected the number of hours they were able to work or study (87.3%) and the type of work they were able to do (91.0%). 14.9% of episodes involved a compensation claim. Figure 2 shows the work status of patients at referral to the pain management service. One in three (33.8%) patients were unemployed due to their pain condition.

Figure 2 – Work status of patients



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.

8029 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

48% of patients had experienced their pain for more than five years, and most (88.7%) 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 3, with the back being the most common (43.5%). 17.0% of patients had pain in one region only, with the remainder identifying multiple regions, as shown in Figure 4.

Table 1: Event precipitating the patient’s pain

Triggering event	%
Injury at work/school	21.5
No obvious cause	17.6
Related to another illness	11.0
After surgery	11.0
Motor vehicle crash	9.6
Injury in another setting	7.5
Injury at home	7.2
Related to cancer	1.7
Other	12.9

Figure 3 – Site of patient’s main pain

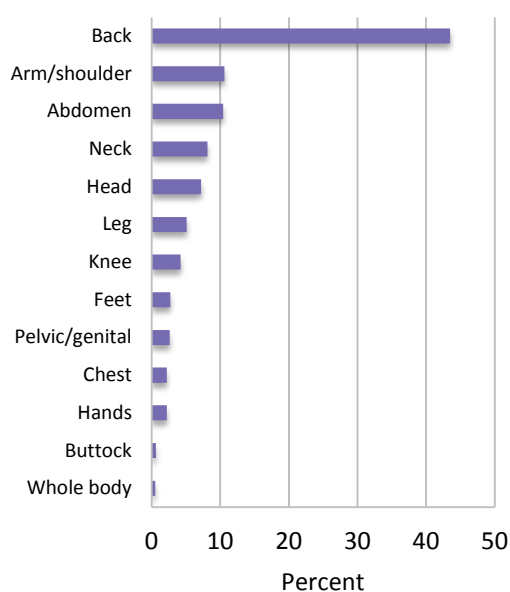
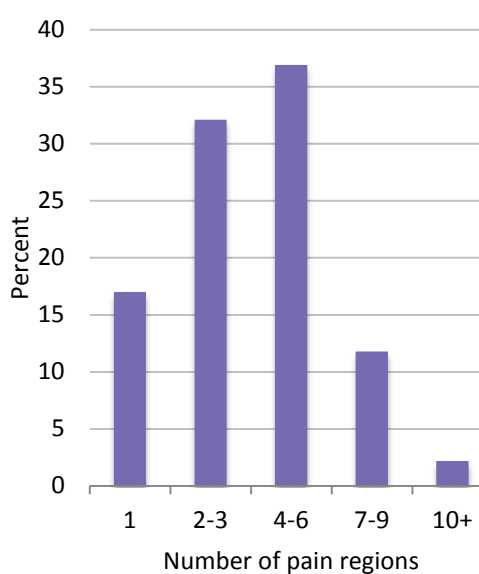


Figure 4: Number of pain sites



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.

Table 2: BPI scores for intensity and interference subscales

BPI	Mean	SD	Interpretation
Pain Intensity	6.4	1.7	Mod/Severe
- Worst pain	8.0	1.7	
- Least pain	4.8	2.6	
- Average pain	6.5	1.9	
- Pain now	6.3	2.4	
Pain Interference	7.0	2.0	Severe

Comorbid conditions

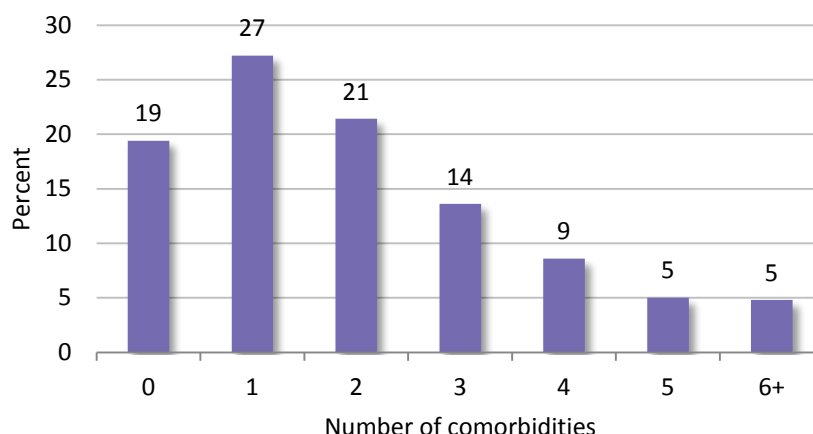
The patient questionnaires included a list of 12 medical conditions, and asked patients to indicate which (if any) they experienced in addition to their pain. Nearly 40% of patients reported that they experienced depression and/or anxiety. The percent of patients with each of these conditions is shown in Table 3.

Table 3: Patient comorbidities

Medical condition	Percentage
Depression/Anxiety	39.4
Osteoarthritis, degenerative arthritis	27.3
High blood pressure	23.3
Diabetes	11.2
Heart disease	7.8
Ulcer or stomach disease	7.0
Rheumatoid arthritis	6.6
Lung disease	5.5
Stroke or neurological condition	5.1
Anaemia or other blood disease	4.4
Cancer	4.2
Kidney disease	2.8
Other medical problems	28.5

The clinical complexity of patients referred to pain management services is further illustrated in Figure 5, which shows the proportion of people experiencing one or more of the 12 listed medical conditions.

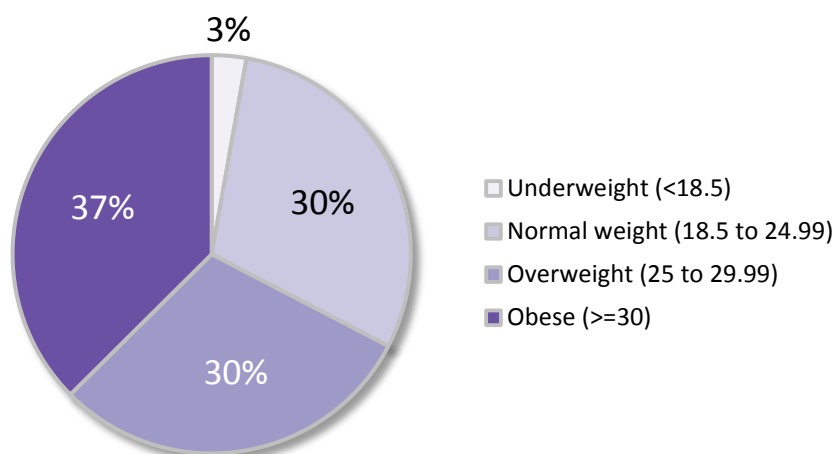
Figure 5 - Distribution of patients by number of comorbidities



Body Mass Index

The average Body Mass Index (BMI) of patients was 29.0 (SD=7.5) which lies in the Overweight category, but bordering on Obese. The percentage of patients in each BMI category is shown in Figure 6.

Figure 6 – 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	20.1	12.8	Moderate
Anxiety	14.0	10.9	Moderate
Stress	21.0	11.5	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.

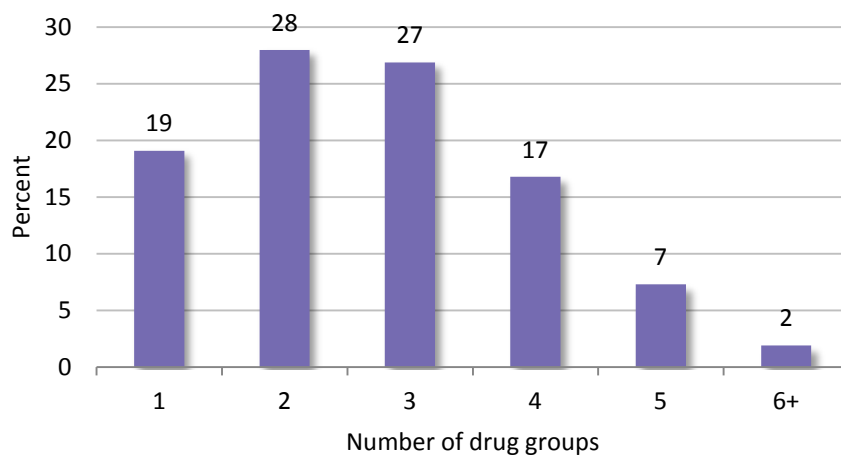
The average score on the PSEQ following referral to the pain services was 20.8 (SD=13.2), a score classified as 'Moderate' but bordering on severe impairment (identified by scores less than 20).

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 29.7 (SD=13.9), a score classified as 'Moderate', but again bordering the most extreme category of high (reflected by scores in excess of 30).

Medication use

At referral to the service, 54.4% 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 74.3 mg. On average, patients were using medications from three 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 7 shows the proportion of patients using one or more of these drug types.

Figure 7 - 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

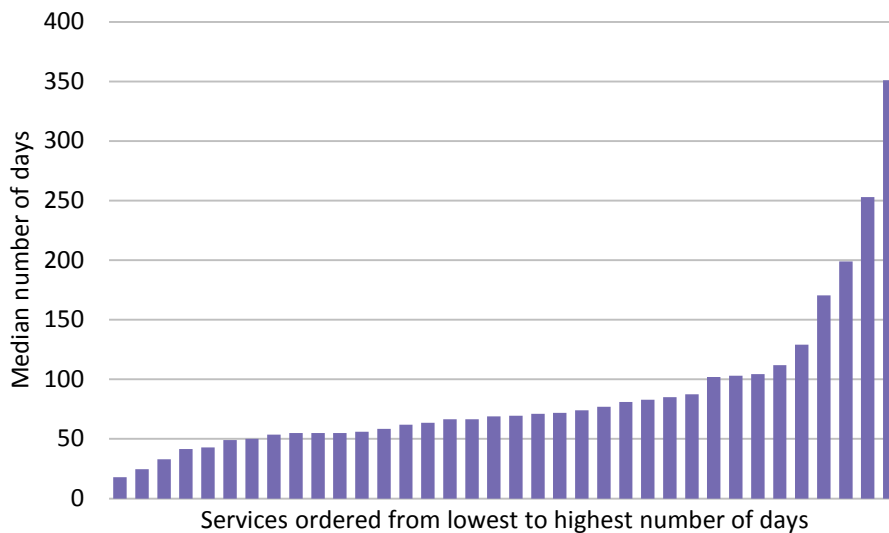
Health service	Median	Mean
General practitioner	4	5.2
Medical specialist	1	1.3
Health professionals other than doctors	1	3.4
Hospital emergency department	0	0.6
Hospital admission	0	0.3
Diagnostic tests	1	1.4

Pain management services provided

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. 7866 episodes of care were reported during 2015.

The median time from receiving a patient referral to the start of the episode was 71 days (average = 128.4). There was considerable variability across the 37 services on this measure, ranging from 18 to 351 days (see Figure 8). Episodes began with a single or multidisciplinary assessment of the patient (48.5%) or with a group education or pre-assessment program (51.5%).

Figure 8 - Number of days from referral to episode start by service



Patient outcomes

Pain management units provided information on the outcomes of 824 patients who completed a treatment pathway during 2015. These completed treatment pathways were predominantly group pain programs (75%), followed by individual appointments (15%).

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

Pain

Figures 9 and 10 show the proportion of patients who made clinically significant improvements in their average pain, worst pain and the degree to which pain interfered with daily activities. On all measures around one half of patients reported at least minimally significant improvement.

Figure 9 – Proportion of patients who made clinically significant improvement in their average and worst pain.

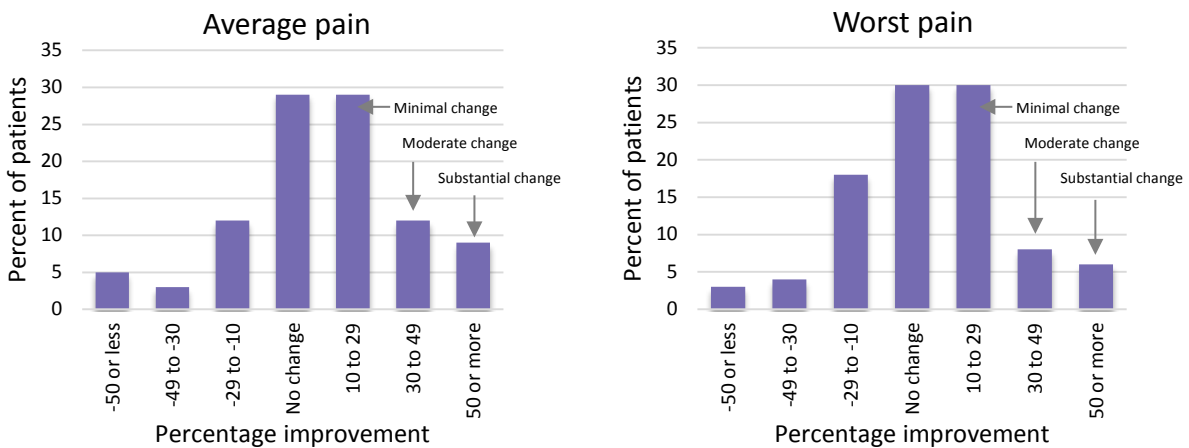
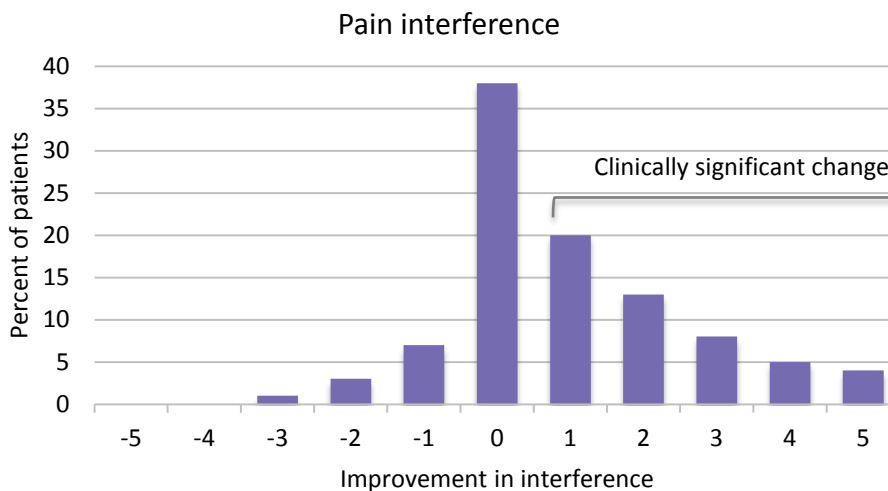


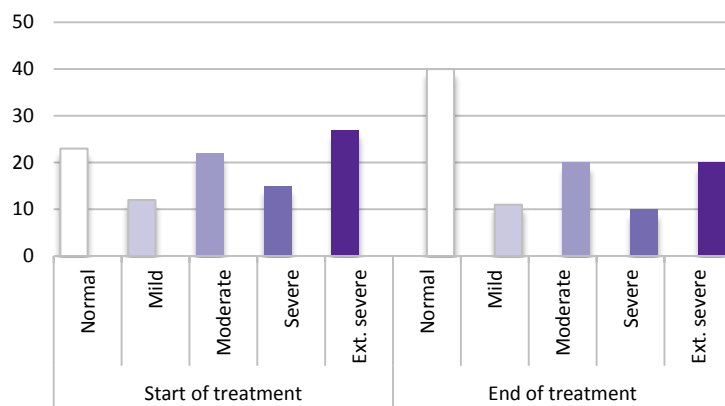
Figure 10 – Proportion of patients who made clinically significant improvement in pain interference.



Mood

Figures 11 to 13 show outcomes for patients on the depression, anxiety and stress subscales of the DASS. The severity of patients at the start and end of treatment is shown, and the proportion who made clinically significant improvement reported.

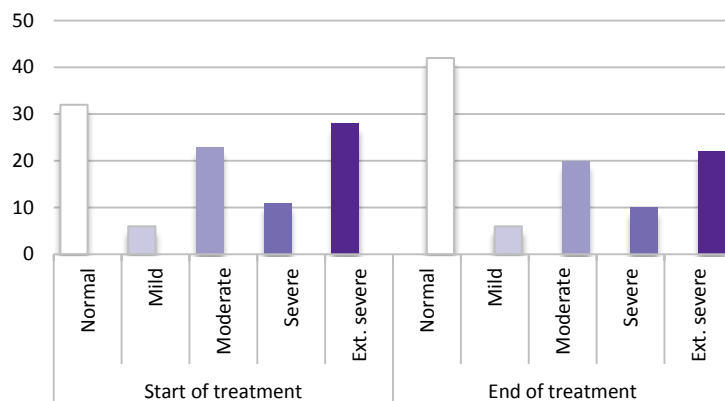
Figure 11 - Depression



36% of all patients reported clinically significant improvement, 52% did not change and 12% deteriorated.

Of those patients who had moderate or worse depression at the start, 49% made clinically significant improvement

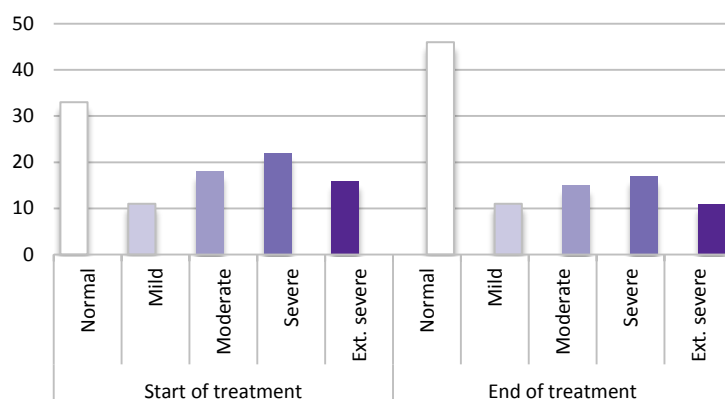
Figure 12 - Anxiety



26% of all patients reported clinically significant improvement, 62% did not change and 12% deteriorated.

Of those patients who had moderate or worse anxiety at the start, 38% made clinically significant improvement

Figure 13 - Stress



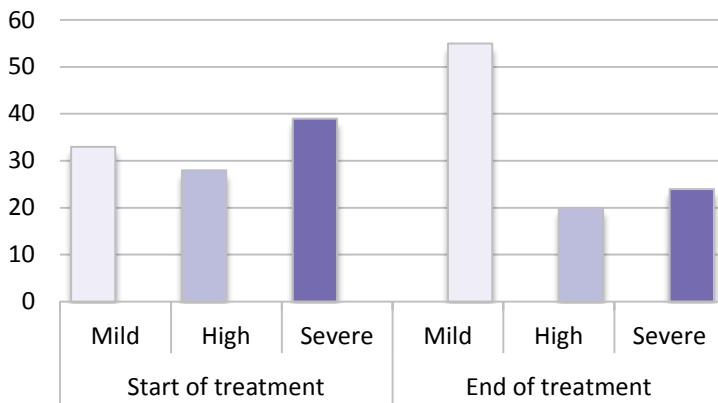
33% of all patients reported clinically significant improvement, 53% did not change and 14% deteriorated.

Of those patients who had moderate or worse stress at the start, 50% made clinically significant improvement

Cognition

Figures 14 and 15 show patient change in pain self-efficacy and pain catastrophising. The severity of scores at the start and end of treatment is shown, and the proportion of patients who made clinically significant improvement reported.

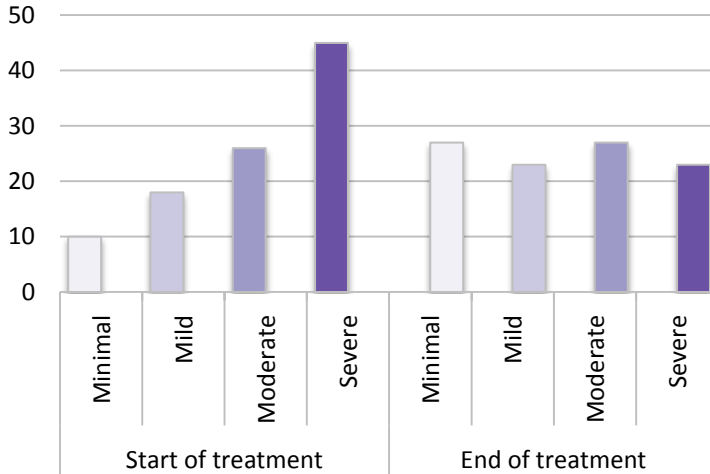
Figure 14 - Pain Catastrophising



32% of all patients reported clinically significant improvement, 62% did not change and 6% deteriorated.

Of those patients who had high or worse levels of catastrophising at the start, 47% made clinically significant improvement

Figure 15 - Impairment in Pain Self-Efficacy



45% of all patients reported clinically significant improvement, 47% did not change and 8% deteriorated.

Of those patients who had moderate or worse self-efficacy at the start, 49% made clinically significant improvement

Medication use

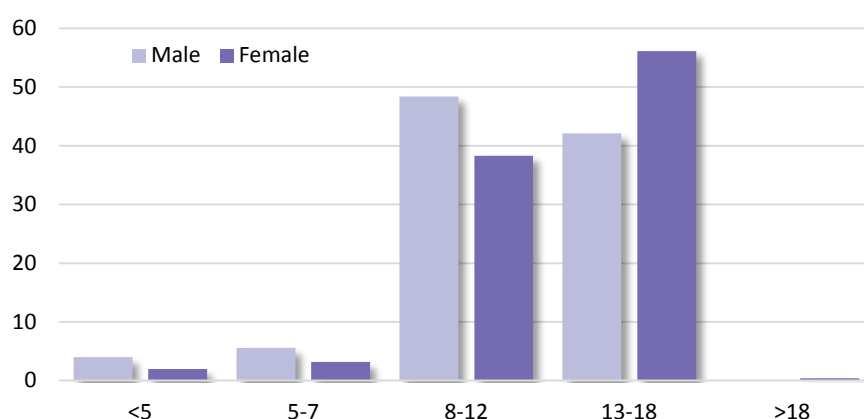
A number of patients were using opioid medication on a regular basis at entry to the pain service. For patients who completed a treatment pathway, the average oral morphine equivalent daily dose was 61mg at the start, and 42 mg at the completion of treatment. Many patients were able to take their opioid medication less frequently, with 26% no longer taking opioid medication on more than two days per week. 39% of patients also reduced the number of drug groups used.

Paediatric patients

Patient demographics

Participating paediatric pain management services contributed data for 378 patients during 2015. Of these patients, 67% were female, with an average age of 12.6 years at the time of referral. Males were younger on average at 11.5 years. The distribution by gender and age is shown in Figure 16.

Figure 16: Age and gender distribution of patients



Most patients were born in Australia (91.9%) and 5.3% identified as being of Aboriginal and/or Torres Strait Islander origin. Patients were generally referred to the pain management service by a specialist practitioner (81.3%).

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.

515 of these initial questionnaires were completed (258 completed by the child, 257 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 49% responded that their child had experienced the pain for more than 12 months. Most (71.9%) 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 17, with the abdomen the most common (24.2%). Just over one in four patients had pain in one region only, with the remainder identifying multiple regions (see Figure 18).

Table 6: Event precipitating the patient’s pain

Triggering event	%
No known cause	38.2
Injury	21.1
Illness	18.3
After surgery	8.9
Other	13.4

Figure 17: Site of patient’s main pain

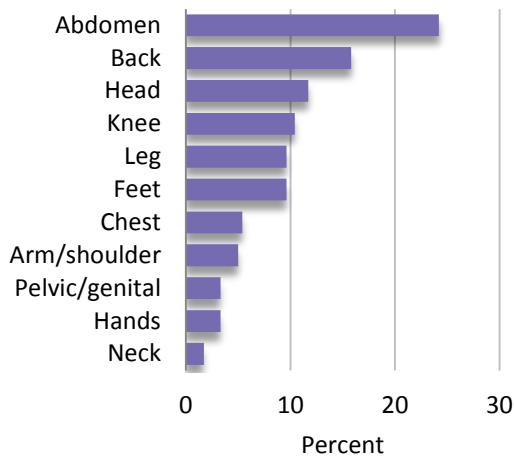
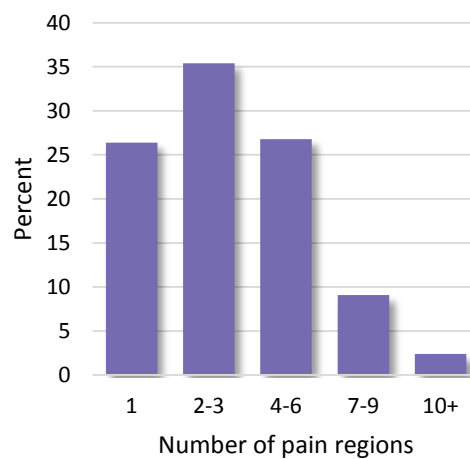
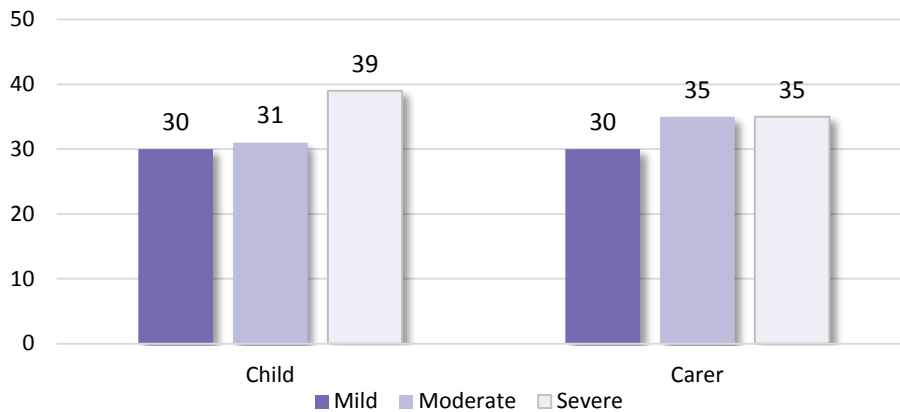


Figure 18: Number of pain sites



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 both child and carer was 5.5 (moderate severity), however children were more likely than their carers to rate their pain in the severe range (see Figure 19 below).

Figure 19: 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.

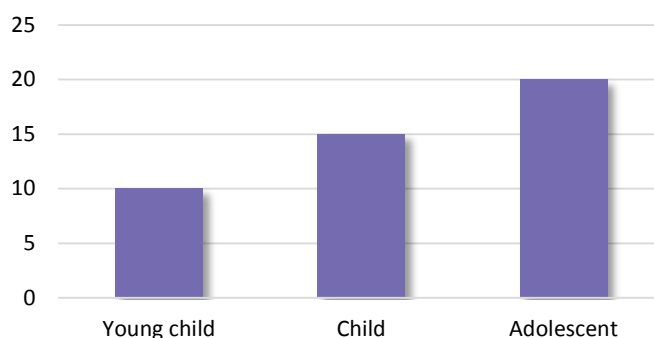
Table 7: Percentage of patient with disabilities and comorbid conditions

Disability	% of patients	Comorbid condition	% of patients
Sight impairment	2.6	Chronic disease	16.9
Hearing impairment	1.6	Mental health condition	14.5
Intellectual disability	2.4	Cancer	1.6
Physical disability	4.2	Other	17.4
Other disability	4.0		

Role functioning

Children missed a considerable number of school days in the previous school term as a result of their pain, with this number increasing with age (see Figure 20). While 16% of adolescents were in paid employment, pain affected the number of hours that most (85%) were able to work.

Figure 20: 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 85% of both carers and children rated the child's quality of life in this 'at risk' range.

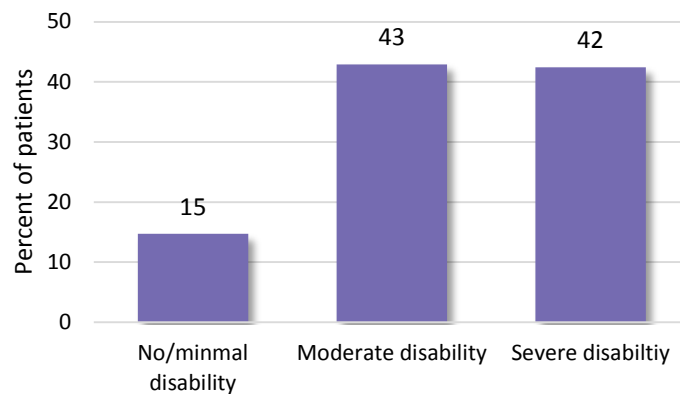
Table 8: Patient and carer quality of life scores

Domain	Child	Carer
Psychosocial	55.0	50.5
Physical	39.6	37.3
Total score	49.6	45.9

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 26.3, reflecting moderate disability. The distribution of scores by severity category is shown in Figure 21, indicating that over 4 in 5 children rated their functional disability as either moderate or severe.

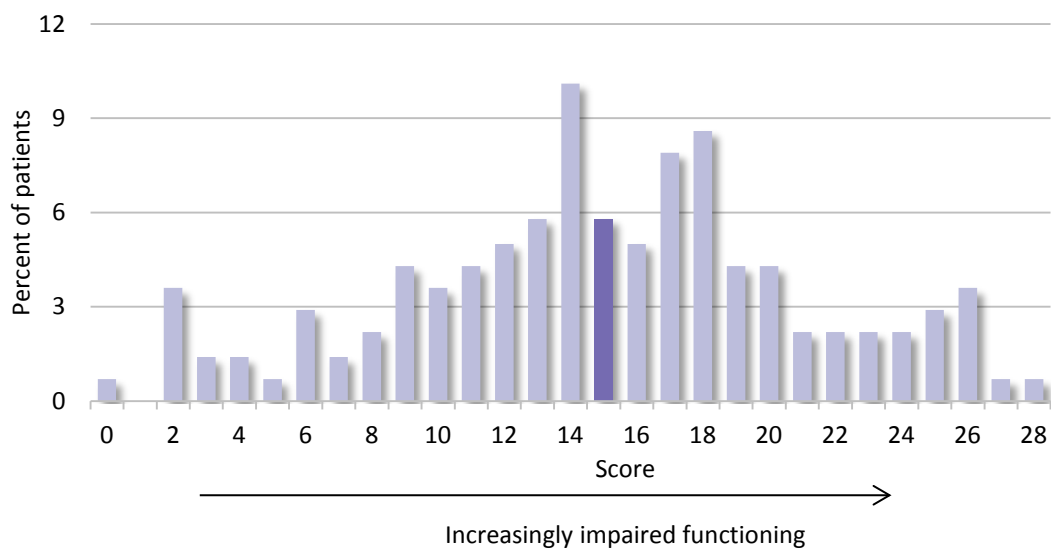
Figure 21: Disability at referral by severity category



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 22 with the average score highlighted.

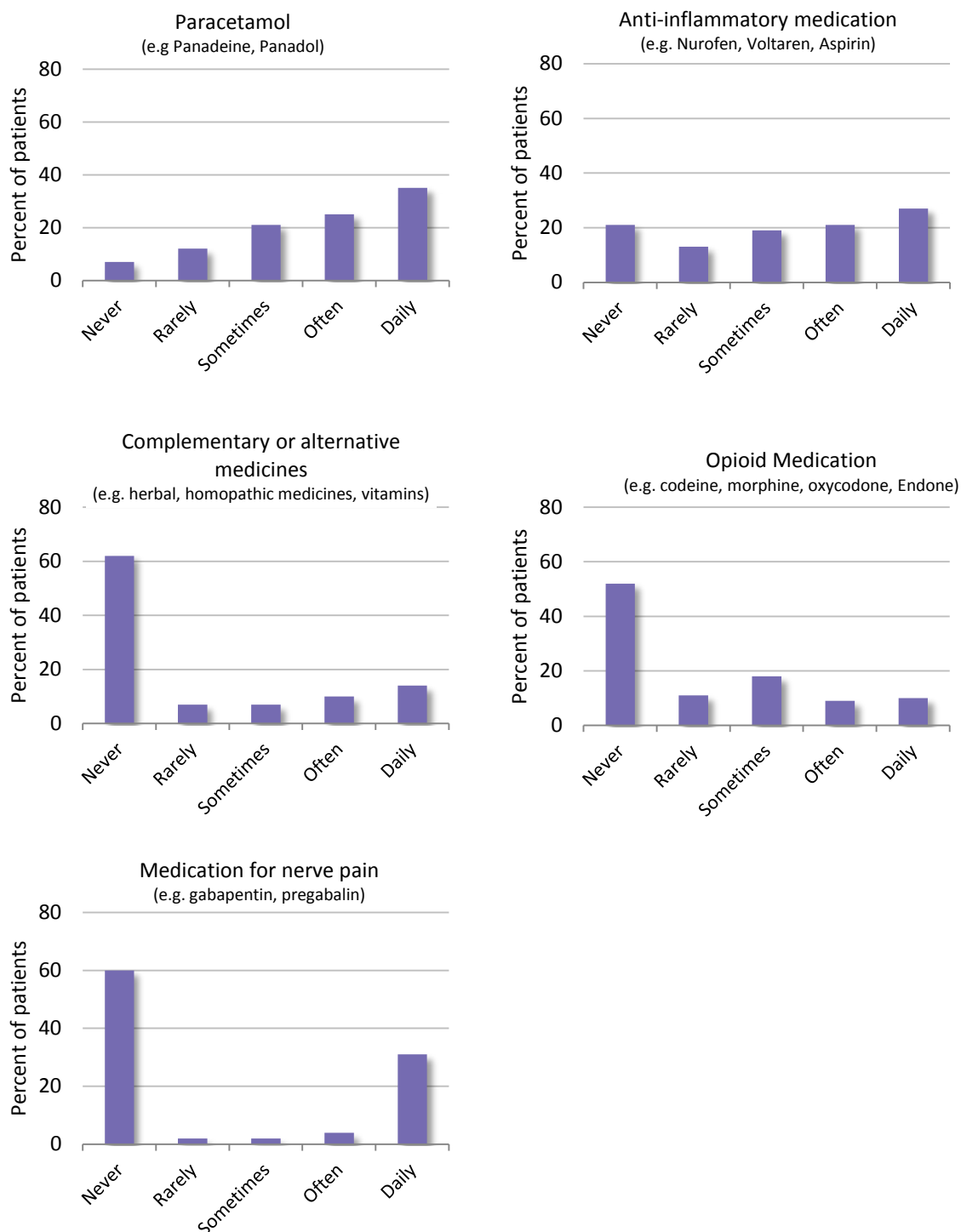
Figure 22: Distribution of pain-related worry scores



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 23: Percentage of patients using medication by frequency of use.

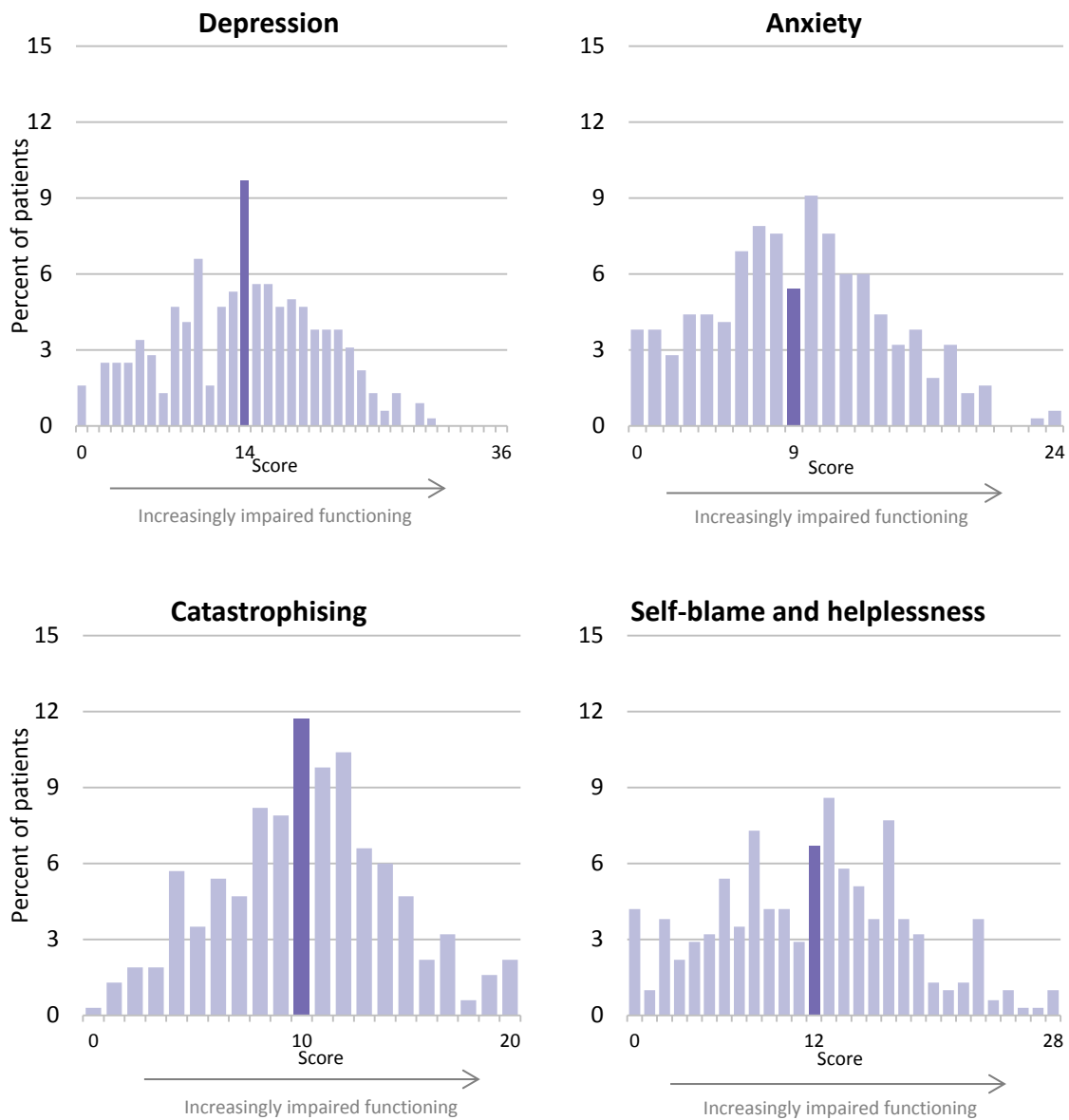


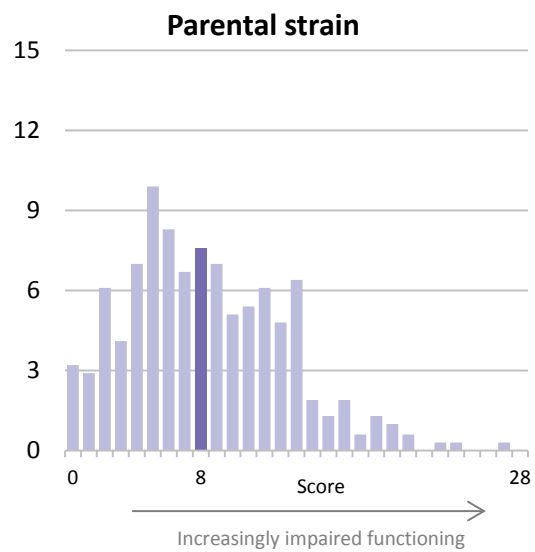
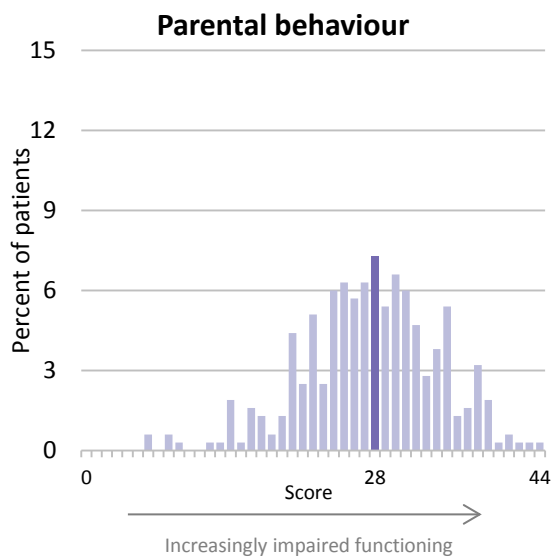
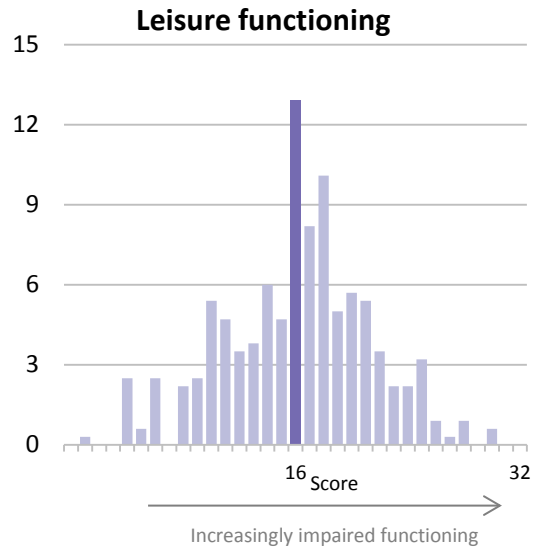
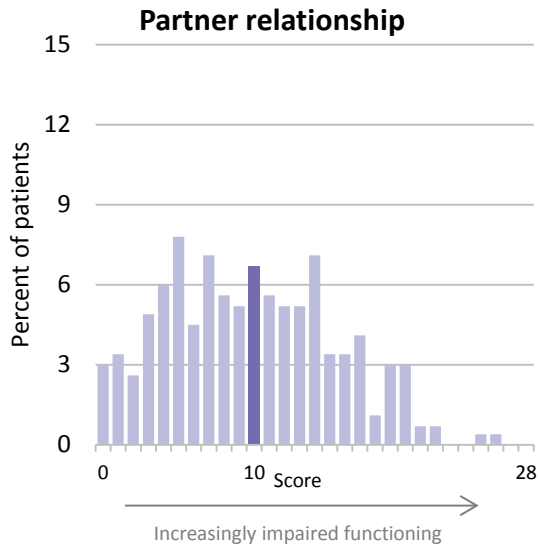
Impact of pain on the carer

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 24: Distribution of scores on the Bath Parent Impact subscales





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: Patient use of health services

Health service	Median	Mean
General practitioner	2.5	3.5
Medical specialist	2.0	3.3
Allied health professionals	1.5	3.7
Other therapist	0.0	0.8
Hospital emergency department	0.0	1.3
Hospital admission	0.0	0.6
Diagnostic tests	2.0	2.5

Pain management services provided

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. 379 episodes of care were reported at the paediatric pain services during 2015.

The median time from receiving a patient referral to the start of the episode was 31 days (average = 47 days). Most episodes (87%) started within 3 months of receiving the referral. Nearly all episodes (97.1%) began with a single or multidisciplinary assessment of the patient and continued with individual appointments with clinicians, rather than group pain programs.

Future directions

This 2015 ePPOC report presents data from over 11,000 patients, 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 2016, with additional services in Queensland and New Zealand planning to join the collaboration. The focus during 2016 will include increasing the number of patient outcomes, and establishing benchmarks for quality improvement. We will also be working to refine the current dataset to ensure the information collected remains relevant, useful and able to address questions of interest within the persistent pain management sector.

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

Appendix A – Services providing data for this report

Adult pain management services:

New South Wales:

Concord Repatriation Hospital Pain Clinic
Greenwich Hospital Pain Management Service
Hunter Integrated Pain Service
Illawarra-Shoalhaven Chronic Pain Service
Lismore Hospital Multidisciplinary 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

New Zealand:

Burwood Hospital

Queensland:

North Queensland Persistent Pain Management Service

Victoria:

Advance Healthcare
Austin Health
Barbara Walker Centre for Pain Management, St Vincent's Hospital Melbourne
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 and Management Service
Peninsula Health Chronic Pain Management Service
Precision Ascend Rehabilitation Centre
Victorian Rehabilitation Centre
Western Health Pain Management

Western Australia:

PainCare
Sir Charles Gairdner Hospital

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

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

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

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.

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

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

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. 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

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.

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. 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

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

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).