

Care delivery models for chronic pain

OCTOBER 2021

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Preferred citation: NSW Agency for Clinical Innovation. *Care delivery models for chronic pain: Evidence Report*. Sydney: ACI; 2021.

SHPN (ACI) 210612

ISBN 978-1-76081-834-0

Version: V1; ACI_1844 [10/21]

TRIM: ACI/D21/1629

Published Nov 2021. Next Review 2026.

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Foreword

Many of the barriers to good pain management are not primarily scientific or medical, but organisational.¹

To establish a NSW Health Network, clear and tangible benefits need to be outlined for both members and NSW Health. Members seek the benefit of collaboration and a voice to influence policy. NSW Health seeks support to design and implement healthcare. Neither are able to provide sustainable, value-based healthcare without the other. This joint dependency requires work on both parts. With a voice comes responsibility, transparency and accountability. In the same way, partnerships need to be fostered across changing government and organisational structures.


This report examines available evidence on care delivery for chronic pain management and an estimate of chronic pain related inpatient admissions, clinic and EDs attendances across NSW.

Understanding the demand for chronic pain management, looking at different care delivery models and the evidence about what works and why it works, can help direct future policy, design and implementation of healthcare related to pain management.

Our ongoing challenge is to address the specific challenges facing clinicians to sustain person-centred, value-based healthcare. These will need to be considered separately by the collaborative partnership between members of the Pain Management Network, ACI Executive and NSW Health.

On behalf of the Network, we thank the ACI for assisting our advocacy and enabling this report.

Yours faithfully



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Medical Co-Chair 2020, Founding Co-Chair 2010



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Allied Health Co-Chair, 2016-21

Summary

Introduction

Chronic pain is defined as pain that persists or recurs for more than three months.² It affects about 20% of the population, interfering with daily functioning, and often accompanied by significant distress.³ All pain is understood to be a multifactorial condition that has biological, psychological, and social contributors. Globally, chronic pain is a leading cause of years lived with disability.⁴

This report provides a summary of evidence available about patients who presented to NSW emergency departments (EDs) with chronic pain-related diagnoses; and about care delivery models for management of chronic pain.

Methods

The report draws on three main types of evidence:

- quantitative data from NSW Emergency Department Data Collection (EDDC), NSW Admitted Patient Data Collection (APDC) and the electronic Persistent Pain Outcomes Collaboration (ePPOC)
- research literature identified through searches of PubMed and Google
- experiential evidence gathered through clinician accounts.

Use of services in NSW

In 2018-19, there were 326,120 unplanned presentations with a chronic pain-related principal diagnosis to NSW public EDs. These presentations accounted for 11% of all unplanned presentations to NSW public EDs that year. Rural and regional local health districts (LHDs) had a higher rate of presentations than metropolitan LHDs (6,002 compared with 3,187 per 100,000 population,

age-sex standardised). Over a 10-year period (2009-10 to 2018-19), there was a 53% increase in the number of unplanned ED presentations with a chronic pain-related principal diagnosis, a 36% increase in the per capita rate, and a 36% increase in the age-sex standardised rate.

In 2018-19, 5,554 people attended an ED seven or more times (with at least three presentations with a chronic pain-related principal diagnosis code) in a 12-month period. This cohort are likely to represent people with chronic pain. Over a decade, there was a 91% increase in the number of frequent attenders, a 69% increase in the per capita rate, and a 69% increase in the age-sex standardised rate. Frequent attender rates were higher in rural and regional LHDs compared with metropolitan LHDs (130 compared with 46 per 100,000 people, age-sex standardised).

In 2018-19, there were 134,927 admitted patient episodes with a chronic pain-related principal diagnosis in NSW public and private hospitals. Between 2009-10 and 2018-19, there was a 45% increase in the number of admitted patient episodes for chronic pain, a 28% increase in the per capita rate, and a 23% increase in age-sex standardised rate.

In 2018-19, there were 9,080 active patients registered at 17 specialist adult pain services and 365 active patients registered at three specialist paediatric pain services in NSW.

Evidence on care delivery models

Overall, the research evidence on models of care for chronic pain is mixed, with variability in the local pain programs studied, composition of multidisciplinary teams, and outcomes reported.

Most studies compare pain models to usual care, although some use unimodal care, or a single therapeutic intervention, as a comparator.

The literature search and experiential data collection identified different models of care delivery, with some consistent characteristics across them.

Common features of models of care for chronic pain management include:

- more than one method of treatment (multimodal)
- multidisciplinary, interdisciplinary or integrated care delivered across different disciplines and specialties
- support for patient self-management
- can be operationalised across outpatient, community-based and group-based sessions
- can use telehealth or virtual care.

Experiential evidence was gathered about how care for chronic pain is organised and delivered in NSW. Data was collected from one paediatric and four adult hospital pain clinics, and one primary health network-sponsored community pain management program.

Key findings from the experiential evidence included:

- multidisciplinary team configurations varied across local contexts, however access to physiotherapists, nurses, clinical psychologists and pain specialists was consistent
- treatment was multimodal with a combination of medication, interventional procedures, and psychologically informed pain management programs on an individual or group basis, with various intensity levels
- modes of delivery included face-to-face and telephone – encompassing audio and telehealth
- group formats were often the primary intervention for adults, whereas, for children, groups were considered unsuitable for various reasons, including stigma and distress

- some Aboriginal people prefer individual formats for treatment – or informal 'yarning' about chronic pain while engaging in community exercise sessions – rather than formal groups
- challenges identified by clinicians are ineffective coding for chronic pain, and the demand for care exceeding the capacity to deliver
- innovative approaches locally have been used to increase access to care and capacity to deliver care, but there are concerns about sustainability.

Limitations of the Evidence Report

ED presentations related to chronic pain were selected based on the principal diagnosis only. Not all presentations related to chronic pain may have been captured. The literature search was limited to systematic reviews and randomised controlled trials, and so models evaluated in observational studies have not been captured. No formal critical appraisal of individual studies was undertaken, and categorisation into models such as multidisciplinary or interdisciplinary was done according to the terminology used in the associated paper.

Patients with chronic pain are not a homogeneous population, and there was significant patient variability between studies. This made it difficult to attribute outcomes to a particular care delivery model.

It was only possible to develop case studies and vignettes on a select number of pain clinics. No experiential evidence has been gathered directly from consumers or communities. However, consultation reports from Painaustralia, were considered.

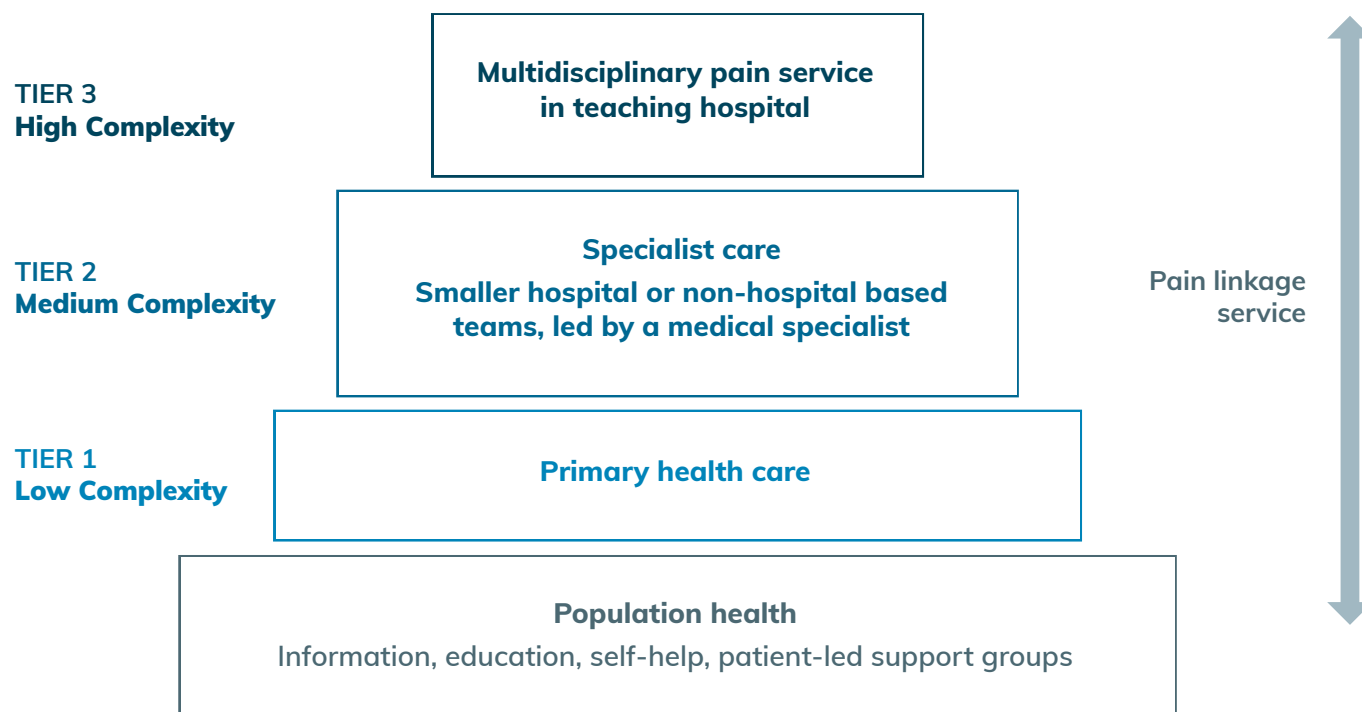
Setting the scene

Introduction

Chronic pain is defined as pain that persists or recurs for more than three months.² Chronic pain affects about 20% of the population, interfering with daily functioning, and often accompanied by significant distress.³ All pain, whether acute or chronic, is understood to be a multifactorial condition that has biological, psychological, and social contributors. Globally, chronic pain is one of the leading causes of years lived with disability.⁴ Patients with chronic pain are not a homogeneous population.⁵

In 2012, NSW Health developed a four-year pain management plan designed to address problems identified by a Ministerial Taskforce of local experts. The Agency for Clinical Innovation (ACI) Pain Management Network was established and tasked with coordinating implementation of the plan. The Ministerial Taskforce developed a pain management model of care to guide public health care delivery in NSW, based on a tiered approach (Figure 1).

Figure 1: Model of care



Source: NSW Pain Management Report⁶

Data and methods

Health and healthcare databases

Databases used included NSW Emergency Department Data Collection (EDDC) and NSW Admitted Patient Data Collection (APDC), accessed via the Hospital Performance Dataset (HoPeD) and NSW Ministry of Health Secure Analytics for Population Health Research and Intelligence. HoPeD was established under clause 17(2) of the Health Administration Regulation 2017. It comprises linked administrative data and was prepared by the Centre for Health Record Linkage (CHeReL).⁷ Patient Outcomes in Pain Management 2019 Mid Year Report, electronic Persistent Pain Outcomes Collaboration (ePPOC), University of Wollongong.⁸

ED presentations and admitted patient episodes for chronic pain and opioid harm were identified using a selection of diagnosis codes. Frequent ED attendance by people with chronic pain was defined as seven or more ED presentations within 12 months with at least three of those ED presentations being a chronic pain-related principal diagnosis. For ED trend data, analysis was restricted to 82 public EDs in NSW that reported continuously and collected reasonably complete diagnosis information since 2009-10. In 2018-19, these 82 EDs accounted for approximately 85% of all NSW public hospital ED activity. For ED data in 2018-19, all NSW public EDs in the EDDC were included. ED analysis was also restricted to unplanned presentations. Appendix 1 of *Care delivery models for chronic pain: Appendices* provides a complete outline of data methods.

Literature search

PubMed was searched on the 14 September 2020 for publications since the development of the *NSW Pain Management Model of Care* in 2012.⁶ Combinations of related terms representing 'chronic pain' and 'models of care', and approaches

such as 'multidisciplinary care' were used. Studies were included if they were systematic reviews of randomised controlled trials, English language, published January 2010 to September 2020, population was people with chronic pain and intervention was care delivery models. In the grey literature, reports such as government documents outlining models of care and evaluation reports were included.

Articles were independently screened by two people, first by title and abstract and subsequently by full text. Conflicts were discussed and resolved in face-to-face meetings. Snowballing (using the reference list of a paper to identify additional papers) of relevant review articles was also undertaken. Search strings and inclusion and exclusion criteria are available in *Care delivery models for chronic pain: Appendices*. 76 studies were included from the peer reviewed literature and nine publications from the grey literature.

Experiential evidence

A purposive sample of six sites was identified through the ACI Pain Management Network, and 30 minute semi-structured virtual interviews were conducted with representatives from the nominated pain clinics and a regional service. The purpose of these interviews was for the representatives to describe how care is organised and delivered in public pain clinics, and what works in different contexts. Individual case presentations (vignettes) were developed for each case – using a standard format and several rounds of iteration and feedback with the representative. An iterative cross-case comparison was used to identify similarities and differences in delivering pain services across different contexts.

Emergency department presentations for chronic pain

People with chronic pain who present frequently to emergency departments have complex management needs and are often exposed to unnecessary and unhelpful treatments and investigations if their care is not coordinated.⁹

Emergency department presentations

In the year 2018-19, there were 326,120 unplanned presentations with a chronic pain-related principal diagnosis to NSW public EDs, made by 268,617 people. These presentations accounted for 11% of all unplanned presentations to NSW public EDs that year.

Among presentations to the ED with a chronic pain-related principal diagnosis, the most common diagnoses were chronic visceral pain (39%), followed by chronic musculoskeletal pain (26%) (Table 1). Presentation rates varied by age and sex (highest for females aged 16-24 years at 6,250 per 100,000 population); across local health districts (LHDs) and were higher in rural and regional LHDs than metropolitan LHDs (6,002 compared with 3,187 per 100,000 population, age-sex standardised); and by Aboriginality (13,462 per 100,000 for Aboriginal people and 3,775 per 100,000 for non-Aboriginal people, age-sex standardised) (Figures 2 and 3). There were 72 EDs with at least 1,000 unplanned presentations with a chronic pain-related principal diagnosis, and four had more than 10,000 presentations (Figure 4).

People presenting to emergency departments

In 2018-19, there were 5,554 people who presented to ED seven or more times within 12 months of their first presentation (with at least three of those presentations noting a chronic pain-related principal diagnosis). Of these people, 3,061 presented 10 or more times. Among the people presenting seven or more times, 37% of their presentations had a chronic pain-related principal diagnosis code.

Rates of frequent attenders varied by age and sex (highest for females aged 16-24 years at 139 per 100,000 people) and by LHDs (higher in rural and regional LHDs than metropolitan LHDs – 130 compared with 46 per 100,000 people, age-sex standardised) (Appendix 4 of *Care delivery models for chronic pain: Appendices*, Figures 1 and 2). Aboriginal people had a higher rate of frequent attendance than non-Aboriginal people (571 per 100,000 for Aboriginal people and 55 per 100,000 for non-Aboriginal people, age-sex standardised). Among the 5,544 people who attended an ED seven or more times within 12 months, 1,801 (32%) always attended the same ED and 3,753 (68%) attended two or more EDs. There were 41 EDs that were visited by at least 100 frequent attenders, and one ED was visited by more than 500 frequent attenders (Appendix 4 of *Care delivery models for chronic pain: Appendices*, Figure 3).

Table 1: Most common chronic pain-related diagnoses for unplanned emergency department presentations, NSW 2018-19

Pain type	Number	Percent (%)
Chronic visceral pain	126,809	39%
Chronic musculoskeletal pain (excluding back pain)	83,676	26%
Chronic primary pain (including back pain)	69,766	21%
Chronic headache and orofacial pain	40,957	13%
Chronic neuropathic pain	4,912	2%
Total	326,120	100%

Figure 2: Number and rate of unplanned emergency department presentations for a chronic pain-related principal diagnosis by age and sex, NSW 2018-19

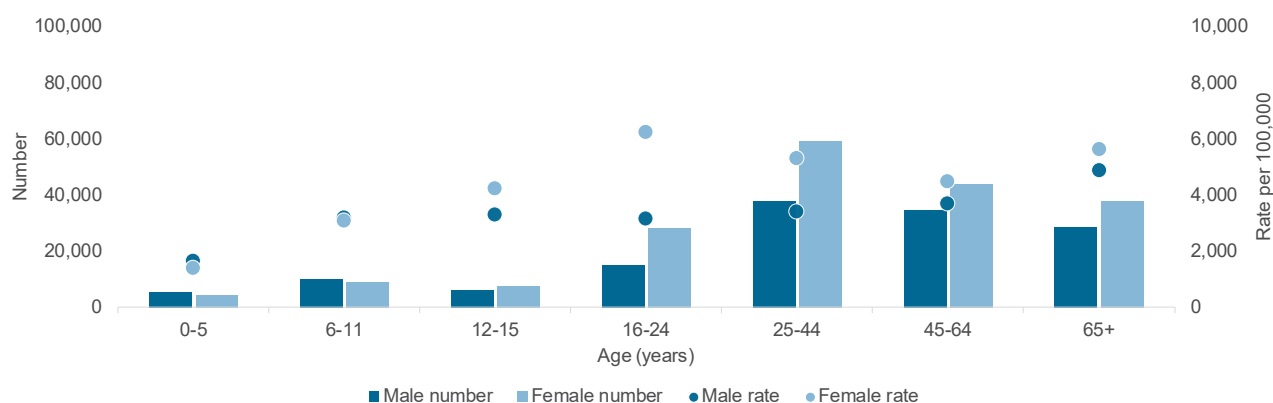


Figure 3: Number and rate of unplanned emergency department presentations for a chronic pain-related principal diagnosis by local health district of residence, NSW 2018-19

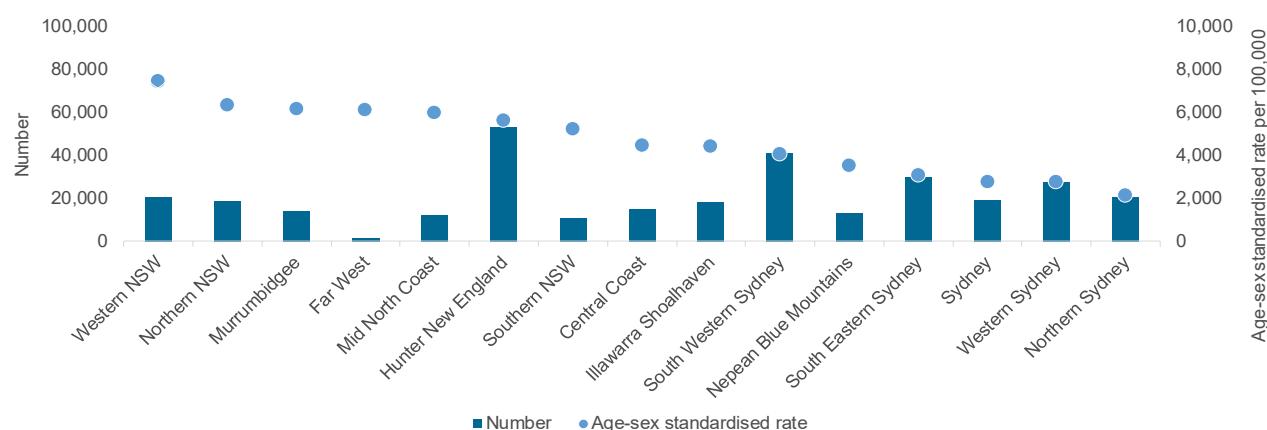
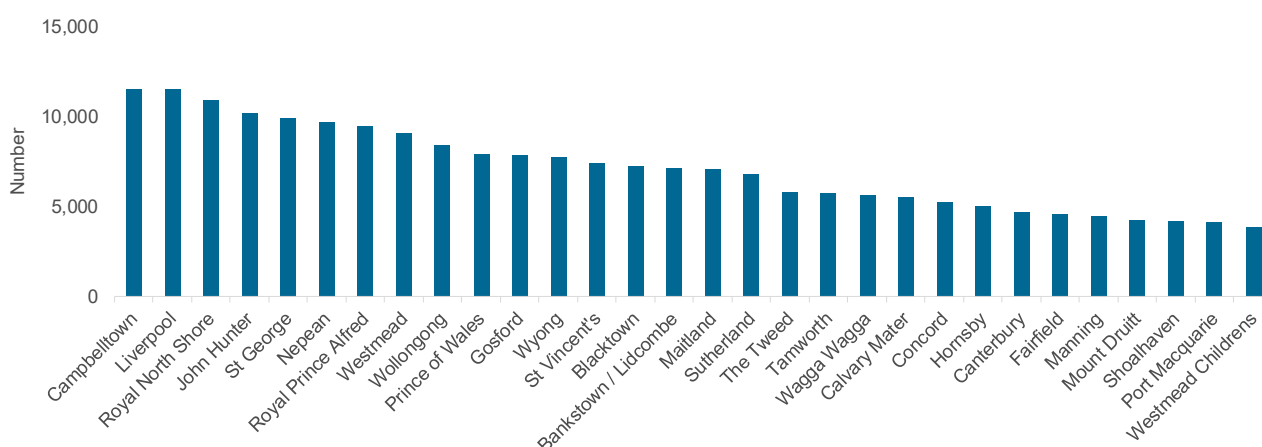


Figure 4: Number of unplanned emergency department presentations for a chronic pain-related principal diagnosis by emergency department, NSW 2018-19 (the 30 EDs with most presentations)



Trends in emergency department presentations for chronic pain

Over the 10-year period, 2009-10 to 2018-19, the number of unplanned ED presentations for a chronic pain-related principal diagnosis increased from 187,452 to 286,921 (53% increase)*. This corresponds to a population rate increase from 2,640 to 3,578 per 100,000 population (36%). The age-sex standardised rate has also increased from 2,607 to 3,548 per 100,000 population (36%) (Figure 5).

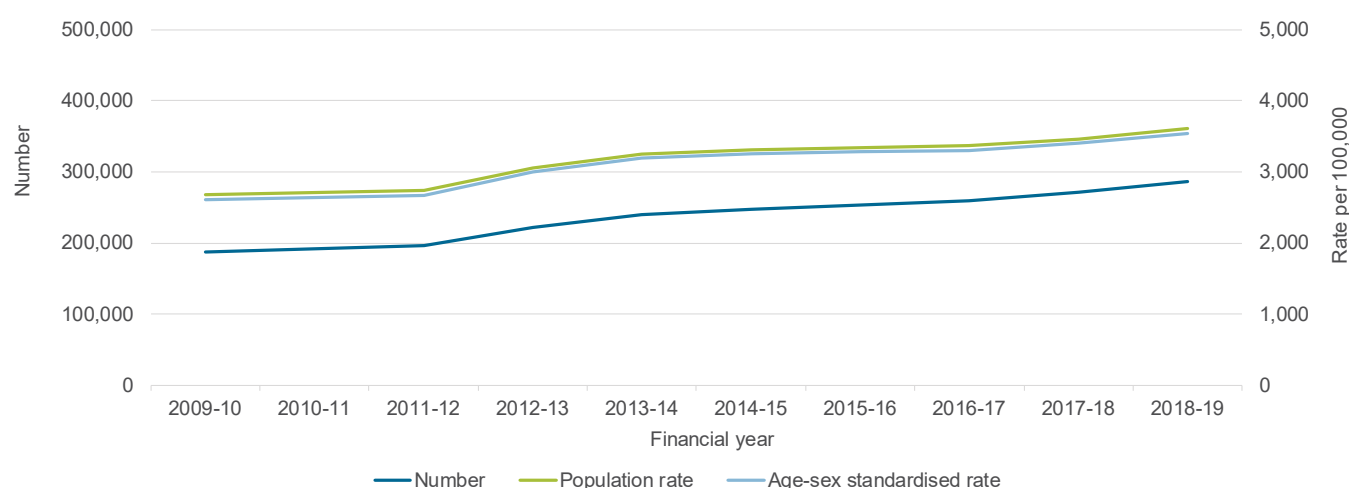
Over the same time period, the number of people presenting to ED for a chronic pain-related principal diagnosis increased from 162,041 to 238,118 (47%)* – a population rate increase of 2,282 to 2,970 per 100,000 population (30%) and an age-sex standardised rate of increase of 2,254 to 2,942 per 100,000 population (31%).

The number of people with chronic pain attending EDs frequently (seven or more presentations within 12 months and at least three of those presentations with a chronic pain-related principal diagnosis) has also increased over time. Between 2009-10 and 2018-19, the number of frequent attenders increased from 2,417 to 4,605 (91%)*. This corresponds to a

population rate increase from 34 to 57 per 100,000 population (69%) and an age-sex standardised rate of increase from 34 to 57 per 100,000 population (69%) (Figures 6 and 7).

There has also been an increase over time in admitted patient episodes (both emergency and planned) with a chronic pain-related code as the principal diagnosis. Between 2009-10 and 2018-19, the number of episodes increased from 93,136 to 134,927 (45%). This corresponds to a population rate increase of 1,311 to 1,683 per 100,000 population (28%) and an age-sex standardised rate of increase of 1,252 to 1,544 per 100,000 population (23%). In 2018-19, 85,331 episodes (63%) were in public hospitals and 49,596 (37%) were in private hospitals. It should be noted that the number of episodes has plateaued in more recent years (Appendix 4 of *Care delivery models for chronic pain: Appendices*, Figure 4).

Figure 5: Number and rate of unplanned emergency department presentations for a chronic pain-related principal diagnosis, NSW 2009-10 to 2018-19*

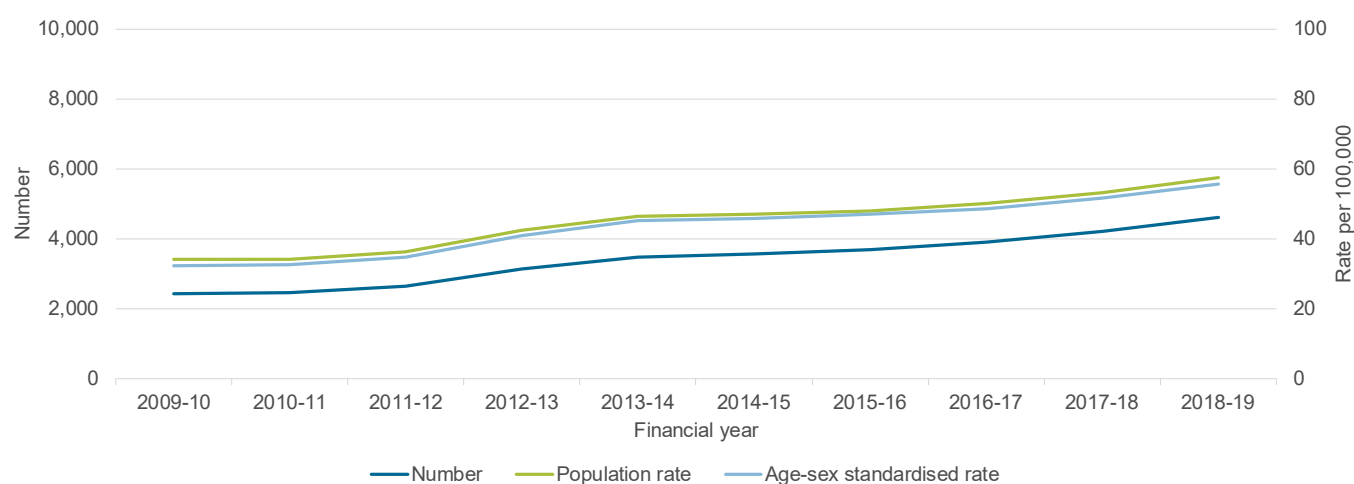


* For ED trend data, analysis was restricted to 82 public EDs in NSW that reported continuously and collected reasonably complete diagnosis information since 2009-10.

Figure 6: Number of people with chronic pain attending an ED frequently (seven or more presentations within 12 months and at least three of those presentations with a chronic pain-related principal diagnosis) by financial year of the first presentation in the 12-month period, NSW 2009-10 to 2018-19*

Financial year	7+ presentations	10+ presentations
2009-10	2,417	1,324
2010-11	2,449	1,351
2011-12	2,642	1,421
2012-13	3,123	1,728
2013-14	3,462	1,834
2014-15	3,571	1,919
2015-16	3,694	1,961
2016-17	3,909	2,112
2017-18	4,210	2,308
2018-19	4,605	2,510

Figure 7: Number and rate of people with chronic pain attending an ED frequently (seven or more presentations within 12 months and at least three of those presentations with a chronic pain-related principal diagnosis) by financial year of the first presentation in the 12-month period, NSW 2009-10 to 2018-19*



* For ED trend data, analysis was restricted to 82 public EDs in NSW that reported continuously and collected reasonably complete diagnosis information since 2009-10.

Specialist adult pain services in NSW

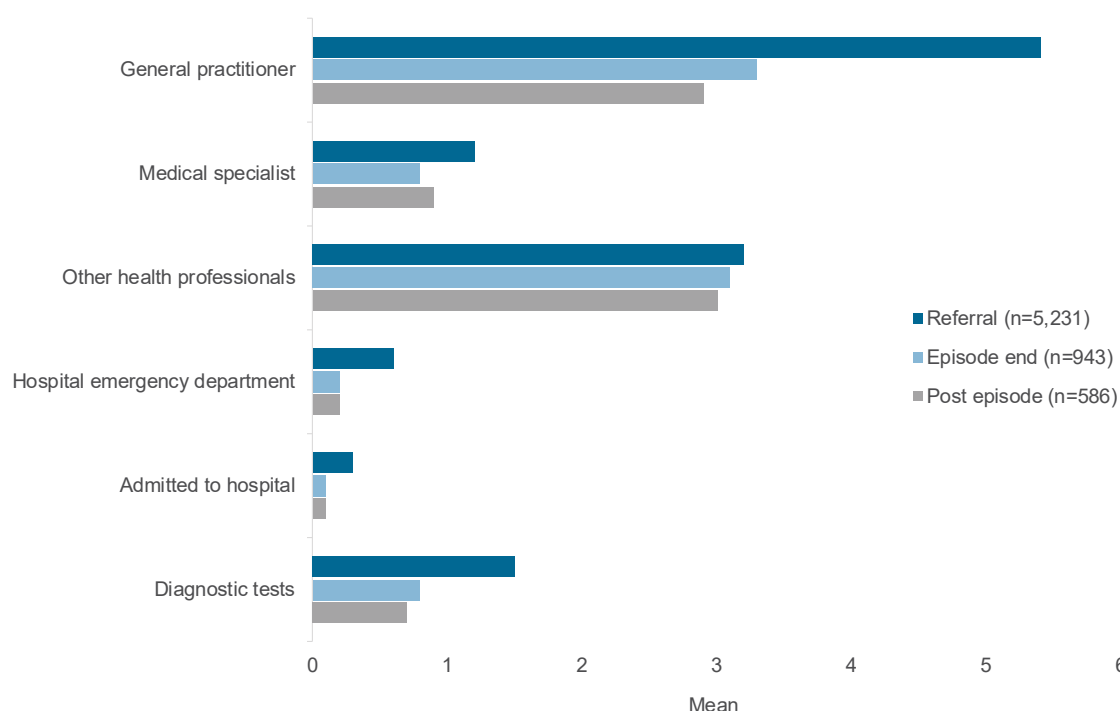
Currently there are 16 specialist adult pain services and one nursing and allied health led adult pain service in NSW for adults experiencing chronic pain. In 2018-19, data were collected from 17 adult pain services in NSW via the ePPOC and analysed by the Australian Health Services Research Institute University of Wollongong.⁸

In 2018-19, there were 9,080 active* patients in the 17 adult pain services and 5,359 new referral questionnaires completed. About 60% of active adult patients were female, the average age was 54 years, 10% required communication assistance, 73%

were outside the normal body mass index range, 24% were from an area of highest disadvantage (compared with 20% of the population), and 6% were Aboriginal and/or Torres Strait Islander (compared with 3% of the population).

In that year, 5,557 episodes of care** were started, with the median time from referral to episode start at 91 days. Most adults were on an individual treatment pathway (67%), about a quarter were on a group program (28%), and a small percentage concurrent (2%) or one-off (2%).

Figure 8: Mean number of times NSW adult patients used each service in the last three months, for patients who returned a questionnaire at referral, episode end or post episode, 2018-19



Note: These results may be biased by a change in the number of patients who returned a questionnaire at referral, episode end or post episode.

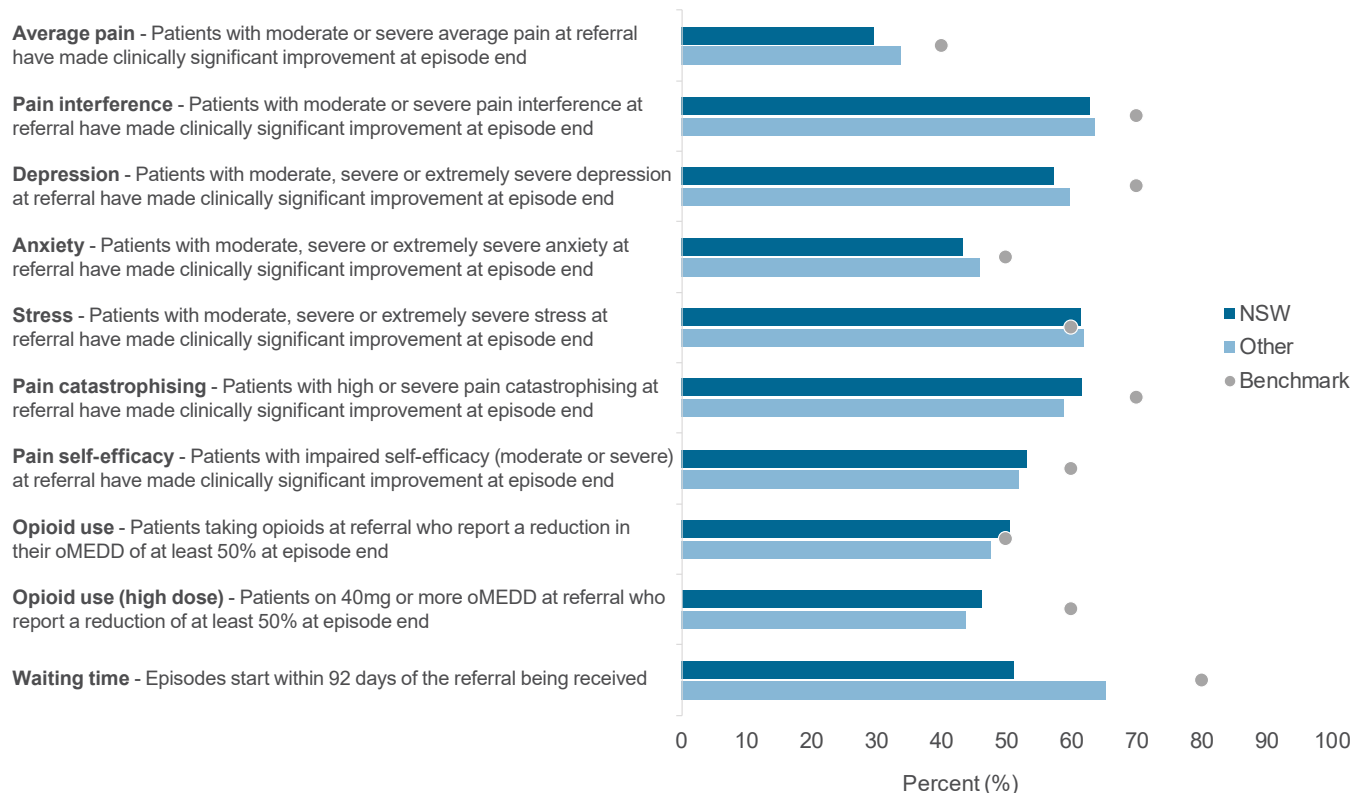
*The completion of a referral questionnaire or the occurrence of a service event determines whether a patient is active. The ePPOC data does not reflect the number of referrals received by pain services in NSW during this time. For most services the number of referrals being actioned by the services is 50% more than the ePPOC data (active cases) shows and in some case more.

**An episode of pain management begins with the first clinical contact with the patient and ends when active treatment is completed or discontinued at a pain service. In some NSW pain services the first contact will be an education session.

Based on the 5,359 completed referral questionnaires, the average number of pain sites was 4.4, the average number of comorbidities was 2.6, 2,031 patients (38%) were unemployed due to pain, and 2,830 patients (53%) had been experiencing pain for more than five years. In relation to opioid use, 3,526 patients (66%) were using opioids more than two days per week and the average oral morphine equivalent daily dose (oMEDD) was 69 mg.

The average number of times NSW adult pain service patients used other healthcare services over three months is shown for patients who completed a questionnaire at referral (n=5,231), episode end (n=943), and post episode (n=586) (Figure 8). Across a series of indicators for pain services, NSW adult pain services performed at a similar level to other adult pain services in Australia and New Zealand (Figure 9).

Figure 9: Benchmark and indicator summary for NSW adult pain services and other adult pain services in Australia and New Zealand, 2018-19



Note: NSW results are based on 919 active adult patients who completed an episode outcome questionnaire and the results for other services in Australia and New Zealand are based on 4,653 active adult patients who completed an episode outcome questionnaire. Some indicators are based on a subset of these patients.

Specialist paediatric pain services in NSW

Currently there are three specialist paediatric pain services in NSW for children experiencing chronic pain.

In 2018-19, data were collected from three paediatric pain services in NSW via ePPOC and analysed by the Australian Health Services Research Institute University of Wollongong.⁸

In 2018-19, there were 365 active* patients in the three paediatric pain services and 409 new referral questionnaires completed (200 patient and 209 carer questionnaires). About 67% of active patients were female, the average age was 12 years, 41% were outside a healthy weight range, 11% were from an area of highest disadvantage (compared with 20% of the population), and 6% were Aboriginal and/or Torres Strait Islander (compared with 6% of the population).

In that year, 272 episodes of care** were started, with the median time from referral to episode start at 42 days. The average length of an episode was 268 days.

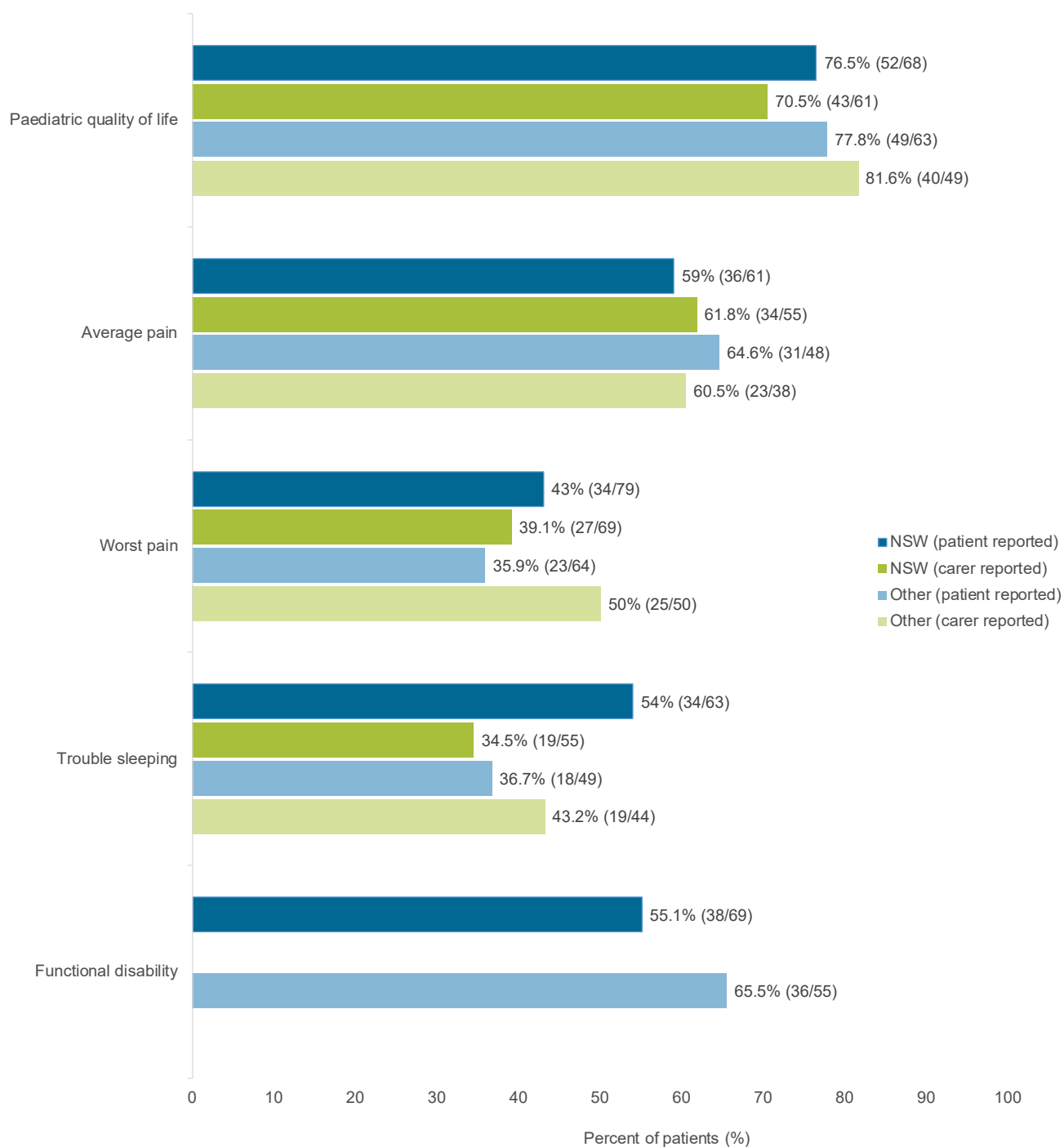
Based on the 209 completed carer referral questionnaires, 94 patients (45%) were using medication daily, 10 patients (5%) were using opioid medication daily (excluding codeine), 121 patients (58%) were experiencing pain for more than 12 months, and the average school days missed in the last two weeks was 3.4 days.

Across a series of domains, the percentage of patients making clinically significant improvements from referral to episode end in NSW paediatric pain services was similar to the percentage in the five other paediatric pain services in Australia and New Zealand (Figure 10).

*The completion of a referral questionnaire or the occurrence of a service event determines whether a patient is active. The ePPOC data does not reflect the number of referrals received by pain services in NSW during this time. For most services the number of referrals being actioned by the services is 50% more than the ePPOC data (active cases) shows and in some cases more.

**An episode of pain management begins with the first clinical contact with the patient and ends when active treatment is completed or discontinued at a pain service. In some NSW pain services the first contact will be an education session.

Figure 10: Percent of patients making clinically significant improvements from referral to episode end for NSW paediatric pain services and other paediatric pain services in Australia and New Zealand, 2018-19



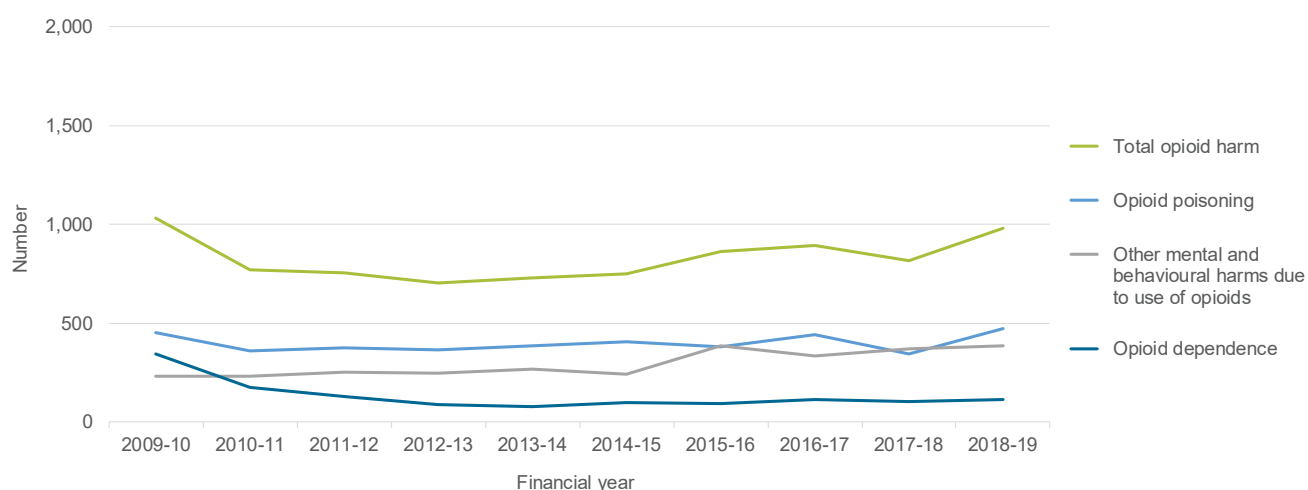
Note: Some indicators are based on a small number of patients. The numerator and denominator for each indicator are provided in the graph in brackets (numerator/denominator).

Feature topic: Opioid harm

Recent years have seen increasing concern about opioid overuse and unintentional misuse. In Australia, between 2013-14 and 2016-17, the rate of opioid medicines dispensed per 100,000 people increased 5%. Across local areas, dispensing rates varied by a factor of 5.1 in 2016-17.¹⁰

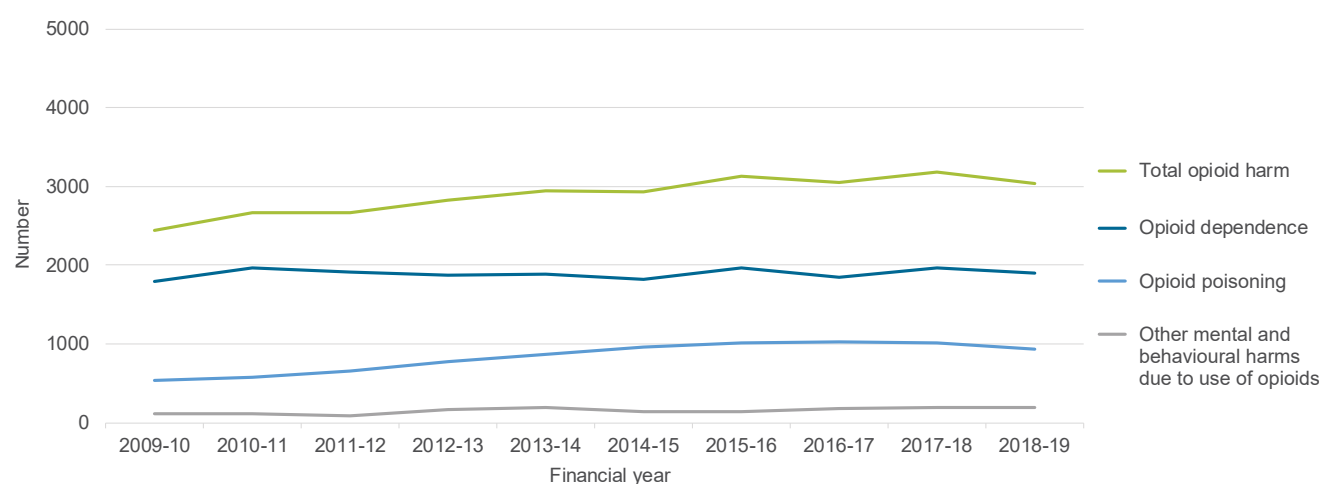
In Australia, the number of opioid deaths (drug-induced deaths that involve a mention of opioids) has increased in the 10 years from 2007 to 2016, from 2.9 to 4.7 deaths per 100,000 population (age adjusted), but was lower than a peak of 6.5 per 100,000 population (age adjusted) in 1999. In 2016, opioid deaths represented 62% of all drug-induced deaths.¹¹

Figure 11: Unplanned emergency department presentations for opioid harm, NSW 2009-10 to 2018-19



In NSW, between 2009-10 and 2018-19, the number of unplanned ED presentations for opioid harm has been reasonably stable (Figure 11), while admitted patient episodes for opioid harm increased from 2,449 to 3,039 (24%) (Figure 12). This corresponds to a population rate increase from 34 to 38 per 100,000 population (10%) and an age-sex standardised rate increase from 35 to 39 per 100,000 population (10%).

Figure 12: Admitted patient episodes with opioid harm principal diagnosis, NSW public and private hospitals, 2009-10 to 2018-19



Care delivery models

Peer reviewed literature

- Most of the studies included in this review comprised a multidisciplinary approach to group-based programs. Studies on interventional procedures, such as radiofrequency lesioning or medial branch blocks were not included.
- The populations included in the studies were heterogenous in nature, with some including quite mildly disabled cases and others more severely disabled and complex cases. The variance in case mix should be considered in the interpretation of these results.
- Additionally, there was significant heterogeneity across studies, with different levels of quality being reported in systematic reviews (some systematic reviews reported insufficient quality, some reported studies varied in scope and methodological quality and some used established methods such as GRADE). There were also wide differences in what was included in the individual pain programs, definitions of interdisciplinary care, which specialities were included in multidisciplinary teams, types of chronic pain and outcomes reported.

Key findings

- The majority of the studies reported findings from using a multidisciplinary approach comprising multimodal treatments, were on adults and delivered in a group setting.¹²⁻²⁵ Most studies included patients with chronic back pain and compared to usual care (such as medical assistance alone, i.e. unidisciplinary care).
- Overall, outcomes from systematic reviews and randomised trials found that pain programs may improve pain, function, disability and quality of life in the short-term and long-term.^{14-19, 26-44} Other outcomes reported included

fewer sick absence days, increased return to work, employability, oswestry disability index, fibromyalgia symptomatology and opioid discontinuation.^{24, 45-52} Many studies reported on the role self-management played in improving outcomes.^{22, 53-56}

- While the majority of studies showed improved outcomes, there were some studies that did not find significant differences in outcomes between groups, including pain reduction, disability score and return to work.^{21, 23, 25, 57-67} Cost-effectiveness studies were lacking.⁶⁸
- In studies looking at virtual care, both electronic and mobile health interventions were found to have had a significant effect on pain intensity, physical function and depression.⁶⁹⁻⁷⁴ In children, a Cochrane review on remotely delivered psychological therapies found reduced headache severity post-treatment, and no beneficial effect at post-treatment or follow-up, or lack of evidence to determine an effect for the remaining outcomes. Participant satisfaction with treatment was positive.⁷⁵
- In children, a systematic review showed that intensive interdisciplinary pain treatment was associated with improved disability after treatment, and small to moderate improvements in pain intensity and depressive symptoms. A randomised controlled trial found immediate effects for disability, school absence, depression, and catastrophising.^{76, 77}
- In Aboriginal and Torres Strait Islander peoples the importance of communication was a theme across multiple systematic reviews.^{78, 79}

Grey literature

- A 2011 Sax Institute review described emergent models for chronic pain management which: recognise the interaction of biological, psychological and social factors; are directed towards greater self-management; necessitate a strong community and primary care sector; are multidisciplinary; and provide specialised pain services. Synthesis of the literature indicated positive outcomes for patients are maximised when there is a prompt, appropriate and targeted care process, screening and appropriate referral, use of multimodal therapies and high intensity care processes.⁸⁰
 - The *NSW Pain Management Plan 2012-2016*, released subsequent to the *National Pain Strategy*, included a pain management model of care.⁸¹ The model of care theoretically consisted of three tiers of service: Tier 1 - primary health care; Tier 2 - specialist care services led by medical specialists; and Tier 3 - multidisciplinary pain services in teaching hospitals. The model of care was intended to enable people to transition across the continuum of care.
 - A 2015 formative evaluation of the pain management model of care in NSW, completed by O'Connell Advisory for the ACI, found:
 - an increase in the number of pain programs delivered
 - a reduction in waiting time
 - a perception by services, staff and patients that there have been improvements
 - a need to develop a communication strategy
 - high regard for the ACI Pain Management website
- Key recommendations included: use the introduction of the primary health networks (PHNs) as an opportunity to improve communication and awareness, test patients perceptions about the improvements in their care, continue to invest in and fully use the ePPOC data collection, develop mechanisms to ensure that each LHD is accountable for how funds allocated to support services, and the provision of services in NSW should be reviewed in light of the reluctance of patients to attend services outside of their local geographic area.⁸²
- A 2017 evaluation of the NSW pain management services 2012-2016 by HealthConsult for ACI found that according to ePPOC data there have been improvements in patients' health and wellbeing outcomes as a result of attending pain management clinics and a reduction in opioid use in the pain clinic population. The implementation was a baseline initiative and the progress achieved has enabled the development and extension of services across NSW. The report had 11 key recommendations including to:
 - promote the findings of the evaluation to primary care clinicians
 - explore strategies to increase the proportion of patients who attend pain clinics
 - continue to support the provision of general practitioner education to address opioid misuse
 - analyse the impact of the pain management plan in the future using ePPOC data
 - continue to work with the PHNs and profession-specific education bodies to deliver update seminars and education
 - explore the issues identified in the evaluation with health professionals
 - assess the ACI pain management website using an annual 'pop-up' survey asking users to identify themselves; and using the input provided to refine website content
 - continue to collaborate with ePPOC
 - test the surveys with a sample for future

evaluations, consider timing of patient, parent and carer surveys and make a formal data request to the Department of Human Services to obtain Pharmaceutical Benefits Scheme and Medicare Benefits Schedule data at the LHD or PHN level.⁸³

- In Australia, national action plans from 2010 and 2019 outline goals including the timely access to consumer-centred, best practice pain management, including self-management, early intervention strategies and interdisciplinary care and support.⁸⁴⁻⁸⁵
- A 2016 publication on the South Australian model, based on the NSW pain model, included three tiers for chronic pain management for low, moderate and high pain severity. The model aims to deliver a statewide referral pathway to improve access, improve integration, improve operational capacity, improve collaborative working relationships and lead to greater awareness by consumers and health professionals about chronic pain.⁸⁶
- In 2020, the World Health Organization revised the *Guidelines on the management of chronic pain in children*. Recommendations are based on systematic reviews and a diverse expert guideline development group.

Key findings included:

- Implementation requires national policies and regulations to ensure wide and equitable access to appropriate and high-quality services for children with chronic pain.
- Chronic pain management in children requires an approach that is tailored to each individual and context, and is multimodal and interdisciplinary, requiring trained healthcare providers and a coordinated, comprehensive, integrated response.
- Four recommendations were articulated for consideration alone or in combination, according to need in children with chronic pain. These recommendations covered interventions for chronic pain management and acknowledged that psychological therapy may be delivered either face-to-face or remotely or using a combined approach. The recommendations should be tailored to specific indications and conditions.
- Capacity is needed both in terms of healthcare providers and in health systems capable of delivering high-quality, recommended services. Training of healthcare providers in chronic pain management in children may need to be augmented.⁸⁷
- Painaustralia has conducted relevant consumer consultations to gather experiences of people living with chronic pain.^{85, 88} For the *National Strategic Action Plan for Pain Management (2019)*, consumers identified lengthy delays in accessing pain services, experiences of stigma, self-management and the need for people with chronic pain to be better supported and heard in their care.⁸⁴
- Painaustralia also gauged how people were impacted by the opioid reforms implemented on 1 June 2020 using an online survey. The analysis of 595 responses identified four main themes:
 - created an additional layer of complexity
 - led to a loss in function and autonomy
 - perpetrated stigma and isolation
 - significantly impacted mental health.⁸⁸

Overview of findings: Experiential evidence

The purpose of gathering experiential evidence was to identify and describe how care is organised and delivered in NSW public pain clinics, including what works in different local contexts.

Insights were gathered from five NSW pain clinics, four adult clinics and one paediatric, and one primary health network sponsored community pain management program.

All of the case studies describe the importance of either an interdisciplinary or multidisciplinary team approach. Community-based models, self-management and capacity building models were also described in some cases.

Multidisciplinary team configurations include pain specialists, anaesthetists, nurses, clinical psychologists, physiotherapists, and administration officers. Physiotherapists, nurses, clinical psychologists and access to pain specialists were consistent across case studies and considered essential to delivering quality pain services.

Treatment is often multimodal in nature, including some combination of medications, interventional procedures, and psychologically-informed pain management programs offered on an individual or group basis, with various intensity levels. Modes of delivery include face-to-face, telephone (audio) and telehealth.

One case described the importance of children and young people receiving individualised care and treatment. It was noted that group interventions can cause distress for children and young people, and the process of comparing experiences within a group can lead to stigma.

In most cases, a multidisciplinary assessment of each patient is followed by a case conference to develop an intervention plan. Case conferencing is considered a significant part of care. It is a

structured way to provide holistic and integrated care based on the person and their specific pain, needs and preferences. The importance of follow up was described in all cases.

One case described the importance of trauma-informed care.

Local innovations in building capacity to deliver pain services include:

- community-based programs for people with chronic pain from non-English speaking backgrounds
- scalable online skills training programs for community nurses, clinical psychologists, physiotherapists and doctors.

An interactive course on the key skills required to assess patients with chronic pain and to train them in pain self-management strategies was developed by the Pain Management and Research Centre at the Royal North Shore Hospital. This training was adapted to build the capacity to teach pain self-management skills to people from non-English speaking backgrounds using non-clinical health workers who speak the community languages. Initial evaluation of these programs, conducted in Newcastle, southern and western Sydney, and Wollongong, has indicated high levels of satisfaction with the programs by participants, with many achieving clinically significant changes.

Challenges include:

- lack of an effective coding system for pain to recognise the size of the problem
- higher demand for pain management services than the capacity to deliver services
- while innovations to increase capacity have been implemented across NSW; sustainability remains an issue with limited resources.

Refer to Appendix 3 of *Care delivery models for chronic pain: Appendices* for the full vignette for each case study.

**‘HIPS’ - An interdisciplinary model,
Fiona Hodson, Clinical Nurse Consultant****John Hunter Hospital, Hunter New England LHD**

The Hunter Integrated Pain Services (HIPS) provides education, multidisciplinary assessment and treatment for people 16 years and over experiencing chronic pain. HIPS is a tier three, full-time service, and the team includes nursing, physiotherapy and psychology staff, and doctors from anaesthesia, liaison psychiatry and pain medicine. Interdisciplinary assessments are conducted by a specialist pain physician and physiotherapist, psychologist or nurse.

Before the COVID-19 pandemic, group-based programs were opt-in or opt-out. This approach was challenging for some patients who could not access groups for various reasons or had complex needs, such as high psychological distress levels. In response to COVID-19 service changes group-based concepts are now delivered using an individual pathway. The one-on-one consultations and the ability to provide care using telehealth offers more flexibility to patients. Anecdotal feedback from patients shows that many patients would not have accessed the service without this level of flexibility. Following the assessment, a management plan is developed. A six week follow-up appointment is scheduled to explore engagement and determine if the person wants support with further treatment.

**Community-based chronic pain
management, Steve Brigham,
Psychologist****Far South Coast of NSW, Southern NSW LHD**

The 'Bega Valley' chronic pain management group program is only delivered twice yearly due to the availability of resources, both financial and staffing. Funding from COORDINARE, the South Eastern NSW PHN, provides a private psychologist, who has pain experience, to co-facilitate the program with a physiotherapist from South East Regional Hospital, using hospital facilities. A multidisciplinary allied health team runs the two group-based, self-management interventions for 10 participants per group. The main facilitators are the private psychologists and the LHD physiotherapist, with input from a pharmacist and an occupational therapist. The program focuses on integrating individually tailored physical activities and exercise and psychological strategies, including cognitive pain management strategies, dealing with flare-ups, coping skills, stress management, relaxation and mindfulness, improving sleep, setting goals and maintaining change.

The program is pre-designed by the Pain Management Research Centre at the University of Sydney and structured to be able to be adapted or replicated by other facilitators and delivered in a manner that is responsive to different people's needs and circumstances. Funding security is a current challenge; it is reviewed annually. The program could be strengthened if supported by a broader multidisciplinary public-based pain clinic.

Group-based interventions, Scott Swinson, Senior Physiotherapist**St George Hospital, South Eastern Sydney LHD**

The Pain Management Unit (the Unit) is integrated with the acute pain service at St George Hospital. Ward rounds are conducted and if a patient is in need of multidisciplinary support then an outpatient referral with the Unit is recommended. The Unit offers multidisciplinary assessments and individual medical specialist and allied health (psychology and physiotherapy) assessments. The multidisciplinary team includes a pain consultant, psychologists, physiotherapists, a nursing unit manager and administration officers.

Comprehensive multidisciplinary team assessments include an initial joint assessment with a pain specialist and physiotherapist, followed by a separate physical assessment and psychological assessment. The multidisciplinary team discusses the assessment and together decides on the best management approach. At the end of the assessment, feedback is provided to the patient by all parties, and appropriate appointments and referrals are made.

A high-intensity program is delivered three to four days a week over four weeks for people with more complex chronic pain-related problems. An alternative moderate-intensity program is offered two days a week over four weeks. Supplementary group sessions are also run weekly by the physiotherapists, and these include group walking and stretching, along with group sessions on strength and mindfulness.

Interdisciplinary model in a rural setting, David Beveridge, Nurse Practitioner**Lismore Base Hospital, Northern NSW LHD**

The clinic is based at Lismore Base Hospital. Up to 14 group programs are delivered remotely to people living in Tweed, Grafton, Ballina and Casino. On referral, people are provided with an educational media link with information on living with chronic pain and triaged to the most appropriate type of assessment, either a single practitioner, combined disciplines or full multidisciplinary review. Treatment is provided through group interventions, which focus on self-management, cognitive behavioural strategies and functional restoration.

Local experience suggests there are significant challenges in presenting a group-based pain program in small rural communities where everyone will know everyone else in the community. The service was quick to adapt in response to the COVID-19 pandemic and offers telehealth. The nurse practitioner role provides additional telehealth support to ensure people are comfortable using the technology and fully engaged in treatment. For example, it is essential to step through how to click the Skype invitation, turn on the microphone and camera, so patients can be fully engaged when using telehealth. Conducting assessments face-to-face is preferred, with follow up treatment then delivered virtually.

**Children's Complex Pain Service,
Susie Lord, Specialist Pain Medicine
Physician**

John Hunter Children's Hospital,
Hunter New England LHD

The Hunter New England Local Health District Children's Complex Pain Service runs clinics two days per week for children with complex pain, who are aged up to 16 years of age at referral, and who live in the Hunter, New England, Mid North Coast, or Far North Coast areas. The team includes a pain specialist, social worker, physiotherapist and clinical psychologist, and strives to deliver equitable, family-centred, trauma-informed and culturally safe care. The whole team sees children and their families for the initial in-depth assessment.

Despite having to meet a number of new people at once, feedback from children and families suggests it is worth it; they appreciate feeling deeply heard and not having to repeat their story to clinicians. Individualised therapy plans are made in collaboration with the child and family. Subsequent appointments are tailored – with different configurations of the multidisciplinary team, the child, parents or everyone. The service has been using telehealth since 2013 and this increased in response to COVID-19. The team coaches children to perform their own neuro-sensory examinations and report their findings, to supplement local doctors' examinations. Although telehealth reduces travel burden, some families prefer to meet clinicians face-to-face to develop relationships and trust; for children with significant trauma experiences this is vital.

**Capacity initiatives for pain services,
Michael Nicholas and Paul Wrigley,
ACI Pain Management Network
Co-Chairs****Statewide perspective**

Building capacity through training and focusing on organisational supports are essential to the long-term, sustainable and effective delivery of pain services. An interactive course on the key skills required to assess patients with chronic pain and to train them in pain self-management strategies was developed by the Pain Management and Research Centre at the Royal North Shore Hospital.

The online, webinar style courses have been conducted with groups of community health care providers in regional areas across the state with funding support from PHNs. This training was adapted to build the capacity to teach pain self-management skills to people from non-English speaking backgrounds using non-clinical health workers who speak the community languages. The resources have been translated into Chinese, Arabic, Greek, Italian, Vietnamese, and Macedonian. Initial evaluation of these programs, conducted in Newcastle, southern and western Sydney, and Wollongong, has found high levels of satisfaction with the programs by participants, with many achieving clinically significant changes. Ongoing support depends on local funding and resources.

Limitations

In ED data, diagnoses are recorded by medical, nursing or clerical personnel at the point of care, by keyword searching or selecting from tables of limited diagnoses. These personnel are not trained in clinical coding and there may be variation across EDs in coding practices. An analysis of ED data at Northern Sydney LHD found that a substantial number of ED presentations with a chronic pain-related presenting problem did not receive a chronic pain-related principal diagnosis. Among a sample of about 6,500 ED presentations with a chronic pain-related presenting problem, about 55% were coded with a chronic-pain related principal diagnosis code. ED presentations for chronic pain may be underestimated in this analysis, where only principal diagnosis codes were available. Northern Beaches Hospital opened in October 2018, but its data is not included in the EDDC. The impact of this on the results was small (Appendix 5, *Care delivery models for chronic pain: Appendices*).

The literature search was limited to systematic reviews and randomised controlled trials, and so recent models evaluated in observational studies not yet included in a systematic review would not be captured. To enhance the sensitivity of the search, specific care delivery models were added to the search string, but this list may not have been comprehensive. No formal critical appraisal of individual studies was undertaken. Naming of care delivery models such as multidisciplinary or interdisciplinary was done according to the terminology used in the associated paper, rather than an assessment by authors against the International Association for the Study of Pain definitions. Patients with chronic pain are not a homogeneous population, and there was much patient variability between studies.⁸⁸

Case studies or vignettes were developed about a subset (six of 18) of pain clinics. Experiential data collection was limited to one informant per site. No experiential evidence has been gathered from consumers or communities.

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Glossary

APDC	NSW Admitted Patient Data Collection
CHeReL	Centre for Health Record Linkage
EDDC	NSW Emergency Department Data Collection
ED	Emergency department
ePPOC	electronic Persistent Pain Outcomes Collaboration
HoPeD	Hospital Performance Dataset
Interdisciplinary treatment	Multimodal treatment provided by a multidisciplinary team collaborating in assessment and treatment using a shared biopsychosocial model and goals. An example is the prescription of an antidepressant by a physician alongside exercise treatment from a physiotherapist, and cognitive behavioural treatment by a psychologist. This type of treatment involves all members of the team working closely together with regular team meetings.
Integrated care	Care provided by a team, with the involvement of a supervisor or coordinator to facilitate communication across specialties and settings.
LHD	Local health district
Multidisciplinary treatment	Multimodal treatment provided by practitioners from different disciplines, such as the prescription of an antidepressant by a physician alongside exercise treatment from a physiotherapist, and cognitive behavioural treatment by a psychologist. This method of treatment involves all professions working separately with their own therapeutic aim.
Multimodal treatment	The concurrent use of separate therapeutic interventions with different mechanisms of action within one discipline aimed at different pain mechanisms, such as the use of pregabalin and opioids for pain control by a physician.
oMEDD	Oral morphine equivalent daily dose
PHN	Primary health network
Unimodal treatment	A single therapeutic intervention directed at a specific pain mechanism or pain diagnosis. For example, the application of exercise treatment by a physiotherapist, or analgesic medication prescribed by a GP.

Acknowledgements

We would like to thank the ACI Pain Network co-chairs and expert advisory group, and the external peer reviewers who provided feedback and advice.

- **Professor Deborah Schofield**
Macquarie University
- **Professor Fiona Blyth**
University of Sydney
- **Dr Malcolm Hogg**
Melbourne Health

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