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*Agency for Clinical Innovation*

*Phase 3 Evaluation of the NSW Pain Management*

*Final Draft Evaluation Report*

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**22<sup>nd</sup> February, 2017**

The evaluation of the Phase 3 PMP 2012-2016 was conducted for the NSW Agency of Clinical Innovation by HealthConsult Pty Ltd. HealthConsult would like to acknowledge the invaluable input of the Evaluation Governance Committee and the timeliness in which the advice was provided.

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## Executive Summary

On the 5<sup>th</sup> October, 2016 the Agency for Clinical Innovation (ACI) engaged HealthConsult to:

*‘conduct Phase 3 of the Evaluation of the Pain Management Plan (PMP) 2012-2016.*

### ES 1 BACKGROUND

- The NSW Government provided over \$26 million to fund the roll out of the PMP 2012-2016.
- The PMP funding recognised the need for additional resources; transformation in the way health services work together and transformation in the way health professionals and the broader community understand and deal with pain.
- The PMP supported 19 pain services across NSW with varying levels of support and funding.
- In addition the PMP provided training and workforce development to health professionals and enabled the development of a Pain Management website for clinicians and patients.

### ES 2 EVALUATION METHODOLOGY

- The evaluation of the PMP was conducted in three phases by three different organisations.
- This Phase 3 evaluation was guided by the developed ACI data plan and was designed to answer five key evaluation questions:
  - Has patients’ experience of pain management programs and services improved?
  - Have health and wellbeing outcomes improved for people living with chronic pain?
  - Are patients less reliant on opioids to manage their chronic pain?
  - How has the PMP impacted on health service utilisation, costs, efficiency and funding models?
  - How has the PMP impacted on the primary sector’s capacity and practice for managing patients with chronic pain?
- It is important to note that this Phase 3 evaluation was not designed to assess all components of the PMP (e.g. achievements of pain clinics, Work Injury Screening and Early intervention (WISE) study, comprehensiveness and/or completeness of the electronic Persistent Pain Outcomes Collaboration (ePPOC) dataset etc.) but rather focus on the above five questions.
- The phase 3 evaluation data collection included a mixed method design that involved gathering data from primary care clinicians (through interviews (n=24) and online survey (n =51)); from patients with chronic pain (n=350) and parent/carers of people with chronic pain ((n=33) through online survey); and extraction of secondary data sources (e.g. Pharmaceutical benefits Schedule (PBS), Medicare Benefits Schedule (MBS), ePPOC, Google Analytics).
- Although the evaluation data has some limitations (e.g. limited ability to disaggregate data sources such as MBS, PBS and ePPOC, low survey response to parent/carer survey) the available data enables some key findings to be drawn about the impact of the PMP.

### ES 3 EXPERIENCE OF PATIENTS WITH CHRONIC PAIN

#### *Access to pain management services*

- The current median waiting time for patients waiting to access pain management and support services, as identified through the analysis of ePPOC data, is 63 days.
- Majority of patients that responded to the evaluation survey reported to be able to access the best possible treatment and care to manage their pain.
- Qualitative data gathered through interviews with primary care clinicians found that primary care clinicians perceive that the current wait time for their patients to access pain management clinics is 12-18 months. These views are not consistent with ePPOC data which shows only 3% of patients wait greater than 12 months to attend a pain management service.

#### *Awareness of ACI website*

- The evaluation found that NSW ACI pain management website has had a steady demand based upon the number of page views. There has been rapid growth in interaction with the objects (documents, videos and so on) embedded within the website over time, which suggests users are increasingly utilising the resources.

#### *Information available to patients to help manage their pain*

- Majority of patients that responded to the evaluation survey reported being able to find information to help manage their pain (> 50%) and to understand the information given to them to help manage their pain (> 85%).
- Majority of patients (> 68%) that responded to the evaluation survey, that are currently or had previously been attending a pain clinic reported that the information provided to them was useful.

#### *Techniques being used by patients to manage their own pain*

- The evaluation found that the most common techniques patients reported to use to self-manage their pain included keeping physically active (>70%) and using complementary medicine (>70%) followed by (>60%) participating in relaxation/meditation activities, attending support groups and/or going to physical therapy. Using over the counter (OTC) medication attracted the lowest response rate (about 10%).

### ES 4 EXPERIENCES OF TREATMENT/SUPPORT FROM PAIN CLINICS

- The evaluation found that the main source of referral to pain clinics is from their GP followed by other doctors/health professionals including their Specialist (who may have been a neurologist, neurosurgeon, orthopaedic surgeon, pain specialist or paediatrician).
- The evaluation found that the most common type of treatment/support received from pain clinics by patients was “medications”. The least common treatment/support received from pain clinics by patients was “spinal cord stimulator implant”.
- The evaluation found that a larger proportion of non-metropolitan based patients (63%) reported that the treatment/support received from the pain clinics was useful compared to metropolitan based patients (52%).
- The evaluation found that patients attending pain clinics felt they could have more meaningful conversations with their service providers compared to people that had never attended pain clinics.

## **ES 5 CHANGES IN CHARACTERISTICS OF PATIENTS' PAIN SYMPTOMS**

- The evaluation found that for patients that had attended pain clinics, there has been:
  - a small shift from referral to episode end with NSW patients reporting more periods without pain or more variable pain;
  - an overall reduction in the number of pain regions reported by NSW patients between referral and episode end; and
  - improvements in pain severity ratings and interference subscales based on the BPI scale from referral to end of episode.

## **ES 6 IMPACT ON PATIENTS WELLBEING**

- The evaluation found, that for patients attending the pain clinics, there have been improvements in depression, anxiety and stress levels for NSW patients between referral to end of episode. Overall greater than 45% of patients with moderate or worse depression, anxiety and/or stress at referral made clinically important improvements.
- The evaluation also found that there have been consistent improvements in responsibility and control of pain from patients attending the pain clinics. Specifically 60% of patients with high or worse catastrophising pain at referral made clinically significant improvement and 56% of patients with at least moderate impairment in pain self-efficacy at referral made clinically significant improvement.

## **ES 7 IMPACT ON PATIENTS DAILY TASKS**

- The evaluation found that, for patients attending NSW pain clinics there have been:
  - improvements in employment and/or study status between referral and episode end; and
  - improvements in PSEQ scores (i.e. higher PSEQ scores are strongly associated with clinically significant functional levels) between referral and episode end.
- The evaluation also found, that for those patients that responded to the evaluation survey, that compared to six months ago they understand their pain better and have more skills to manage their own pain.

## **ES 8 IMPACT ON USE OF OPIOIDS TO MANAGE CHRONIC PAIN**

- The evaluation found that for those people that have attended NSW pain clinics, there has been a 36.2% reduction in patients using opioids more than 2 days per week; and a 42.2% reduction in average daily morphine equivalent dose for patients taking opioid medication.
- In contrast, the evaluation also found that the oral Morphine Equivalent milligrams per script has increased across NSW as has the total supply of opioids. This indicates an increase in per capita use of opioids outside the pain clinic population.

## ES 9 IMPACT OF PMP ON HEALTH SERVICES

- The evaluation found that the number of times patients who attended NSW pain clinics have used a health service (including seeing a GP or allied health professional, attending an emergency department etc.) in the prior 3 months has decreased.
- Analysis of MBS data shows that the number of MBS claims for case conferences; pain medicine attendances; and neurosurgical pain relief has increased between 2007 and 2015.
- Whether a reduction in health service use and cost is resulting in the same, worse or better patient outcomes is unknown. An increase in pain medicine attendances alongside a reduction in general health service utilisation may suggest appropriate and growing use of pain management services which is resulting in enhanced use of pain self-management skills and a reduction in demand for other health services. This hypothesis would need further examination to confirm it as true.

## ES 10 IMPACT OF PMP ON PRIMARY CARE SECTOR

### *Awareness of chronic pain management information sources by primary health professionals*

- The evaluation found that both the primary clinician interviews and survey suggest that primary care clinicians obtain information about chronic pain from continuing professional development activities, publications and colleagues. However through interviews with primary care clinicians we found that non-GPs are more likely to make direct contact with the pain clinics compared to GPs.
- The evaluation found that less than a third of surveyed and/or interviewed GPs were aware of the National Pain Strategy; NSW PMP and/or ACI Pain Management website. However at least 50% of non-GPs were aware of these strategies and the ACI website.
- As the evaluation found that GPs were largely unaware of the ACI Pain Management website, a large proportion reported not using it. Whereas non-GP clinicians were more aware of the ACI website (>70%), and used the website for their information and some provided the URL to patients.
- The evaluation found that the majority (>70%) of primary care clinicians surveyed and/or interviewed have attended pain management updates over the preceding three years and the majority of them are also interested in receiving pain management updates.

### *Satisfaction of primary care clinicians with support provided from pain clinics*

- The evaluation found that the most common support received by primary care clinicians from pain management clinics has been “assessment and management within the pain clinic, with letters”.
- The evaluation found that the majority of primary care clinicians that have received support from pain management clinics have reported that the support has been useful. However a theme identified from the GP interviews suggested that although pain clinics are a useful source of support they experience difficulty in accessing the service for their patients.

### *Understanding of best practice pain management approaches by primary care clinicians*

- The evaluation found that both GPs and non-GPs rated their current understanding of chronic pain management strategies as competent.
- The evaluation found that the most common change reported by primary care clinicians about how their understanding of managing chronic pain had changed over the last few years included an improved understanding of the effective use of multidisciplinary teams and incorporation of pain education and cognitive approaches.

### *Pain management strategies used by primary care clinicians*

- Primary care clinicians reported that the most *effective* chronic pain management strategies for patients living with pain was maintaining a healthy weight (>78%); participating in psychology sessions (>66%) and participating in relaxation activities (>65%). The most *ineffective* management strategy reported was “taking nutritional or dietary supplements” (>78%).
- The evaluation found that other approaches used by primary care clinicians that they considered to be effective in supporting people living with chronic pain included: cognitive and education approaches; reduced reliance on pharmaceuticals and alcohol; listening to patients; exercise; continuity of services; goal setting; and pet therapy.
- Overall, the evaluation found that the pain management strategies being used by primary care clinicians were broadly consistent with the recommendations of the International Association for the Study of Pain and NSW PMP recommendations for managing chronic pain in a primary care setting.

## ES 11 CONCLUSION

- The evaluation concludes that the ePPOC data shows that there have been improvements in patients’ health and wellbeing outcomes as a result of attending pain management clinics. Specifically, the data shows that these patients have had improvements in reduced pain frequency; pain in fewer regions; improvements in pain severity ratings and interference subscales; improvements in their depression, anxiety and stress levels and in their ability to undertake daily tasks.
- The evaluation concludes that the ePPOC data shows that there has been a reduction in opioid use in the pain clinic population. However the PBS data (whole of NSW population data) shows an increase in oral Morphine Equivalent Daily Dose (oMEDD). Together this suggests that the increase in opioid prescriptions is driven by an increase in opioid prescriptions outside the NSW pain services.
- The evaluation concludes that the PMP has provided funding to establish a comprehensive pain outcomes dataset ePPOC. ePPOC provides a benchmarking method of assessing the quality of services and patient outcomes achieved by the NSW pain services. There should be continued support and funding of ePPOC to enable the continued achievements of the NSW pain services to be measured and reported, and used to study any future changes/enhancements of the pain services.
- Overall, the implementation of the PMP 2012-2016 should be seen as a baseline initiative aimed at improving access to pain management clinics for people suffering with chronic pain and in the provision of support to health professionals managing people suffering from chronic pain. Such an initiative should be continued to build on the significant achievements in the patient population accessing the pain services.
- The evaluation concludes that the progress achieved by the PMP 2012-2016 has enabled the development and extension of multidisciplinary pain services across NSW which are beginning to have an impact on patients with increased access to these services. The next phase of the PMP should be focused on supporting these services, providing education and support to primary care clinicians and continuing to monitor the established routine data collection and reporting on the ongoing achievements of the PMP.

## Recommendations

- R1:** We recommend that the key findings from the evaluation are promoted to primary care clinicians so that they become more aware of the impact the PMP has had on improving access to pain management services, as well as the improvements achieved in patients' wellbeing through attendance at these services.
- R2:** As pain clinics have been shown to be able to reduce opioid use in individuals who have undergone treatment, increasing the proportion of patients who attend pain clinics is likely to reduce opioid use in NSW. Therefore strategies to increase numbers of patients attending pain clinics should be explored, noting there will be resource implications to be considered. In addition, if a decision is made to increase the resourcing of pain clinics, we recommend investigation into whether existing clinics are best placed to deliver the additional services or whether new clinics need to be established.
- R3:** We recommend that the ACI continue to support the provision of GP education to address opioid misuse and educate them further on non-medication strategies for managing patients suffering from chronic pain.
- R4:** Future analysis of the impact of the PMP on health services should be done using annual ePPOC data. The analysis should be done at multiple levels including State, LHD and clinic levels. Appropriate comparators should then be used at each level to enable an assessment of the impact of PMP where different service and/or funding models are being used.
- R5:** We recommend that the ACI continue to work with the PHNs and/or profession-specific education bodies (e.g. RACGP; Australian Physiotherapy Association) to deliver pain management update seminars/chronic pain management education that is promoted and available to primary care clinicians. In particular, we recommend exploring the best ways to increase GP awareness of the National Pain Strategy, NSW PMP and resources available on the NSW ACI website.
- R6:** In order to further understand the challenges being experienced by primary care clinicians in supporting their patients who suffer from chronic pain, we recommend the ACI explore the issues identified in the evaluation with health professionals working in primary, secondary and tertiary services that support patients with chronic pain. Such exploration would examine the dynamics of the relationships, the referral patterns, opiate misuse, and access to pain clinics. This information could then be analysed to identify barriers and enablers which could be used to ensure that primary, secondary and tertiary health services are working together to better support each other and those suffering with chronic pain.
- R7:** In order to have a greater capacity to understand the types of users accessing the information and resources on the ACI Pain Management website, we recommend that an annual 'pop-up' survey is conducted asking users to identify themselves by a short selection of categories (e.g. person suffering from chronic pain, parent/carer of a person suffering from chronic pain etc.). In addition, as a means of understanding what aspects of the website could be enhanced, ACI could conduct a more

comprehensive survey annually to understand which features of the website users like, what they don't and what information they feel is missing.

- R8:** We recommend that the ACI continue their collaboration with ePPOC and work with the University of Wollongong and pain clinic services to enable subsequent analysis of the data to be at a more disaggregate level in future evaluations of the PMP.
- R9:** Future evaluations of the PMP that involve both patient and parent/carer surveys should ensure dissemination does not happen concurrently to minimise confusion of the survey responders. We suggest separate dissemination and stronger differentiation between patient and parent/carer surveys during future evaluations of the PMP.
- R10:** For future evaluations of the PMP that involve target population surveys, we recommend including testing of the survey with a sample (e.g. n=3 is sufficient) of the intended target audience in advance of survey release as an aid to decreasing the dropout rates.
- R11:** For future evaluations of the PMP, we recommend a formal data request is made to the Department of Human Services to obtain PBS and MBS data at the LHD or PHN level, annually from 2012, by opiates. Such analysis, for example, may identify areas that need targeted education and/or show reduction in opiate prescription rates following a targeted education intervention.

On the 5<sup>th</sup> October, 2016 the Agency for Clinical Innovation (ACI) engaged HealthConsult to:

*‘conduct Phase 3 of the Evaluation of the Pain Management Plan 2012-2016.*

## 1.1 BACKGROUND

The NSW Government provided over \$26 million to fund the roll out of the four-year Pain Management Plan (PMP) 2012-2016, which recognised the need for additional resources; transformation in the way health services work together and transformation in the way health professionals and the broader community understand and deal with pain. The PMP supported 19 pain services that can be divided into four sub groups including:

- Tier 2 Services - Funded and Supported;
- Tier 2 Services - Supported only services;
- Tier 3 Services - Supporting services; and
- Tier 3 Services - Non-Supporting services.

PMP provided training and workforce development to Tier 2 and 3 health professionals as well as professional development opportunities to Tier 1 primary health care workers in the regions covered by the 19 pain services. The Pain Management Network also developed a Pain Management website which includes a variety of information and resources for both clinicians and patients.

## 1.2 EVALUATION PHASES

The logic model of the PMP informed the development of a three-phase evaluation process. Phases 1 (evaluating the initial implementation of the new funds 2012-2013) and 2 (formative evaluation 2013-2014) are complete. The Phase 3 evaluation (this report) was guided by the developed data plan and was designed to answer five key evaluation questions:

- Has patients’ experience of pain management programs and services improved?
- Have health and wellbeing outcomes improved for people living with chronic pain?
- Are patients less reliant on opioids to manage their chronic pain?
- How has the PMP impacted on health service utilisation, costs, efficiency and funding models?
- How has the PMP impacted on the primary sector’s capacity and practice for managing patients with chronic pain?

## 1.3 PROJECT METHODOLOGY

The methodology used by HealthConsult to evaluate the PMP involved five stages as set out below:

- (1) **Detailed project planning:** We met with the ACI Project Team to receive an initial briefing and finalise the parameters for the project including communication process, stakeholders to be consulted, consultative process to be used, identification of data and information sources, and the target dates for subsequent meetings. This information was included in the project plan, which was provided to the Project Manager on 21<sup>st</sup> October, 2016.

- (2) **Documentation and tools review:** We reviewed the program and prior evaluations documentation and the tools developed to support the Phase 3 evaluation. Working with the Project Manager we amended the tools and built them onto an online survey platform ready for distribution to the target populations.
- (3) **Gather phase 3 evaluation information and data:** We distributed email invites which included links to the three surveys (patient, carer/parent, primary health care clinician surveys) through the networks of the selected pain management clinics on the 5<sup>th</sup> November, 2016. Paper copies of the carer/parent and patient surveys were placed in the waiting rooms of the five pain management clinics (selected by ACI). In addition a link to the carers/parents and patient surveys was also uploaded onto Chronic Pain Australia and Pain Australia's websites and also emailed to their distribution list. We also conducted telephone interviews with 5-6 primary health care clinicians per selected pain management clinic. The evaluation data collection was completed by 12<sup>th</sup> December, 2016.
- (4) **Analyse gathered information and data:** Using the provided ACI data plan as the blueprint (with agreed modifications) we analysed the gathered evaluation information and data according to the specification. Consistent with the data plan, the data analysis utilised all relevant data sources to provide answers to each of the five overarching evaluation questions.
- (5) **Preparation of draft and final report:** We then draw on the evaluation data analysis to produce the draft evaluation report which was provided to the Project Manager on the 16<sup>th</sup> January, 2017 for review and comment. The report was then distributed to the Evaluation Governance Committee for review prior to attending an evaluation review workshop to discuss the draft findings on the 10<sup>th</sup> February, 2017. Taking on board comments from the stakeholders at the workshops, we amended the draft evaluation report and produced the final draft evaluation report. This report was provided for final comment on 16<sup>th</sup> February, 2017. Comments received by 22<sup>nd</sup> February have been incorporated into the Final Evaluation Report (this document).

### 1.4 STRUCTURE OF THIS REPORT

This document presents the draft evaluation report for the Phase 3 evaluation of the PMP 2012-2016. The structure of the remainder of the report is:

- **Chapter 2:** presents an overview of the NSW PMP 2012-2016;
- **Chapter 3:** presents a description of the evaluation data collected and used in the consideration of our evaluation findings;
- **Chapter 4:** presents our analysis of the impact of the PMP on patient experience;
- **Chapter 5:** presents our analysis of the impact of the PMP on health and wellbeing outcomes;
- **Chapter 6:** presents our analysis of the impact of the PMP on opioid use by chronic pain sufferers;
- **Chapter 7:** presents our analysis of the impact of the PMP on health services;
- **Chapter 8:** presents our analysis of the of the PMP on primary health care sector;
- **Chapter 9:** presents our conclusions and recommendations.

This Chapter provides an overview of the NSW PMP 2012-2016 Initiative including its aims and objectives and how it was implemented in each LHD.

## 2.1 DEVELOPMENT OF THE PMP

The NSW PMP 2012-2016 was a response to the 2010 Australian National Pain Strategy, the 2010 International Pain Summit's prioritisation of education and training in pain management for all healthcare professionals, and the 2012 NSW Pain Management Taskforce's Report.

The NSW Pain Management Taskforce Report was directed at driving a cohesive, consistent, state-wide approach to pain management and identifying areas for potential future development. The Report identified the need for more research in the field of chronic pain and its management, and key system components recognised internationally as requirements for better pain management services. These components included the redesign of health services to enable integration across stepped levels of care; workforce development and education; multidisciplinary care at all levels; and public health initiatives to encourage early intervention and the understanding of chronic pain.

## 2.2 FUNDING DEDICATED TO THE PMP

In response to the Taskforces Report, in 2012-2013 the NSW Government allocated an additional \$26 million over four years to implement the PMP. This funding was directed at:

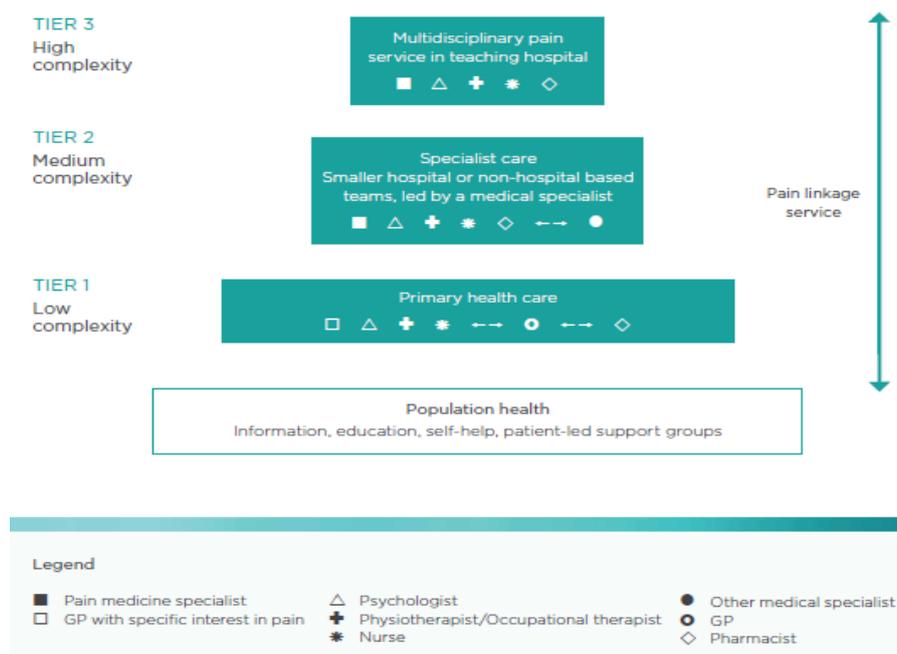
- (1) enhanced funding for community and acute based chronic pain services to support implementation of the proposed model of care for chronic pain services across NSW;
- (2) additional resourcing for chronic pain research;
- (3) greater investment in training, education and workforce development; and
- (4) greater consistency of pain services across NSW to reduce clinical variation.

The aim of the funding was to develop a consistent approach to pain management across NSW. This approach was aimed at addressing all elements of a patient's wellbeing, aimed at achieving effective and lasting pain management. New state-wide tools and resources have been developed to assist with clinical consistency including referral forms, a service directory and patient information flyers which is available on the ACI Pain Management Network website.

## 2.3 IMPLEMENTATION OF THE PMP

As part of the PMP 2012-2014 a tiered service model was introduced to better target pain services to individual patient needs as depicted in Figure 2.1. Tier 1 services are provided by GPs and other primary health care professionals. Tier 2 services are offered through smaller hospitals and non-hospital based pain management teams led by a specialist. Tier 3 services are provided by major teaching hospitals, led by a pain medicine specialist and accredited by the Faculty of Pain Medicine. Funding was also allocated to the Pain Management Research Institute at Royal North Shore Hospital to enhance its role as the leader and coordinator of pain research and training across NSW.

Figure 2.1: Proposed model of care implemented under the NSW PMP 2012-2016



Source: NSW Health (2013). NSW Pain Management Plan 2012-2016 – The Government’s Response to the NSW Pain Management Plan (p4)

Four new Tier 2 pain services were established in regional NSW at Port Macquarie, Orange, Tamworth and John Hunter Children’s Hospital. Chronic pain services were previously not available in these areas. The existing Tier 2 service at Lismore was also enhanced and Port Kembla’s service area was extended to Shoalhaven.

The ACI’s Pain Management Network website was designed to help patients gain a better understanding of their pain and contains information and practical resources to assist them to self-manage their pain in partnership with their healthcare provider. The website includes an online program targeted specifically at young people affected by chronic pain as well as tools for doctors and other healthcare professionals working in the community.

An electronic Persistent Pain Outcomes Collaboration (ePPOC) was established in partnership with the Australian Health Services Research Institute at the University of Wollongong. This collaboration allows NSW Health to collect and compare data between NSW pain services (de-identified) to help improve service delivery and inform future research projects.

Specialist pain services employed over 70 additional allied health, nursing, administrative and support staff. Primary care clinicians have been able to access face-to-face and online education in pain management through partnerships between the Pain Management Research Institute and primary care organisations.

Between 2014 and 2016 the ACI Pain Management Network continued to work towards providing improved access to pain management services for all NSW residents. During this period key focus areas included:

- (1) the appointment of five pain fellows;
- (2) work with primary care organisations to trial community education programs on pain management;
- (3) research into reducing opioid use across NSW; and

<sup>1</sup> <http://www.health.nsw.gov.au/PainManagement/Publications/nsw-pain-management-plan.pdf>

- (4) workshops with specialist pain services to identify the essential elements of high performing clinics.

## Evaluation data collection

This Chapter describes the evaluation data collection process and the data used to support the Phase 3 evaluation of the PMP 2012-2016. It is important to note that each table and/or figure is sourced underneath with the data source used to prepare the analysis throughout the document.

### 3.1 PHARMACEUTICAL BENEFITS SCHEME DATA

The Pharmaceutical Benefits Scheme (PBS) provides listings of the medicines subsidised by the Australian government. Access to the PBS data was publicly available. We analysed selected pain related PBS item numbers associated with chronic pain related opioid and non-opioid analgesics for the date range 2007 -2015. We analysed annual calendar year date for NSW as a single state. Disaggregated PBS data by primary health organisation (GP Division, Medicare Local or Primary Health Network) was unavailable for the selected item numbers.

### 3.2 MEDICARE BENEFITS SCHEDULE DATA

The Medicare Benefits Schedule (MBS) provides listings of the Medicare services subsidised by the Australian government. Access to the MBS data was publicly available. We analysed selected pain related MBS item numbers associated with chronic pain related professional attendances and therapeutic procedures for the date range 2007 - 2015. We analysed annual calendar year date for NSW as a single state. Disaggregated MBS data by primary health organisation (GP Division, Medicare Local or Primary Health Network) was unavailable for the selected item numbers.

### 3.3 ELECTRONIC PERSISTENT PAIN OUTCOMES COLLABORATION DATA

The electronic Persistent Pain Outcomes Collaboration (ePPOC) is a research program based at the University of Wollongong that was established as part of the PMP 2012-2016. The ePPOC initiative involves the collection of a standard set of data items and assessment tools by specialist pain services throughout Australia and New Zealand to measure outcomes for their patients as a result of treatment. It is important to note that the ePPOC data relates to a subpopulation of people with chronic pain in NSW that are receiving treatment from specialist pain management services. The ePPOC data will, in time, be used to develop a national benchmarking system for the pain sector, which will lead to better outcomes and best practice interventions for patients in chronic pain. We were provided with analysis of selected indicators from the ePPOC database for patients attending a NSW pain clinic in the period 2013-2016 as per the provided ACI Data Plan. Paediatric data has not been included due to the lack of episode level outcomes at this stage.

### 3.4 ACI GOOGLE ANALYTICS DATA

Google Analytics is an internet analytics service offered by Google that tracks and reports traffic on a specific website. Google Analytics provides internet site administrators with insights into how visitors find and use a specific internet site. We analysed selected Google Analytics indicators for ACI defined

segment filters for Chronic Pain, For Everyone, Heath Professionals, PainBytes and Spinal Cord Injury Pain segments. We analysed data for the date range 2013 to 2016 as per the provided ACI Data Plan.

### 3.5 PRIMARY CARE CLINICIAN INTERVIEWS

We conducted telephone interviews with primary care clinicians associated with the following clinics: Lismore, Orange, St Vincent's, Children's Hospital Westmead; John Hunter Hospital and the North Sydney Persistent Pain and Mental Health Network. In total, 24 primary care clinician interviews were conducted across the five sites. Table 3.1 shows the disciplines of the interviewed primary care clinicians which included: two paediatricians, eight GPs, 10 allied health practitioners (physiotherapists, occupational therapists, psychologists and osteopaths), and four nurses. We segmented the analysis of health professionals into GPs and non-GPs. Although majority of clinicians were nominated by representatives from the five selected pain management clinics, some were recruited by referral from interviewed clinicians.

**Table 3.1: Discipline of clinicians that were interviewed as part of the Phase 3 evaluation**

Location	Paediatrician	GP	Allied health	Nurses	Total number of responses
Lismore	-	2	1	-	3
Orange	-	4	2	1	7
St Vincent's	-	2	3	-	5
John Hunter	-	-	3	3	6
North Sydney	-	-	1	-	1
Westmead Children's	2	-	-	-	2
<b>Total</b>	<b>2</b>	<b>8</b>	<b>10</b>	<b>4</b>	<b>24</b>

Source: PMP Clinician Interviews 2016

### 3.6 SURVEYS OF TARGET POPULATIONS

Surveys were distributed to primary care clinicians with an interest in chronic pain, people living with chronic pain, and the parents/carers of people living with chronic pain. Patients and parents/carers were recruited through ACI networks and affiliated organisations (through email distribution lists of Pain Australia and Chronic Pain Australia and were also uploaded for access on their websites) as well as through attendance at the selected pain management clinics. In addition, where patient contact emails were available at the pain clinics, patients and parents/carers surveys were distributed via an email invite with a link to the online survey. Primary care clinician surveys were distributed through ACI networks, pain clinic networks and through PHN (primary health network) clinician newsletters.

Table 3.2 shows that the total number of survey responses received was: 350 patient surveys, 52 carer surveys, and 51 clinician surveys. Survey responses were designated to pain clinic catchment areas. There were 140 of 434 number of survey respondents who did not provide clinic details. Further, 32 respondents were attending private clinics or clinics outside NSW. Nine clinicians did not provide their location.

**Table 3.2: Total number of survey responses by survey type by location**

Location	Clinicians	Patients	Parents and carers	Total no. of responses
Lismore	1	9	10	20
Orange	8	17	1	26
St Vincent's	21	63		84
John Hunter	12	61	2	75
North Sydney		42	3	45
Westmead Children's		7	5	12
Private and non-NSW		22	1	32
No clinic listed	9	129	11	140
<b>Total</b>	<b>51</b>	<b>350</b>	<b>33</b>	<b>434</b>

Source: Patient PMP survey 2016, Clinician PMP Survey 2016 and Parent/Carer Survey 2016. Clinician's clinic catchment area based upon postcode of services delivered. Patient and carer clinic catchment area based upon responses to current and previous clinic attendance. No clinic includes non-responses (including partially filled surveys) and non-attenders.

Although in total we received 350 valid patient responses. There were 30 respondents that dropped out by Question 6 (how long have you lived with chronic pain?) and a further 33 respondents dropped out by Question 13 (are you attending a chronic pain clinic?). Respondents completing partial survey are included in our analysis if that question was answered. Of the 350 patient respondents, 286 respondents completed the survey in full.

### 3.6.1 Profile of patient survey respondents

Table 3.3 describes the age profile of the patient survey respondents. Review of Table 3.3 shows that majority of survey respondents were aged between 50-69 years of age (69%) and there was little difference based on clinic attendance status. The age profile of respondents was also found to be equally distributed across metropolitan and non-metropolitan areas (data not shown).

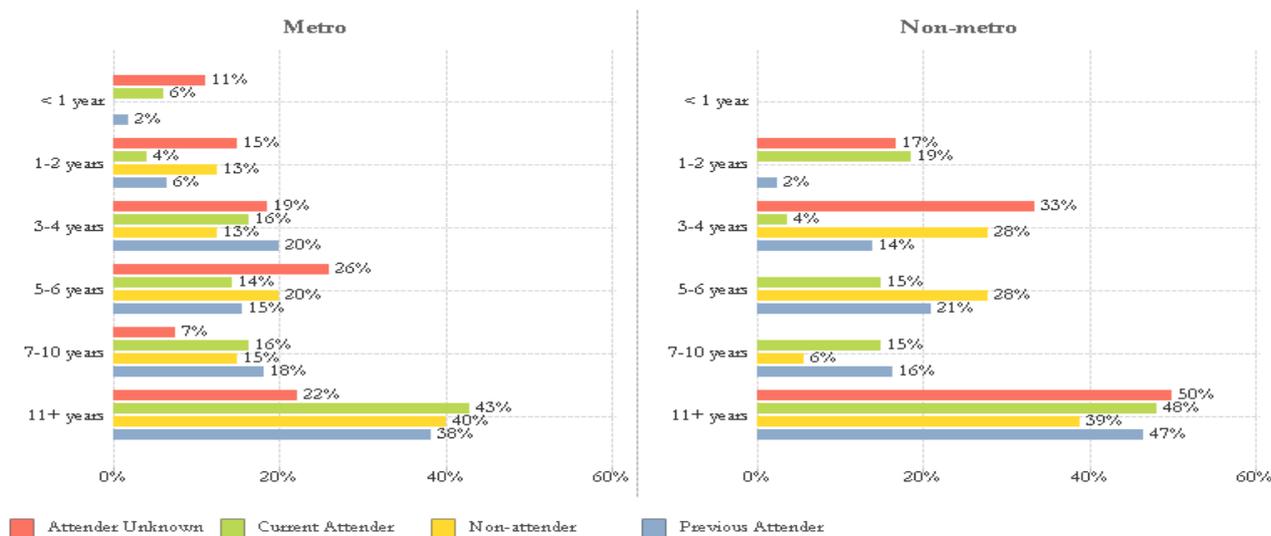
**Table 3.3: Patient survey responses by age and clinic attendance status**

Age	Attender Unknown		Current Attender		Never Attended (non-attender)		Previous Attender	
	N	% of total	n	% of total	n	% of total	n	% of total
19 or younger	1	2%	2	3%			4	3%
20-29	3	5%	3	4%	2	3%	6	4%
30-39	6	10%	2	3%	10	17%	11	7%
40-49	10	16%	10	13%	13	22%	33	22%
50-59	11	17%	30	39%	15	26%	42	27%
60-69	15	24%	20	26%	11	19%	31	20%
70-79	6	10%	8	11%	6	10%	20	13%
80 or over	1	2%	1	1%	1	2%	6	4%
No response	10	16%						
<b>Total</b>	<b>63</b>	<b>100%</b>	<b>76</b>	<b>100%</b>	<b>58</b>	<b>100%</b>	<b>153</b>	<b>100%</b>

Source: Patient PMP survey 2016

Figure 3.1 shows that majority of patient survey respondents reported they had lived with chronic pain for seven years or more. This finding was consistent across both metropolitan and non-metropolitan areas, with similar rates reported for each of these geographical categories. A higher proportion of individuals who were current or previous clinic attenders reported living with pain for seven years or more compared to non-clinic attenders.

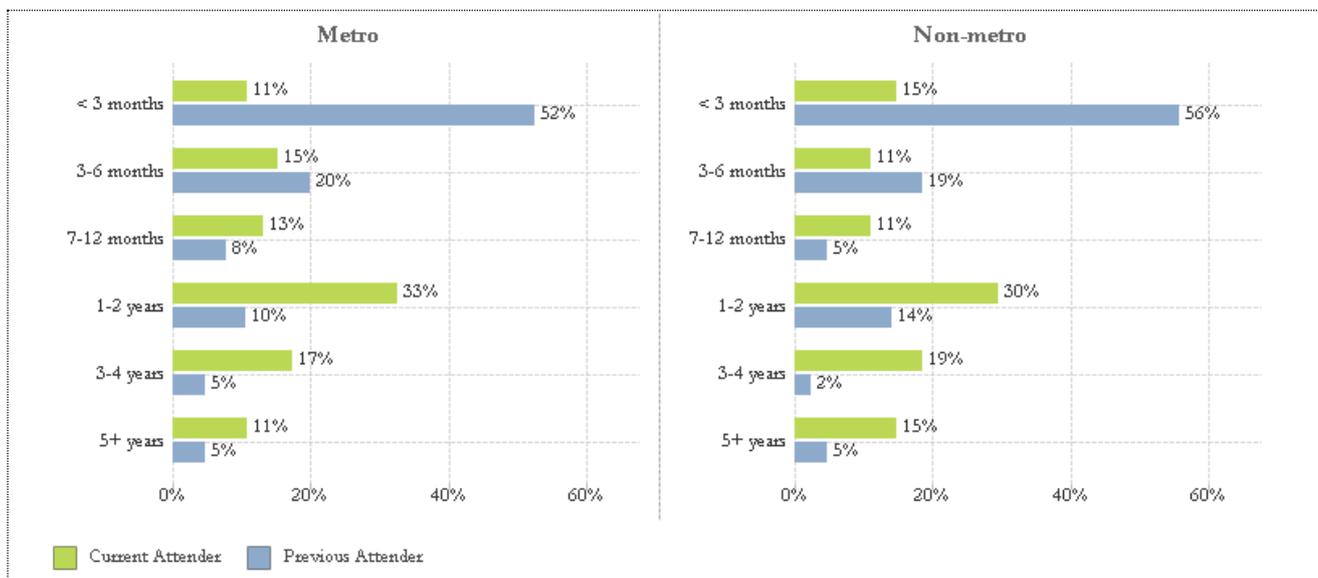
Figure 3.1: Length of time patients living with pain



Source: Patient PMP survey 2016. Metropolitan patient N = 226, Non-metropolitan patient N = 94.

Figure 3.2 shows that most current clinic attenders had been attending a pain clinic for 1 year or more. By contrast, most previous clinic attenders had attended a pain clinic for three months or less. It is important to note that the survey did not differentiate between a single treatment episode and multiple treatment episodes. Further, the length of self-reported current treatment extends beyond the term of most pain clinic treatment terms.

Figure 3.2: Length of time patients have been attending a chronic pain clinic



Source: Patient PMP survey 2016. Metropolitan patient N = 151, non-metropolitan patient N = 70

Due to the dissemination method of the patient survey, a range of people suffering from chronic pain in NSW responded, not only those attending pain clinics. Table 3.4 shows the distribution of those that had attended a pain clinic by location. Table 3.3 shows that 66% of survey respondents either currently attended or had previously attended a NSW pain clinic. Another 18% of respondents did not report whether they were currently, or had previously attended, a pain clinic. Only about half of these respondents answered the subsequent questions (approximately N=23 metropolitan based and N = 6 for non-metropolitan based patients). Due to the low number of non-metropolitan based patients responding to the survey, they have not been included in the analysis presented in Chapters 4 onwards. There was a different profile of responses from clinic non-attenders, where the response numbers

where reasonable for later questions and therefore the data has been presented in Chapter 4 onwards (e.g. minimum N=40 metropolitan based and N = 18 for non-metropolitan based patients).

**Table 3.4: Profile of patient survey responses by attendance at a pain clinic**

Attendance Status	Number	% of total
Attender Unknown	63	18%
Current Clinic Attender	76	22%
Never attended (non-attender)	58	16%
Previous Attender	153	44%
<b>Total</b>	<b>350</b>	<b>100.00%</b>

Source: Patient PMP survey 2016

### 3.6.2 Profile of parent/carer survey respondents

Table 3.5 shows the age profile of the parents/carers that responded to the parent/carer survey. The analysis shows that most parents/carers in both metropolitan and non-metropolitan areas were aged over 50 years. In total, there were 21 valid responses from parents and carers across metropolitan and non-metropolitan areas. Given these small numbers, the results from the parent/carer survey should be interpreted with caution.

**Table 3.5: Parent/carer survey responses by age and region**

Age	Metropolitan	Non- Metropolitan	Total
20-29	-	7%	3%
30-39	5%	-	3%
40-49	32%	21%	27%
50-59	47%	-	27%
60-69	16%	43%	27%
70-79	-	14%	6%
80 or over	-	14%	6%
<b>Total</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>

Source: Parent/Carer PMP survey 2016.

Table 3.6 shows that the age of person being cared for by the responding parents/carers were aged under 60 years in both metropolitan and non-metropolitan areas. In metropolitan areas 53% of people being cared for were aged less than 29 years of age. By contrast, in non-metropolitan areas this was 14%.

**Table 3.6: Age of patient being cared for by parent/carer survey respondents by region**

Age	Metropolitan	Non-Metropolitan	Total
15-19	37%	-	21%
20-29	16%	14%	15%
30-39	5%	-	3%
40-49	5%	14%	9%
50-59	5%	29%	15%
60-69	11%	14%	12%
70-79	5%	14%	9%
80 or over	11%	7%	9%
No response	5%	7%	6%
<b>Total</b>	<b>100%</b>	<b>100%</b>	<b>100%</b>

### 3.6.3 Profile of clinician survey respondents

Table 3.7 presents the discipline of the clinician survey respondents by pain clinic. The analysis shows that most clinician survey respondents were GPs (45%) followed by allied health professionals (24%) which included a mix of physiotherapists, psychologists, pharmacists and occupational therapists.

**Table 3.7: Profile of disciplines of primary care clinicians**

Location	Specialist	GP	Allied health	Nurses	Other	Total number of responses
Lismore			1			1
Orange		3	3	2		8
St Vincent's	4	10	5	1	1	21
John Hunter	1	9		1	1	12
No clinic listed	1	1	3	3	1	9
<b>Total</b>	<b>6</b>	<b>23</b>	<b>12</b>	<b>7</b>	<b>3</b>	<b>51</b>

Source: Clinician PMP survey 2016

## 3.7 LIMITATIONS OF THE EVALUATION DATA

Through implementing the phase 3 evaluation we have identified the following limitation with the data used in the phase 3 evaluation:

- The google analytics data is limited by the inability to know whether it was people suffering from chronic pain using the website; parents/carers of people with chronic pain or others.
- The ePPOC data, although a very rich source, was not provided at the patient level or at clinic level due to the volume of currently available data and clinic identification issues; therefore analysis was limited to a NSW population level analysis.
- There are limitations in the use of, and interpretation of the survey data. Firstly there is no comparator data pre the implementation of PMP to compare the survey results to. Secondly, surveying patients, parents/carers and clinician from only five pain management clinics may not be representative of the views of patients, parents/carers and clinicians across NSW. Therefore the analysis present from the surveys and interviews should be considered informative rather than conclusive.
- Dissemination strategy of the surveys was restricted to five pain management clinics. This impacted on the number of responses. In particular the number of survey responses for the parent/carer surveys was too low to draw any findings from. However, due to the additional interviews with clinicians, we felt that the clinician survey data was robust enough to include as it represented similar findings to that of the qualitative interviews.
- Publicly available PBS and MBS data could not be disaggregated below the level of NSW state. Although not a specific limitation for this evaluation (as ePPOC data was provided in an aggregate level); this may limit more comprehensive analysis in future evaluations of the PMP.

## Impact on patient experience

This Chapter presents information gathered to support the assessment of the impact of the PMP on patients' experience of pain management services including access to services, experience of attending pain clinics and pre-assessment education programs. In addition this Chapter presents findings more broadly in regards to ability of patients to find and understand information to help manage their pain, the types of techniques they use to self-manage their pain. Where appropriate the analysis compares survey responses of individuals who have previously or are currently attending a pain clinic with those that have never attended a pain clinic. Also, although, no data from the parent/carer survey has been included (due to the low number of survey responses), some analysis has been provided in Appendix C.

### 4.1 ACCESS TO PAIN MANAGEMENT SERVICES

We examined ePPOC data to determine the impact of the PMP on waiting times. The provided ePPOC data suggests that the current average (mean) number of days for accessing pain management services in NSW is 96 days, with the median being 63 days<sup>2</sup>. Further, this waiting time does not vary by episode start mode, that is the median number of days to episode start is 63 regardless of whether the episode started with a single or multidisciplinary assessment, or 'treatment start' (which is generally an education/orientation program).

Unfortunately a time series analysis was not possible. The ePPOC indicators are derived from services that commenced data contributions to ePPOC at different times between 2013 and 2016. The currently available waiting list data represents the mean waiting time recorded in the current ePPOC dataset.

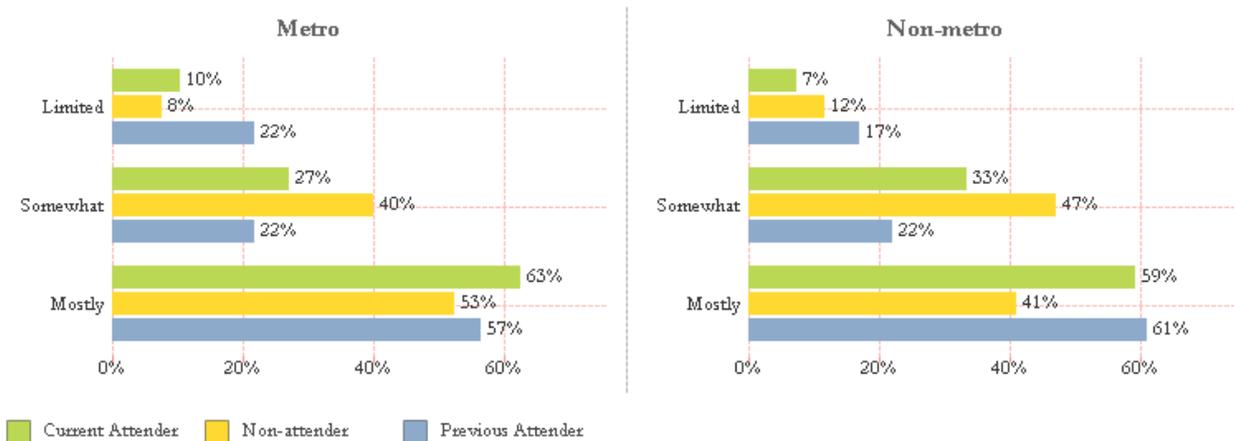
**F1: The current median waiting time for patients waiting to access pain management and support services, as identified through the analysis of ePPOC data, is 63 days.**

The evaluation patient survey asked patients "are you able to access services to help you manage your pain". Figure 4.1 shows that patients in both non-metropolitan and metropolitan areas reported similar access to services to help manage their pain, with majority reporting (>78%) that they can 'somewhat' to 'mostly' access services to help them manage their pain.

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<sup>2</sup> The median scores are likely more accurate than the mean as it doesn't take outliers into account to the same degree as the average score.

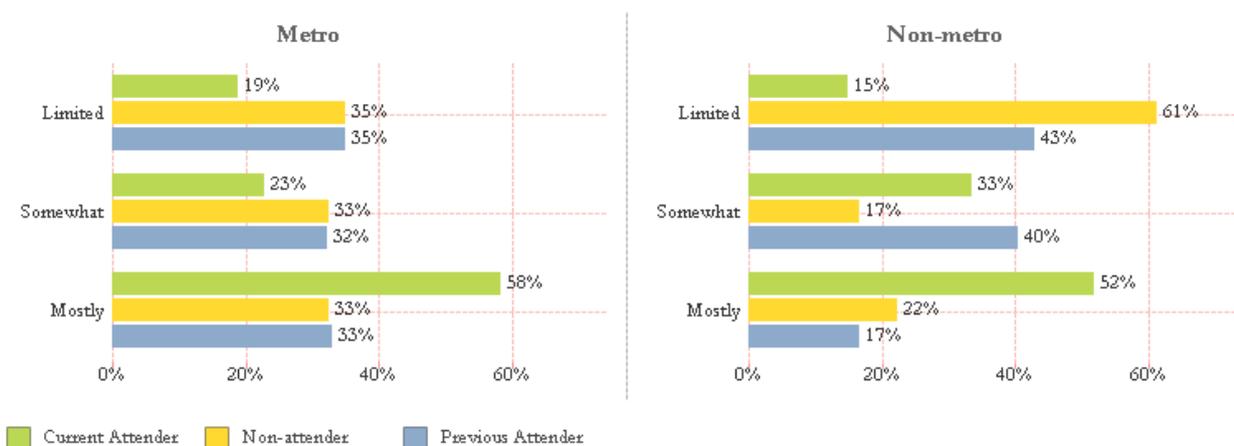
**Figure 4.1: Extent to which patients report being able to access services to help manage their pain**



Source: Patient PMP survey 2016. Scale = 0 “not at all” to 10 “completely” where 0-3 = limited; 4-7= “somewhat” and 8-10 = “mostly”. Metropolitan patient N = 194, Non-metropolitan patient N = 85. Note that the red coloured bar (“attender unknown”) describes patients who did not provide their clinic attendance status in their survey responses.

The evaluation patient survey also asked patients “do you believe you can access the best possible treatment and care”. Figure 4.2 shows that current pain clinic attenders in metropolitan (81%) and non-metropolitan (85%) areas reported they were “mostly” to “somewhat” likely to access the best possible treatment and care compared to previous clinic attenders (65% for metropolitan patients and 57% for non-metropolitan patients).

**Figure 4.2: Extent to which patients believe they can access the best possible treatment and care**



Source: Patient PMP survey 2016. Scale = 0 “not at all” to 10 “completely” where 0-3 = limited; 4-7= “somewhat” and 8-10 = “mostly”. Metropolitan patient N = 197, non-metropolitan patient N = 87. Note that the red coloured bar (“attender unknown”) describes patients who did not provide their clinic attendance status in their survey responses.

**F2: Majority of patients that responded to the evaluation survey reported to be able to ‘somewhat’ to ‘mostly’ access the best possible treatment and care to manage their pain.**

Through qualitative interviews with primary care clinicians, the perception was that the wait time for pain clinics is between 12-18 months. However the ePPOC data shows that only 3% of patients have waited greater than 12 months. In fact most pain clinics assess the patients within 30 days of receiving a referral in order to assist in triage of patients on the waitlist.

**F3: Qualitative data gathered through interviews with primary care clinicians found that primary care clinicians perceive that the current wait time for their patients to access pain management clinics is 12-18 months. This is not consistent with the ePPOC data.**

## 4.2 DISTANCES PATIENTS ARE TRAVELLING TO ACCESS SERVICES

In order to assess the distances that patients are travelling to access chronic pain management services, ePPOC data was examined to determine the mean distance travelled for patients attending each NSW Pain Clinic. Data for 16 facilities were included for the period covering 2013 to 2016. The data examined the travel distances of 7,704 patients at 12 metropolitan facilities and 3,176 patients at four rural facilities. Due to the limited disaggregation and de-identification of individual sites, ePPOC data was unable to provide additional insights into distances travelled by individual patients.

Analysis of the data showed that the mean travel distance by patients to metropolitan pain clinics was 35.5 kilometres and 84.7 km for patients travelling to non-metropolitan pain clinics. This data shows that patients attending non-metropolitan pain clinics travel, on average, 49.2km more than patients attending metropolitan pain clinics.

**F4: The mean distance travelled by patients to metropolitan pain clinics is 35.5 kilometres and 84.7 km for patients travelling to non-metropolitan pain clinics.**

There was no available comparison data to explore whether travelled distance had changed as a result of the implementation of the PMP. However, funding available under the PMP was used, in 2015, to conduct a six month pilot study evaluating the use of telehealth as a modality for chronic pain management. The pilot was conducted at two of the NSW chronic pain clinics; the Children’s Hospital Westmead and Orange Hospital (OHS). The two hospitals agreed to participate believing that telehealth would assist them to improve access to specialist multidisciplinary services for their patients who lived in rural and remote NSW. More particularly, they sought to provide improved support to the clinicians who manage these patients in the community. The data shown in Table 4.1 is extracted from the pilot evaluation report<sup>3</sup> and shows that as a result of the telehealth pilot, there was an overall 9,180 km saved by patients participating in telehealth. In addition, 83% of clinicians reported that the desired outcome was achieved using the telehealth modality and 100% of patients reported that they were happy to continue to receive telehealth services.

**Table 4.1: Key metrics recorded for the pilot from July 2015-December 2015**

Site	Total number of km saved	% of sessions achieving desired outcome (clinician rated)	% of patients who reported they were happy to continue to receive telehealth
OHS	5,834	83	100
CHW	3,346	75	100
<b>Total</b>	<b>9,180</b>	<b>83</b>	<b>100</b>

Source: ACI (2015) Chronic Pain Telehealth Pilot Project. Evaluation Report 2016

**F5: Through use of telehealth services funded through the PMP across two pain clinic pilot sites, patients were shown to save 9,180 km travelled, through use of an alternative medium to access pain services.**

## 4.3 AWARENESS OF, AND ACCESS TO RESOURCES ON ACI WEBSITE

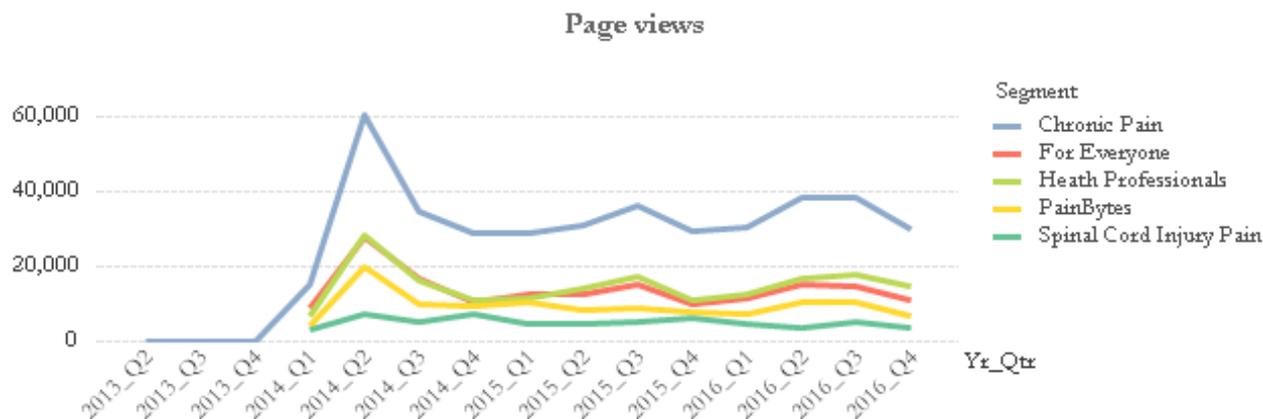
The NSW ACI’s pain management website was launched on 25<sup>th</sup> March 2014. The website is designed so different segments of the website are targeted at different populations: “for everyone”; “for youth: PainBytes”; “spinal cord injury pain” and “health professionals”.

<sup>3</sup> ACI (2015) Chronic Pain Telehealth Pilot Project. Evaluation Report 2016

Through analysis of data extracted from Google Analytics, there appears to be a steady demand on the NSW ACI website based upon the number of page views. Although it is not possible to determine the proportion of visitors to the ACI pain website that suffer from pain conditions, nor are we able to determine the proportion of the pain sufferers in NSW that use the website resource, the website set up enables analysis to be done by the segments.

Figure 4.3 shows that after a brief testing phase (occurring mostly between Quarter 4 2013 and Quarter 2 2014), the ACI Chronic Pain website has been accessed relatively steadily since Quarter 3 2014, growing from 34,729 page views in Quarter 3 2014 to 38,352 page views in Quarter 3 2016 equating to an increase of 3,623 page views per month or 10.4%.

Figure 4.3: Google Analytics – page views by quarter



Source: <https://analytics.google.com/analytics/web/#report/defaultid/a29487920w55624762p56644284/>

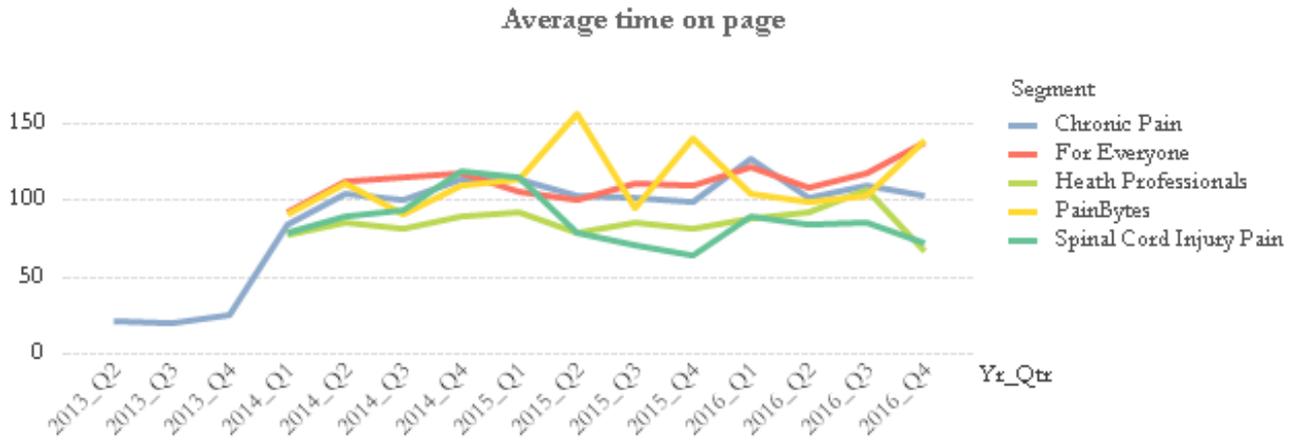
Visual inspection of Figure 4.3 shows that “Chronic Pain” (which measures visitors to the main site and all of its pages collectively) spiked at launch with every one of the individual segments recording their highest quarterly page views within the launch window.

As we were not able to access total chronic pain patient numbers, we are unable to draw any conclusions about the growth in site usage versus the population of ‘pain’ patients in NSW. Neither is it feasible to understand the proportion of NSW pain sufferers making use of the NSW ACI’s pain management website resources. However, assuming that general population growth in NSW is a reasonable proxy we might expect a growth rate of around 5.5% driven by population increases, the growth in the ACI pain management website (as measured by ‘page views’) of 10.4% has demonstrated a significantly higher growth rate.

Figure 4.4 shows the average time on page has fluctuated a little over time within a relatively narrow range of between 86 and 111 seconds with a mean of 103 seconds. The Health Professionals and Spinal Cord Injury Pain segments attract the shortest average time on pages with 87 and 88 seconds respectively.

<sup>4</sup> Data was downloaded by week for the period November 2013 to December 2016 and aggregated by quarter from the Google analytics utility. We applied ACI defined segment filters for Chronic Pain, For Everyone, Heath Professionals, PainBytes and Spinal Cord Injury Pain segments per the definitions available at: Chronic Pain [<https://analytics.google.com/analytics/web/template?uid=Ij3xswdMQ6aBFz6AU3Um-Q>]; PainBytes [<https://analytics.google.com/analytics/web/template?uid=fgR7ltVFRMO6efkadBuHow>]; For Everyone [<https://analytics.google.com/analytics/web/template?uid=ygevQgwmRB-wrYTj5jO-IA>]; Health Professionals [<https://analytics.google.com/analytics/web/template?uid=yA2kmArkRuqu4c4iWwOqdw>]; and Spinal Pain Figure 4. Error! Main Document Only.: Google [[https://analytics.google.com/analytics/web/template?uid=ga0xyj56T7m\]QcwgxWF3VQ](https://analytics.google.com/analytics/web/template?uid=ga0xyj56T7m]QcwgxWF3VQ)]

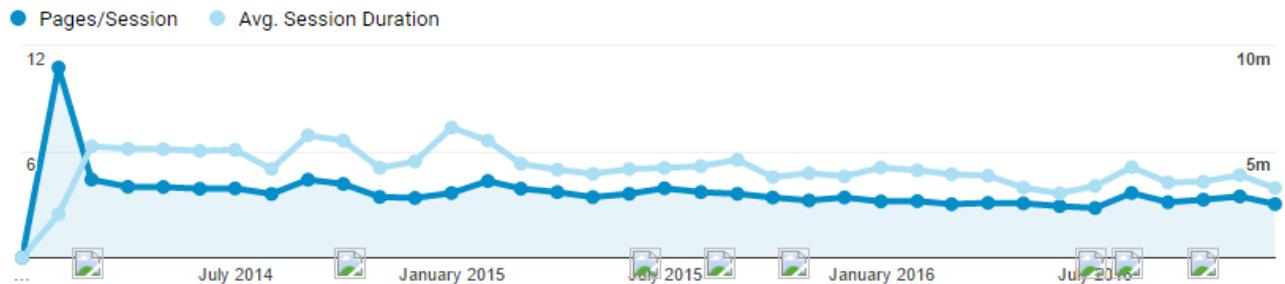
Figure 4.4: Google Analytics – average time on page by quarter



Source <https://analytics.google.com/analytics/web/#report/defaultid/a29487920w55624762p56644284/>

To help put these figures in context and better understand how visitors are engaging with the ACI pain management website, Figure 4.5 examines ‘sessions’. Sessions record a visitors’ interaction with the website from when they first land on a page to when they leave. Figure 4.5 presents the average session duration and the average number of pages visited during a session. In April 2014, the average session duration was 5 minutes and 8 seconds and the average pages per session was four, both of these metrics have been trending downwards. For example, in November 2016 the average session duration was 3 minutes and 54 seconds and the average pages per session was 3.47. This translates to 1 minute and 21 seconds less time per session and approximately 0.53 fewer pages visited during the session. It is not possible to say what exactly is driving these changes but improvements in website design, improved navigation and increased user familiarity will likely contribute to shorter and more focused visits. Most patient related segments have experienced overall moderate increases in average time on page which may suggest user utility is increasing.

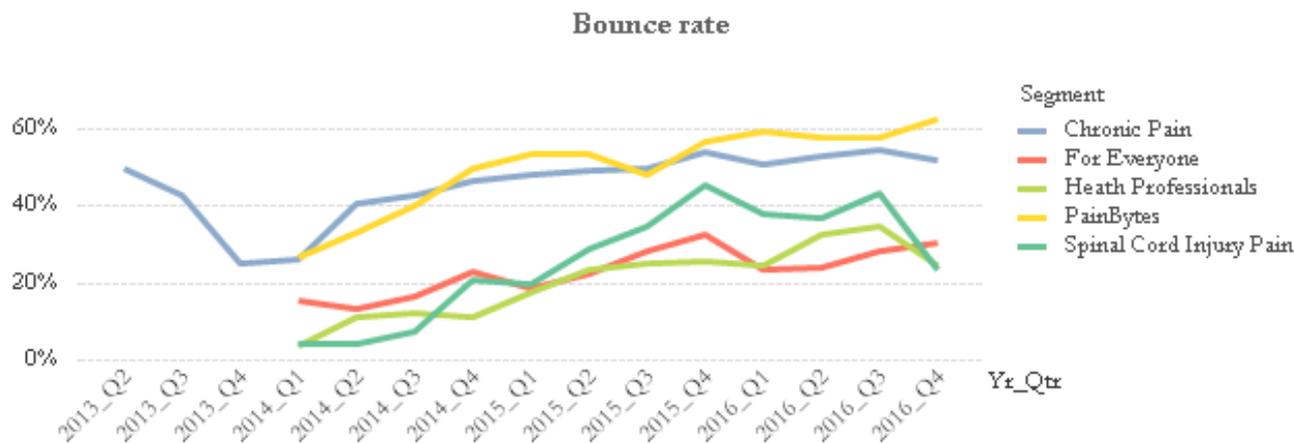
Figure 4.5: Google Analytics – average session duration and pages per session



Source <https://analytics.google.com/analytics/web/#report/defaultid/a29487920w55624762p56644284/>

Figure 4.6 examines bounce rates which shows, as a percentage of visits to the NSW ACI website, how many terminate after visiting the first page. Analysis of the data shows that bounce rates have increased over the period for all segments. A drop in Quarter 4 2016 for the Chronic Pain, Spinal Cord Injury Pain and Health Professionals Segment was noted.

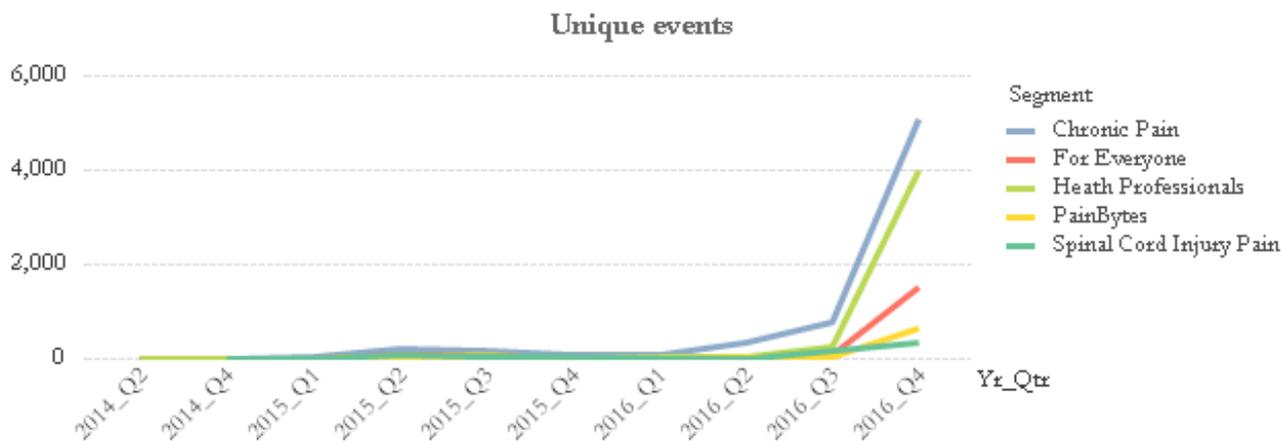
Figure 4.6: Google Analytics – bounce rate by quarter



Source <https://analytics.google.com/analytics/web/#report/defaultid/a29487920w55624762p56644284/>

The way in which Google Analytics measures unique events such as downloading documents and watching videos embedded with the ACI website changed in Quarter 4 2016. Figure 4.6 consequently ought not to be interpreted as a sudden jump in object interaction, this is not the case. However, the volumes of interactions captured in Quarter 4 2016 suggests that users are utilising the resources made available to them. Specifically, 11,633 unique events were recorded for Quarter 4 2016 (as at 14<sup>th</sup> December, 2016).

Figure 4.7: Google Analytics – unique events by quarter



Source <https://analytics.google.com/analytics/web/#report/defaultid/a29487920w55624762p56644284/>

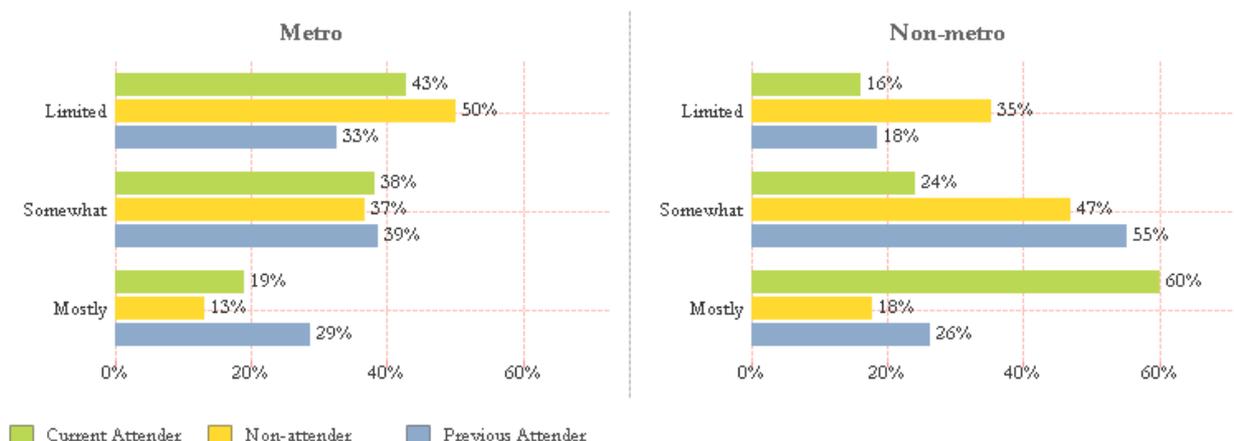
We analysed data about the individual consumption of video content on the ACI pain management website between March 2014 and December 2016. In that period more than 42,000 videos have been played and nearly 15,000 of those were watched to the end (refer to Appendix A for the analysis).

**F6: The NSW ACI pain management website has had a steady demand based upon the number of page views. The average time on page has fluctuated over time within a relatively narrow range between 86 and 111 seconds with a mean of 103 seconds, average session duration has dropped from 5:08 minutes to 3:54 minutes. Users regularly download videos and documents from the site with 11,633 events recorded in Quarter 4 2016 and more than 42,000 videos played between site launch in March 2014 and October 2016. All this data suggests users are increasingly utilising the resources.**

#### 4.4 ABILITY TO FIND INFORMATION TO HELP MANAGE THEIR PAIN

The evaluation patient survey asked patients whether they can find information about how to help manage their chronic pain. Figure 4.8 shows that for patients living in non-metropolitan areas, across all patient groups (i.e. individuals currently attending pain clinics; those that had previously attended a pain clinic; and those that had never attended a pain clinic), were consistently more likely to report being able to ‘somewhat’ or ‘mostly’ find information to help manage their pain compared to patients living in metropolitan areas. Overall, patients reported to be able to find information to help manage their pain.

Figure 4.8: Extent to which patients report being able to find information to help manage their pain



Source: patient PMP survey 2016. Scale = 0 “not at all” to 10 “completely” where 0-3 = limited; 4-7= “somewhat” and 8-10 = “mostly”. Metropolitan patient N = 181, Non-metropolitan patient N = 80. Note that the red coloured bar (“attender unknown”) describes patients who did not provide their clinic attendance status in their survey responses.

No data for parents/carers caring for people with chronic pain is included due to a limited number of responses (n=5 for patients ≤ 19 and n = 22 for patients > 20).

**F7: Majority (> 50%) of patients that responded to the evaluation survey reported being able to find information to help manage their pain.**

The evaluation patient survey asked patients ‘at which of these services have you sought help to manage your pain?’. Respondents could select more than one source but were required to identify whether sourcing this information was within the last six months and/or ever.

Table 4.2 shows that for those patients living in metropolitan and non-metropolitan areas, the most common services where they have sourced help in the last six month is from their GP (88%, 87%), their Specialist (68%, 53%) and their Physical Therapist (59%, 49%). When analysing what services they had sourced for help ‘ever’, the spread of services sought was more wide spread for both metropolitan and non- non-metropolitan patients.

Table 4.2: Information sources people suffering from chronic pain have sought for help

Services sought for help	Metropolitan patients				Non-metropolitan patients			
	Ever		In last 6 months		Ever		In last 6 months	
	n	% of Total	n	% of Total	n	% of Total	n	% of Total
ACI Pain Management Network website	45	35%	27	14%	9	16%	10	12%
Other pain websites	37	29%	48	26%	16	29%	16	19%
Pain Clinic (in hospital)	61	48%	62	33%	24	43%	23	28%
Complementary therapist	61	48%	47	25%	17	30%	21	25%
General Practitioner	34	27%	164	88%	11	20%	72	87%
Hospital	47	37%	52	28%	16	29%	18	22%

Services sought for help	Metropolitan patients				Non-metropolitan patients			
	Ever		In last 6 months		Ever		In last 6 months	
	n	% of Total	n	% of Total	n	% of Total	n	% of Total
Information sessions	47	37%	23	12%	16	29%	5	6%
Nutritionist/Dietician	44	34%	25	13%	20	36%	8	10%
Other	30	23%	16	9%	10	18%	5	6%
Physical therapist	46	36%	110	59%	28	50%	41	49%
Private Pain Clinic (not in a hospital)	52	41%	39	21%	17	30%	11	13%
Psychologist/Counsellor	49	38%	65	35%	25	45%	20	24%
Specialist	61	48%	128	68%	27	48%	44	53%
<b>Total</b>	<b>128</b>	<b>100%</b>	<b>187</b>	<b>100%</b>	<b>56</b>	<b>100%</b>	<b>83</b>	<b>100%</b>

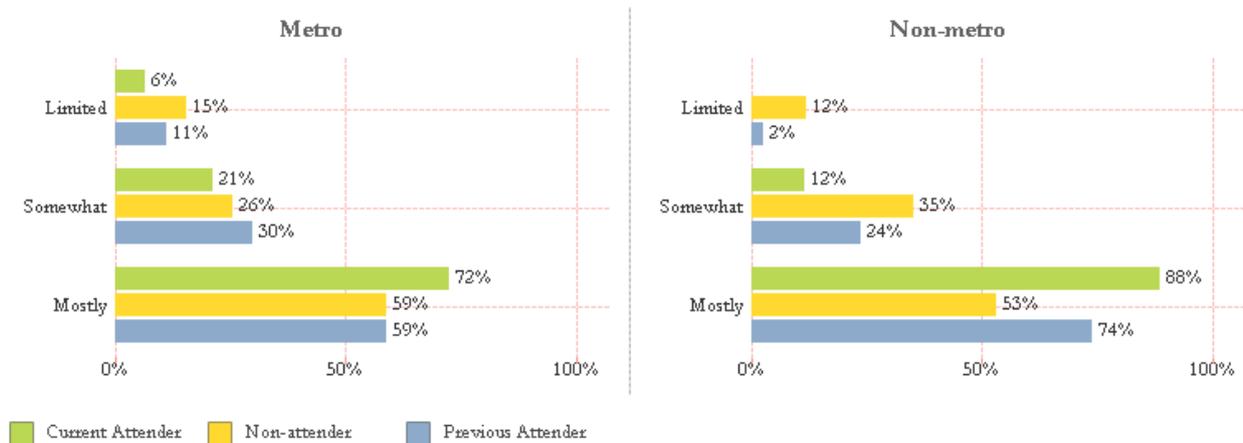
Source: Patient PMP survey 2016. Metropolitan patient N = 187, Non-metropolitan patient N = 83. Other pain websites = Australian Pain Management Association, Pain Australia and/or Chronic Pain Australia websites

**F8: The most common services where metropolitan and non-metropolitan patients, respectively, have sourced help in the last six month is from their GP (88%, 87%), their Specialist (68%, 53%) and their Physical Therapist (59%, 49%).**

#### 4.5 ABILITY TO UNDERSTAND THE INFORMATION GIVEN TO THEM

The evaluation patient survey asked patients “do you understand the information you have been given about your pain?” Figure 4.9 shows that patients in non-metropolitan areas were consistently more likely to report ‘mostly’ being able to understand the information given to them compared to metropolitan patients.

Figure 4.9: Extent to which patients report being able to understand the information given to them



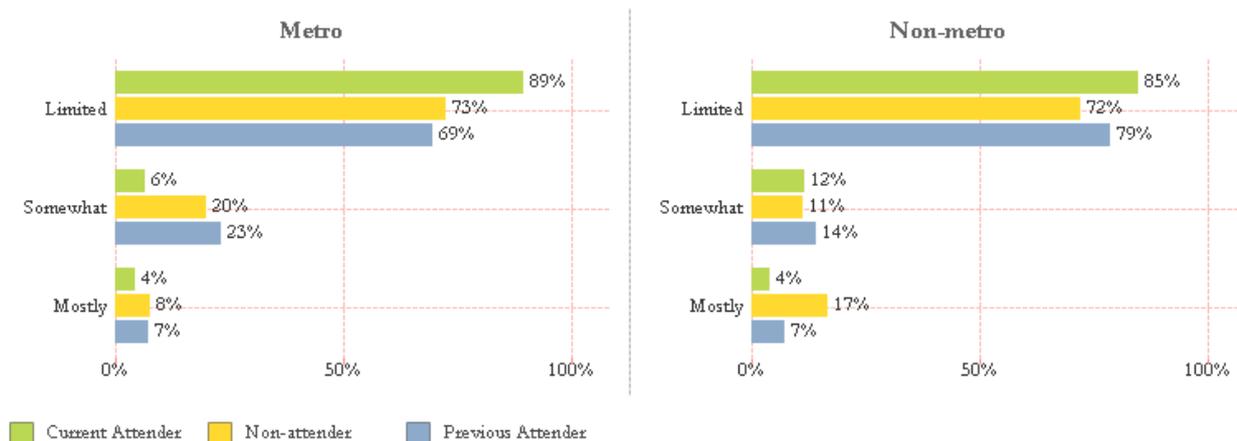
Source: Patient PMP survey 2016. Scale = 0 “not at all” to 10 “completely” where 0-3 = limited; 4-7= “somewhat” and 8-10 = “mostly”. Metropolitan patient N = 193, non-metropolitan patient N = 85. Note that the red coloured bar (“attender unknown”) describes patients who did not provide their clinic attendance status in their survey responses.

**F9: Majority (> 85%) of patients that responded to the evaluation survey reported to be able to understand the information given to them to help manage their pain.**

#### 4.6 SELF-MANAGEMENT OF PAIN WITHOUT MEDICATION

Patients were asked in the evaluation survey, to what extent they feel they can manage their pain without pain medication. Figure 4.10 shows that the majority of patients in both metropolitan (>67%) and non-metropolitan areas (>72%) reported that they could **not** manage their pain without pain medication. For those attending or previously attending pain clinics, this likely reflects one of the main reasons for referral to a specialist pain service for assessment and management.

Figure 4.10: Extent to which patients feel they can manage their pain without medication



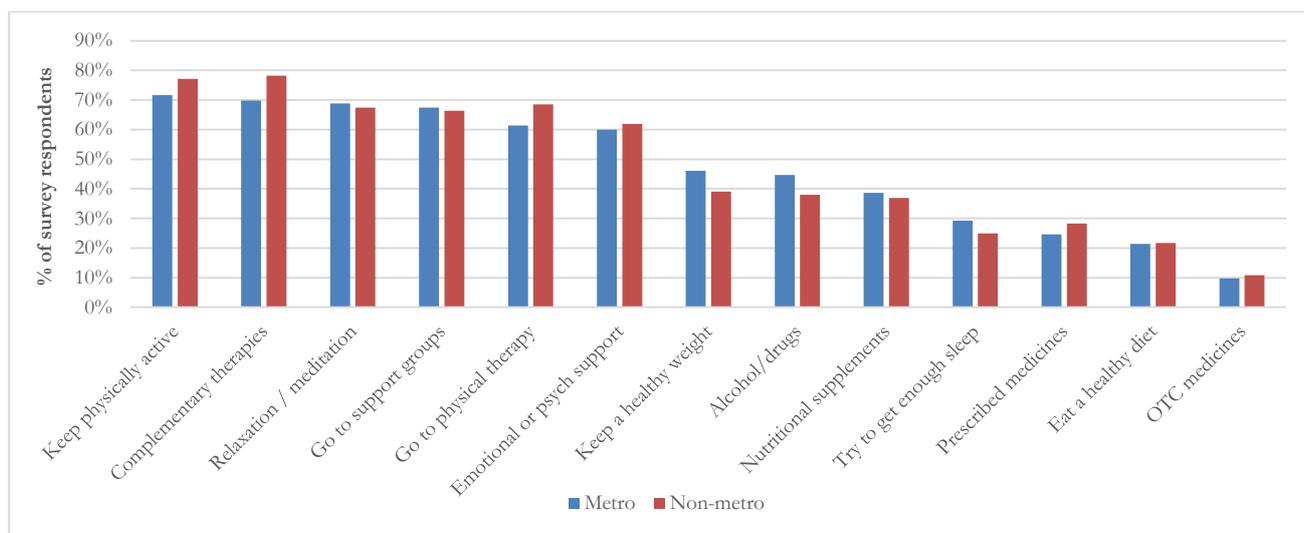
Source: Patient PMP survey 2016. Scale = 0 “not at all” to 10 “completely” where 0-3 = limited; 4-7= “somewhat” and 8-10 = “mostly”. Metropolitan patient N = 195, non-metropolitan patient N = 86. Note that the red coloured bar (“attender unknown”) describes patients who did not provide their clinic attendance status in their survey responses.

**F10: Majority of patients with chronic pain that responded to the evaluation survey, regardless of geographic location, report being unable to manage their chronic pain without medication. For those attending or previously attending pain clinics, this likely reflects one of the main reasons for referral to a specialist pain service for assessment and management.**

#### 4.7 TECHNIQUES PATIENTS USE TO MANAGE THEIR OWN PAIN

Figure 4.11 presents the patient survey results in relation to the question about what techniques they use to self-manage their pain. Respondents selected from 13 self-management pain techniques. Figure 4.11 shows that amongst the 13 listed self-management pain techniques there was no difference in the response rate based on location of patient. The most common techniques (>70%) used by patients to self-manage their pain included keeping physically active and using complementary medicine followed by (>60%) relaxation/meditation, attending support groups and/or going to physical therapy. Over the counter (OTC) medication attracted the lowest response rate (about 10%).

Figure 4.11: Patient self-administered pain management modalities

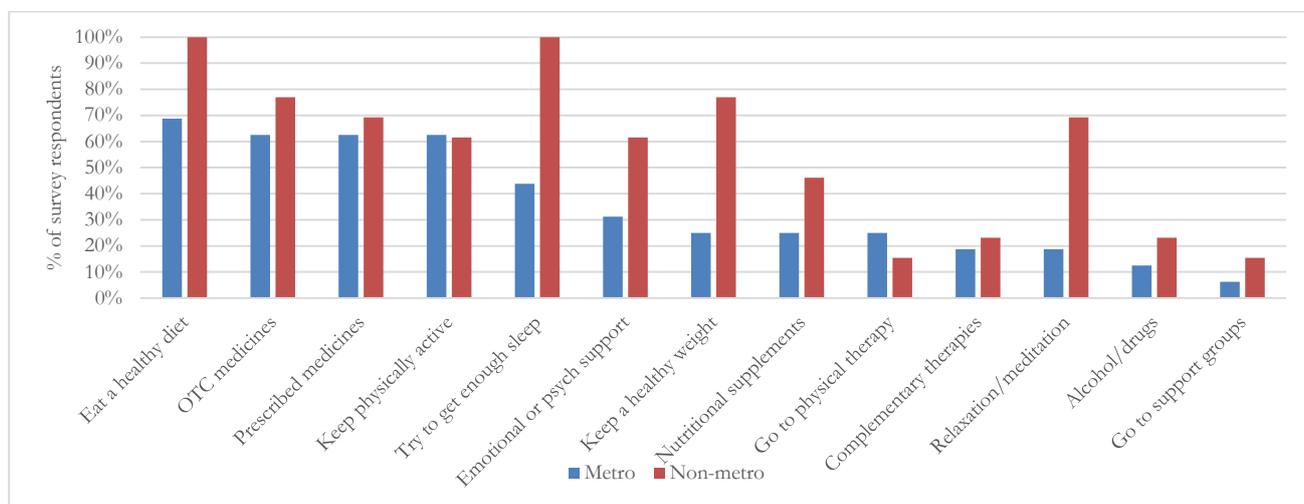


Source: Patient PMP survey 2016. Metropolitan N =215; Non-Metropolitan N=92

**F11: Of the 13 self-management pain techniques that patients that completed the evaluation survey could select, the most common techniques (>70%) included keeping physically active and using complementary medicine followed by (>60%) relaxation/meditation, attending support groups and/or going to physical therapy. OTC medication attracted the lowest response rate (about 10%).**

The parents/carers survey also asked “which of the following does the person you support with chronic pain do to help manage their pain? Figure 4.12 shows that were some obvious differences in responses received from metropolitan based parents/carers compared to non-metropolitan based parents/carers which is different to the responses received from patients (see Figure 4.11). Also of significant difference was that a large proportion of parents/carers report the use of over the counter medications (>60%), whereas patients ranked this as the lowest modality used. Caution should be taken when interpreting this data due to the lower number of responses, however the obvious differences between parent/carer responses compared to patient responses suggests some bias in the answering by patients or parent/scarers being unaware of the modalities being used.

**Figure 4.12: Patient self-administered pain management modalities reported by parents/carers**

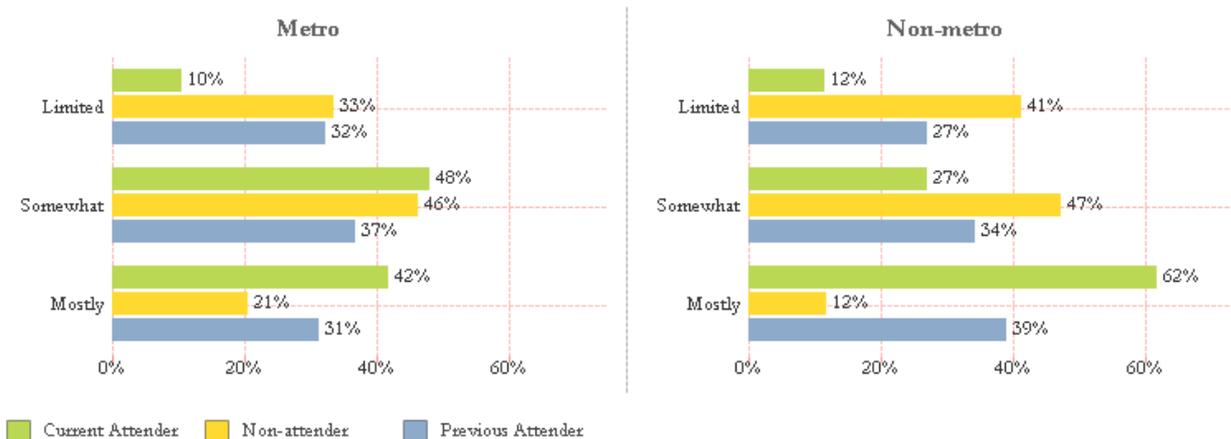


Source: Parent/Carer PMP survey 2016. Metropolitan N =16; Non-Metropolitan N=13

#### 4.8 USEFULNESS OF THE INFORMATION PROVIDED ABOUT CHRONIC PAIN

The evaluation patient survey asked patients “have you found the information useful in helping manage your pain”. Figure 4.13 shows that a higher proportion of patients that are current or previous clinic attenders, were likely to report the information was ‘mostly’ helpful.

Figure 4.13: Extent to which patients report the provided information being useful



Source: Patient PMP survey 2016. Scale = 0 “not at all” to 10 “completely” where 0-3 = limited; 4-7= “somewhat” and 8-10 =”mostly”. Metropolitan patient N = 196, non-metropolitan patient N = 84. Note that the red coloured bar (“attender unknown”) describes patients who did not provide their clinic attendance status in their survey responses.

**F12: Majority of patients (> 68%) with chronic pain that are currently or had previously been attending a pain clinic reported that the information provided to them was ‘somewhat’ to ‘mostly’ useful.**

#### 4.9 EXPERIENCES OF PAIN MANAGEMENT CLINICS

For those patients that had attended a pain clinic, the evaluation patient survey asked, “where did you hear about this Chronic Pain Clinic?” Table 4.3 shows of those patients that are attending or have previously attended a chronic pain clinic, the main source of referral for both metropolitan based and non-metropolitan based patients is their GP followed by other doctor/health professional including their Specialist (who may have been a neurologist, neurosurgeon, orthopaedic surgeon or pain specialist). Of note, is that in the paediatric setting, the paediatrician is the referring clinician not a GP.

Table 4.3: How patients who had attended pain clinics became aware of the clinic

Source of referral	Metropolitan based patient		Non-metropolitan based patient	
	n	% of total	n	% of total
Friend/family member	10	7%	5	7%
General Practitioner (GP)	57	38%	36	51%
Hospital/Emergency Department	13	9%	1	1%
Internet/website	6	4%	1	1%
Allied health professional	13	9%	7	10%
Other doctor/health professional/specialist	45	30%	17	24%
Other	7	5%	3	4%
<b>Total</b>	<b>151</b>	<b>100%</b>	<b>70</b>	<b>100%</b>

Source: Patient PMP survey 2016. Metropolitan patient N = 151, Non-metropolitan patient N = 70

**F13: The main source of referral for both metropolitan based and non-metropolitan based patients to a chronic pain clinic is their GP followed by other doctor/health professional including their Specialist (who may have been a neurologist, neurosurgeon, orthopaedic surgeon or pain specialist).**

The evaluation patient survey also asked, of those patients attending chronic pain clinics, “what type of treatment and/or support they had received”. Table 4.4 shows that the most common type of treatment/support received from pain clinics by both metropolitan and non-metropolitan based patients was “individual assessments” followed by “multidisciplinary assessment”. This is expected as one of these types of services are required prior to a patients’ support/treatment plan being developed. Subsequent to this service, the most common treatment/support received by both metropolitan and non-metropolitan based patients was “medications” followed by “individual pain management program/therapy sessions” and “educational resources”. The least common treatment/support received from pain clinics by both metropolitan and non-metropolitan based patients was “spinal cord stimulator implant”.

**Table 4.4: Type of treatment and support receive from pain clinics**

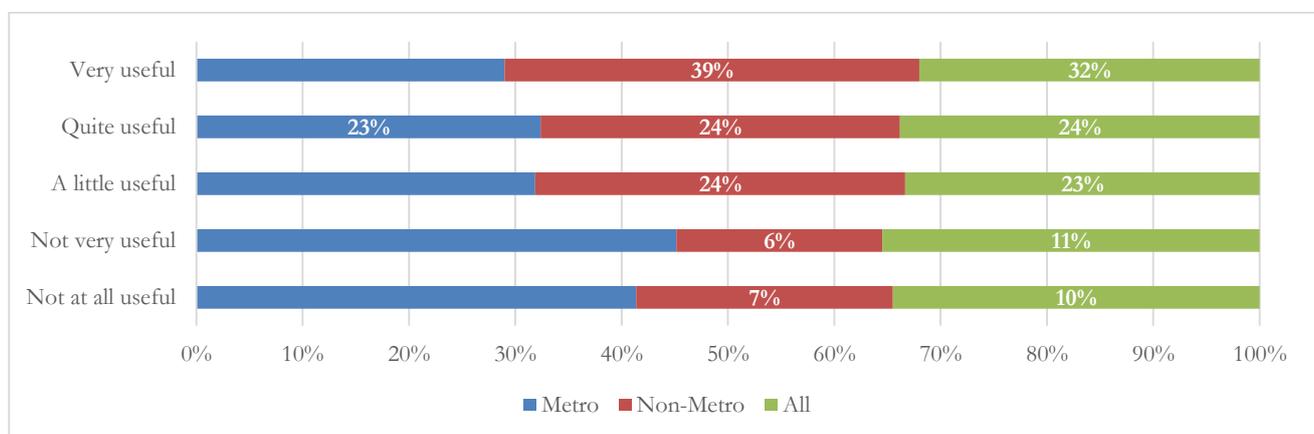
Type of treatment/support received	Metropolitan based patient		Non-metropolitan based patient	
	n	% of total	n	% of total
Individual assessments	93	62%	45	64%
Medications	64	42%	34	49%
Multidisciplinary assessment	60	40%	39	56%
Individual pain management program/therapy sessions	40	26%	29	41%
Other	35	23%	13	19%
Educational information session/DVD	33	22%	28	40%
Educational resources	30	20%	29	41%
Individual progress review sessions	29	19%	15	21%
Spinal cord stimulator implant	14	9%	7	10%

Source: Patient PMP survey 2016. Metropolitan patient N = 151, Non-metropolitan patient N = 70

**F14: The most common type of treatment/support received from pain clinics by both metropolitan and non-metropolitan based patients was “medications”. The least common treatment/support received from pain clinics by both metropolitan and non-metropolitan based patients was “spinal cord stimulator implant”.**

The evaluation patient survey also asked patients “how useful they found the treatment/support received from the pain clinics”. Figure 4.14 shows that a larger proportion of non-metropolitan based patients (63%) reported that the treatment/support received from the pain clinics was “quite useful” to “very” compared to non-metropolitan based patients (52%).

**Figure 4.14: How useful was the treatment and support provided by the pain clinic**



Source: Patient PMP survey 2016. Metropolitan patient N = 151, Non-metropolitan patient N = 70

**F15: A larger proportion of non-metropolitan based patients (63%) reported that the treatment/support received from the pain clinics was “quite useful” to “very useful” compared to metropolitan based patients (52%).**

The evaluation survey also offered patients the opportunity to provide free text responses to several optional questions. The three questions were: 1) What new information, management strategies or skills did you learn at the chronic pain clinic; 2) How could the chronic pain clinic have been more helpful for you; and 3) is there anything more you would like to say about your pain, how you've tried to manage it, and ways in which you may be better supported. A summary of the coded data is in Appendix D.

Analysis of the themes identified mixed responses to each of the three questions. Overall, negative and equivocal responses outweighed positive responses across the three questions. However, this weighting towards negative responses should not be interpreted as necessarily reflecting generalised public sentiment towards the PMP. We believe these free text responses provided an avenue for people living with chronic pain to make their voices heard. We believe respondents may have used this available avenue to voice their frustration. In summary, chronic pain is clearly the source of a great deal of distress for individuals and their families and challenging for health professionals to manage. These free text responses thus also reflect the unfortunate reality that in some cases, chronic pain is an intractable clinical problem.

**F16: The evaluation found that the most common strategies or skills being learnt by patients attending pain clinics were: cognitive approaches, including CBT, counselling and individual reframing of experience (37%); physical self-management strategies including pacing, ADL and exercise (21%); and appropriate use of medications including addiction and AOD issues (19%).**

**F17: The evaluation found that the most common areas where patients attending pain clinics thought pain clinic could be more helpful to them were: negative experience including lack of empathy from health professionals and perceived poor diagnosis and treatment (44%); positive experience including staff did the best they could (30%); and access issues including constraints of geography, cost, waiting time and health literacy (8.8%).**

#### 4.10 EXPERIENCES OF PRE-ASSESSMENT EDUCATION SESSIONS

There were several questions included in the patient survey which explored patients' experiences of the pre-assessment education and orientation sessions. There was one structured question which was not answered by any current or previous clinic attenders. This data has not been presented as their responses are not interpretable (i.e. they are unlikely to have attended these sessions which are offered by specialist pain management clinics). However, clinic attenders did provide free text responses to the open questions.

Representative quotes received for the question “What new information, management strategies or skills did you learn at the Chronic Pain Clinic?” included:

- *“Pain should not hinder your life. Medications are not the answer and can cause addiction”*
- *“Education class (8 weeks) was great. Individual physiotherapy and access to the gym was brilliant.”*
- *“That it is all about pacing yourself and working on it every day”*
- *“They were focused solely on taking the medication away. Very little consideration was given to pain management and quality of life. I was told to read a book which wasn't helpful.”*

- *“Relief with pain medication. Everything else I have done through my own research because we have very limited resources in the country. The chronic pain clinic only provided medication.”*
- *“The most important thing was that I was listened to, believed and given positive feedback about my management of pain”*

Representative quotes received for the question “How could the Chronic Pain Clinic have been more helpful for you?” included

- *“Support of pain clinic was exactly what I needed. without that support I would be in a very bad place now”*
- *“They did the best they could. I find it impossible to be self-motivated or to exercise much. I can’t walk far”*
- *“Provide better follow up after exiting”.*
- *“I had a lot of trouble with GP's not taking the advice of the pain clinic and red flagging me as a drug seeker/junkie because there was a typo in the letter from the pain clinic. None of this did great things for my mood or general well-being. After weeks of this going back and forward and nothing happening for me while I was still in great pain. I was forced to find street drugs to manage my pain so that I could continue working.”*
- *“I still believe that my attacks of acute pain have a physical reason and would like to know that pain clinic could accept my belief.”*
- *“To be able to see them more often. To have some sort of follow up from one of the members of the pain team with having to wait usually 3 months for another appointment, maybe a type of phone service, so they can touch base, to see progress and offer support. More contact with my doctors”*

## Impact on health and wellbeing outcomes

This Chapter presents information gathered to support the assessment of the impact of the PMP on the health and wellbeing outcomes for people living with chronic pain.

### 5.1 CHANGES IN PATIENTS' PAIN SYMPTOMS

This section assesses the impact, if any, of the PMP on patients pain symptoms. The data sources used to assess this indicator, as described in the ACI data plan, were: ePPOC data; and the evaluation survey of patients with chronic pain.

#### 5.1.1 Changes in the characteristics of chronic pain

The ePPOC data includes patient reported changes in pain frequency. **Table 5.1** shows that there is a shift in pain frequency reported by patients in NSW between referral and episode end. These data reflect the usual characteristics of chronic pain, with the most common (reported by 77.5% of patients) being pain that is always present but varying in intensity. At episode end, the data indicate there has been a small shift with patients reporting more periods without pain or more variable pain. These shifts are small but they do raise the prospect that further gains of this nature may be possible.

**Table 5.1: Changes in the characteristics of chronic pain**

Pain frequency	Referral	Episode end	Percentage change
Always present (same intensity)	12.6%	8.8%	-30.2%
Always present (varying intensity)	77.5%	72.4%	-6.6%
Often present	6.4%	11.3%	76.6%
Occasionally present	2.6%	3.9%	50.0%
Rarely present	0.9%	3.6%	300%
<b>Total</b>	<b>100%</b>	<b>100%</b>	<b>-</b>

Source: ePPOC.

**F18: The ePPOC data suggest that there has been a small shift with patients reporting more periods without pain or more variable pain from referral to end of episode. These shifts are small but they do raise the prospect that further gains of this nature may be possible.**

#### 5.1.2 Number of pain regions reported

The ePPOC data includes patient reported changes in the number of pain regions. Table 5.2 shows that there has been an overall reduction in the number of pain regions reported between referral and episode end from NSW patients attending pain clinics. When chronic pain is experienced at multiple sites it is often called Chronic Widespread Pain, and this is known to be resistant to change. The NSW

ePPOC data, however, indicate that the extent of such pain can change over time, especially in those with higher numbers of pain sites.

**Table 5.2: Number of pain regions reported**

No. pain regions	Referral	Episode end	Percentage (%) Change
1	15.8%	16.5%	4.4%
2	17.6%	14.4%	-18.2%
3	10.2%	18.5%	81.4%
4	20.3%	13.8%	-32.1%
5	14.0%	15.1%	7.9%
6	6.5%	8.6%	32.3%
7	7.0%	6.8%	-2.9%
8	4.3%	3.9%	-9.3%
9	2.5%	0.9%	-64.0%
10	0.7%	0.4%	-42.9%
11 or more	1.1%	1.1%	0%

Source: ePPOC.

**F19: The ePPOC data suggests that there has been an overall reduction in the number of pain regions reported by NSW patients between referral and episode end.**

### **5.1.3 Change in pain ratings and interference subscale**

The Brief Pain Inventory (BPI) scale 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; and 7-10 = severe pain. The IMMPACT group's recommendations for assessing clinical significance for numeric pain scales are that a change of:

- $\geq 10\%$  represents minimally significant change;
- $\geq 30\%$  represents moderate clinically significant change;
- $\geq 50\%$  represents substantial clinically significant change.

Table 5.3 shows that there are improvements in pain rating and interference subscales based on the BPI instrument. On the 'average pain' item, 29% of patients made minimally significant change, 12% made moderate clinically significant change, and 11% substantial clinically significant change. On the worst pain item, 30% made minimally significant change, 9% made moderate clinically significant change, and 8% substantial clinically significant change. Further, 64% of patients who experienced at least moderate pain interference at referral showed a clinically significant improvement at the end of their episode.

Table 5.3: Change in pain ratings and interference subscale

Assessment tool (BPI)	Score at referral	Average change
Worst pain	7.8	-0.7
Least pain	4.3	-0.8
Average pain	6.0	-0.8
Pain now	5.9	-0.9
Interference	6.8	-1.7

Source: ePPOC. NSW services n=583.

**F20: The ePPOC data suggest that there were improvements in pain severity ratings and interference subscales based on the BPI scale from referral to end of episode.**

## 5.2 IMPACT ON PATIENTS' MENTAL WELLBEING

This section examines the impact of patients' mental health wellbeing through analysis of various data sources including ePPOC; and the survey of patients living with chronic pain.

### 5.2.1 Changes in depression, anxiety and stress levels

The ePPOC data includes the Depression, Anxiety and Stress Scale 21 (DASS21) instrument which is a 21-item self-report instrument designed to measure three commonly reported negative emotional states of depression, anxiety and tension/stress. Table 5.4 shows that there have been measured improvements by the DASS21 tool from referral to episode end. Overall the ePPOC data showed that:

- 58% of patients with at least moderate depression at referral made clinically important improvement;
- 45% of patients with at least moderate anxiety at referral made clinically important improvement;
- 56% of patients with at least moderate stress at referral made clinically important improvement.

Table 5.4: Changes in DASS21 tool

Assessment tool (DASS)	Score at referral	Average change
Depression	19.6	-5.8
Anxiety	13.1	-2.2
Stress	21.0	-4.0

Source: ePPOC. NSW services n=583.

**F21: The ePPOC data suggest that there have been improvements in depression, anxiety and stress levels for NSW patients between referral to end of episode. Overall around 50% of patients with moderate or worse depression, anxiety and/or stress at referral made clinically important improvements.**

### 5.2.2 Changes in a patients thoughts and feelings related to their pain

The pain catastrophising scale (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 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; and >30 = severe. Clinically significant change requires a change in score of six or more points, combined with movement to a different severity category.

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 at all' confident 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.

Table 5.5 shows the ePPOC data for the PCS and PSEQ total score for patients living with chronic pain in NSW between 2013 and 2016. The ePPOC data suggest that 60% of patients with high or worse catastrophising pain at referral made clinically significant improvement. For the PSEQ, the average change was 10.8. The ePPOC data suggested 56% of patients with at least moderate impairment in pain self-efficacy at referral made clinically significant improvement.

**Table 5.5: Change in catastrophising pain and pain self-efficacy scores**

Assessment tool	Score at referral	Average change
<b>PCS</b>		
Rumination	9.2	-3.1
Magnification	5.2	-1.7
Helplessness	13.0	-4.6
<b>Total</b>	<b>27.4</b>	<b>-9.4</b>
<b>PSEQ*</b>		
<b>Total</b>	<b>21.7</b>	<b>10.8</b>

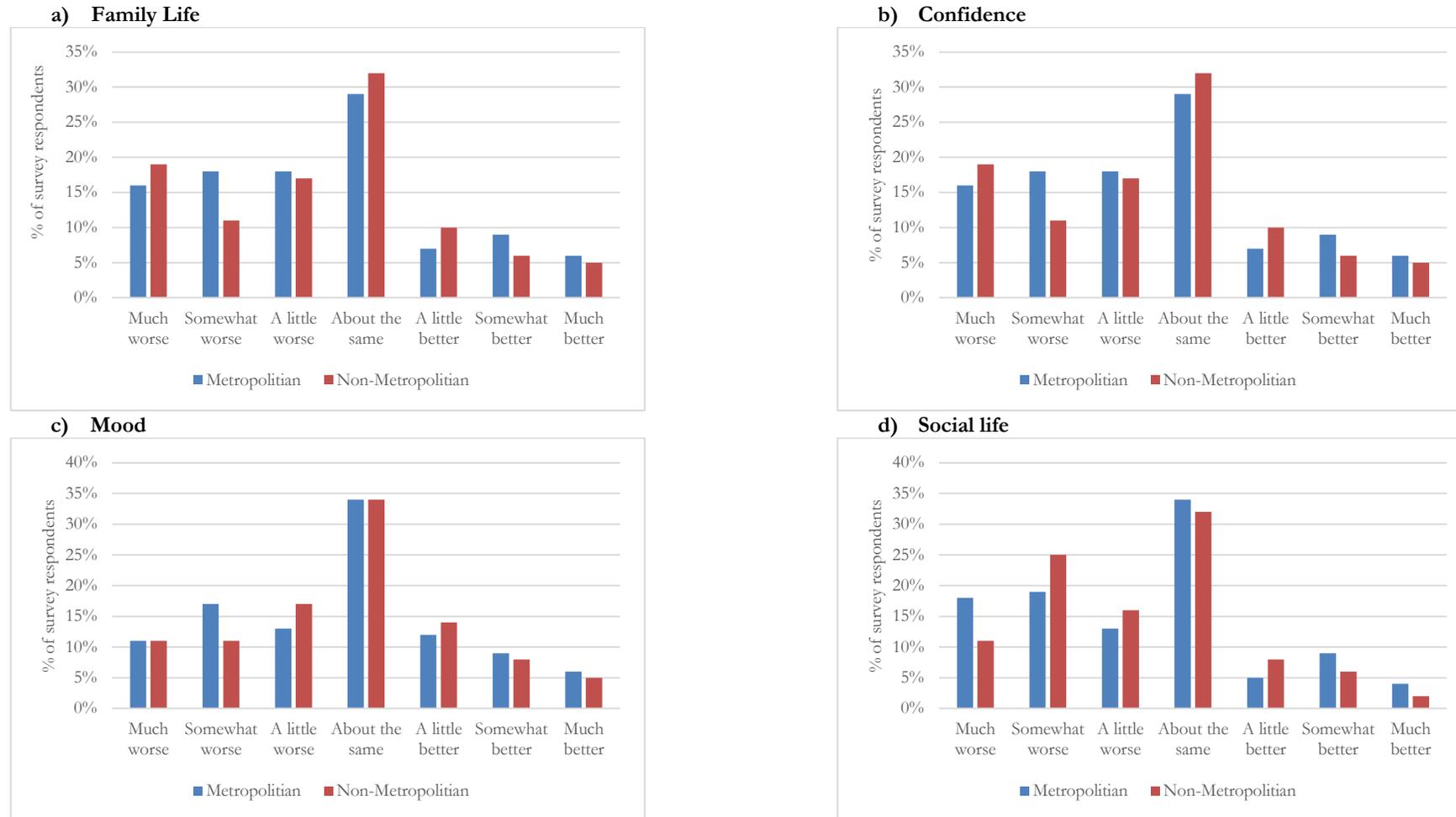
Source: ePPOC. NSW services N=583.

**F22: The ePPOC data shows that there have been consistent improvements in responsibility and control of pain. Specifically 60% of patients with high or worse catastrophising pain at referral made clinically significant improvement and 56% of patients with at least moderate impairment in pain self-efficacy at referral made clinically significant improvement.**

### ***5.2.3 Impact of chronic pain on various aspects of a patients' life***

The evaluation patient survey asked patients "compared to eight weeks ago, have the following aspects of your life stayed the same, got better or worse?" Figure 5.1 presents an analysis of the survey results in regards to the impact chronic pain has had on several aspects of patients' lives including (a) family life; (b) confidence; (c) mood; and (d) social life. Overall there was little difference in the responses when comparing metropolitan patient responders to non-metropolitan patient responders. Although most patients reported "about the same" across all four areas, there was a trend with a higher proportion of responses being between "much worse" and "a little worse" compared to "a little better" and "much better".

Figure 5.1: Aspects of patients' lives which have stayed the same, got better or worse over last eight weeks



Patient PMP survey 2016.

**F23: Majority of patient that responded to the evaluation survey reported that the impact their chronic pain has had on various aspects of their lives (e.g. family life, mood, confidence and social life) over the last eight weeks has remained about the same. There was little difference between responses from metropolitan compared to non-metropolitan patients.**

### 5.3 IMPACT ON DAILY TASKS OF PEOPLE LIVING WITH PAIN

This section examines the impact of the PMP, if any, on daily tasks undertaken by people living with chronic pain.

#### 5.3.1 Changes in employment status

The ePPOC questionnaire includes a question asking patient “which of the following best describes your current work status?” Table 5.6 presents the analysis of this data at referral compared to episode end. The data suggests that there have been improvements in employment/study status between referral and episode end for people with chronic pain in NSW. For example, the percentage of individuals in full time paid employment increased from 6.8% at referral to 8.0% at episode end. Similarly, individuals in part time paid employment increased from 10.2% to 11.0%; unemployed due to pain decreased from 38.6% to 34.9%; on leave from work due to pain decreased from 9.1% to 6.0%. Further, the number of individuals studying increased from 4.0% to 4.4%; engaged in voluntary work from 3.8 to 5.7%; and in retraining from 1.5% to 1.6%.

**Table 5.6: Employment/study status of people with chronic pain**

Employment and/or study status	Referral	Episode end
Full time paid employment	6.8%	8.0%
Part time paid employment	10.2%	11.0%
Retired	19.6%	23.4%
Unemployed due to pain	38.6%	34.9%
Unemployed (not pain related)	4.2%	4.0%
Home duties	11.9%	14.4%
On leave from work due to pain	9.1%	6.0%
Studying (e.g. school, university)	4.0%	4.4%
Voluntary work	3.8%	5.7%
Retraining	1.5%	1.6%
At work – limited hrs &/or duties	9.9%	6.2%

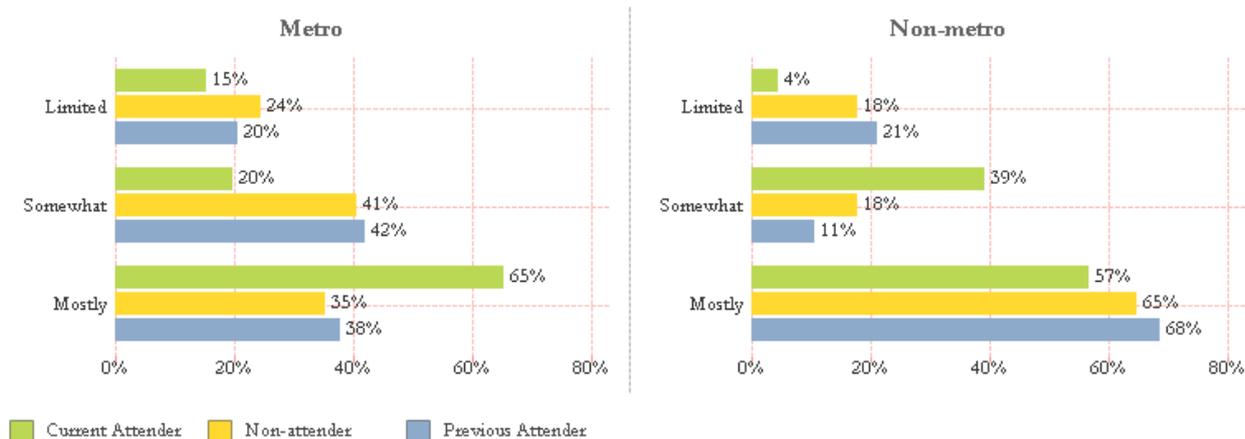
Source: ePPOC. N=547.

#### **F24: The ePPOC data suggests that there have been improvements in employment and/or study status between referral and episode end for people with chronic pain in NSW.**

The evaluation patient survey also asked patients “over the last eight weeks, how much their pain restricted their work (paid or unpaid)/training or education”. Figure 5.2 shows that majority of patients reported that their chronic pain has either ‘somewhat’ or ‘mostly’ restricted their ability to work/study. This is different to the learnings from the analysis of the ePPOC data. However it is important to note ePPOC includes data from patients attending pain management clinics only and examines outcomes following pain clinic attendance. Focusing on those patients that responded to the evaluation survey and also attend pain clinics (i.e. current or previous attenders), majority of these patients are still reporting that their chronic pain is impacting their work/study life. This could be due to ePPOC data measuring a change in work capacity following pain clinic intervention whereas the evaluation survey data is measuring a change in work and education capacity over an eight week block that may or may not have included an intervention.

Also of note, non-metropolitan patients reported much higher proportions of their chronic pain “mostly” impacting on their work/study life compared to metropolitan patients, except for patients that were current attenders of pain clinics.

Figure 5.2: Impact on work/education/training compared to eight weeks ago



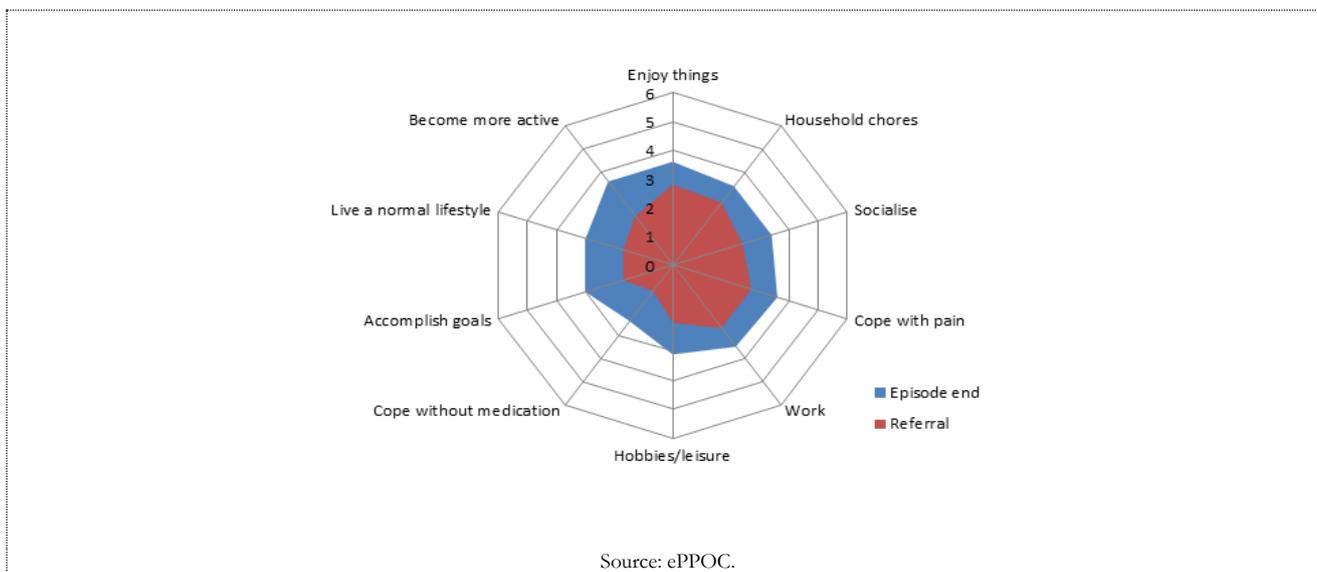
Source: Patient PMP survey 2016. Scale = 0 “not at all” to 10 “completely” where 0-3 = limited; 4-7= “somewhat” and 8-10 =”mostly”. Metropolitan patient N = 176, non-metropolitan patient N = 78. Note that the red coloured bar (“attender unknown”) describes patients who did not provide their clinic attendance status in their survey responses.

**F25: The majority of patients surveyed for the evaluation reported that their chronic pain has either ‘somewhat’ or ‘mostly’ restricted their ability to work/study over the last eight weeks. This difference between data in ePPOC and evaluation survey data is likely due to ePPOC measuring a change in work capacity following pain clinic intervention whereas the evaluation survey data is measuring a change in work capacity over an eight week block that may or may not have included an intervention.**

### 5.3.2 Changes in pain self-efficacy

The Pain Self-Efficacy Questionnaire (PSEQ) is a 10-item questionnaire, developed to assess the confidence people with ongoing pain have in performing activities while in pain. The ePPOC data set captures this data at referral and at episode end. In general, higher PSEQ scores are strongly associated with clinically significant functional levels and provide a useful gauge for evaluating outcomes in chronic pain patients. Figure 5.3 presents a ‘spider’ plot representation of changes in self-efficacy for individual PSEQ items from referral to episode end. This ePPOC PSEQ analysis shows improvements in PSEQ scores between referral and episode end among NSW patients with chronic pain and who have attended a pain management service.

Figure 5.3: Changes in PSEQ item scores from referral to end of program



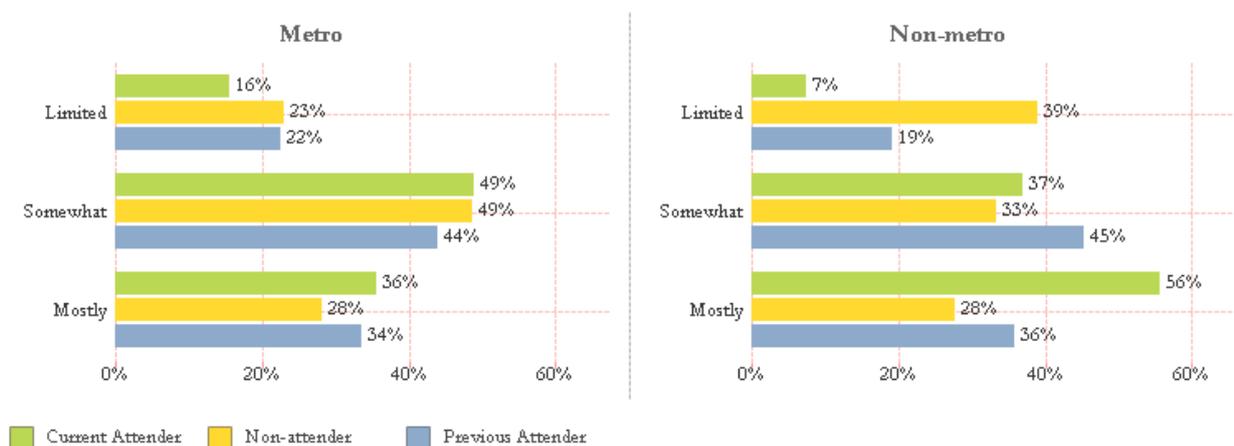
Source: ePPOC.

**F26: Low pain self-efficacy is a predictor of long term disability and depression for people living with chronic pain. The ePPOC data suggest that there were improvements in PSEQ scores (i.e. higher PSEQ scores are strongly associated with clinically significant functional levels) between referral and episode end among NSW patients living with chronic pain.**

**5.3.3 Changes in patient understanding and skills in managing their chronic pain**

The evaluation patient survey asked patients “compared to six months ago, do you understand your pain better”. Figure 5.4 shows that majority (61%) of patients reported to understand their pain ‘somewhat’ to ‘mostly better’ compared to six months ago. There was little difference in these results when comparing metropolitan patients compared to non-metropolitan patients. There was also little difference between current or previous clinic attenders to non-clinic attenders except in the non-metropolitan group for non-attenders where 39% reported having less of an understanding about their pain.

**Figure 5.4: Changes in patient understanding of their chronic pain compared to six months ago**

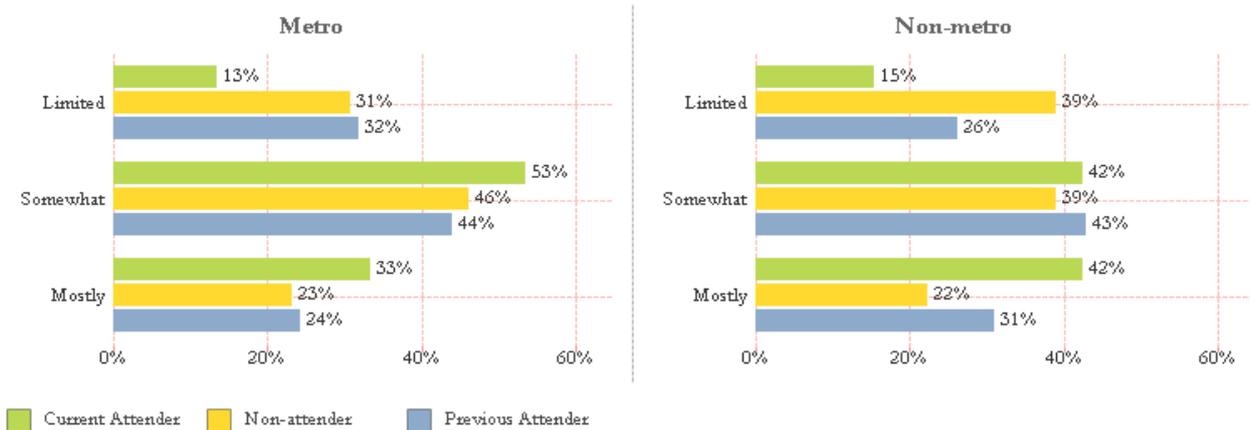


Source: Patient PMP survey 2016. Scale = 0 “not at all” to 10 “completely” where 0-3 = limited; 4-7= “somewhat” and 8-10 = “mostly”. Metropolitan patient N = 191 non-metropolitan patient N = 87. Note that the red coloured bar (“attender unknown”) describes patients who did not provide their clinic attendance status in their survey responses.

**F27: Majority (61%) of patients surveyed reported to understand their pain ‘somewhat’ to ‘mostly’ better now compared to six months ago.**

The evaluation patient survey also asked patients “compared to six months ago, do you have more skills to manage your pain”. Figure 5.5 shows again that majority (61%) of patients reported to have ‘somewhat’ to ‘mostly’ more skills to manage their pain compared to six months ago. There was little difference in these results when comparing metropolitan patients compared to non-metropolitan patients and when comparing current or previous clinic attenders to non-clinic attenders.

Figure 5.5: Changes in patient skills to manage their chronic pain



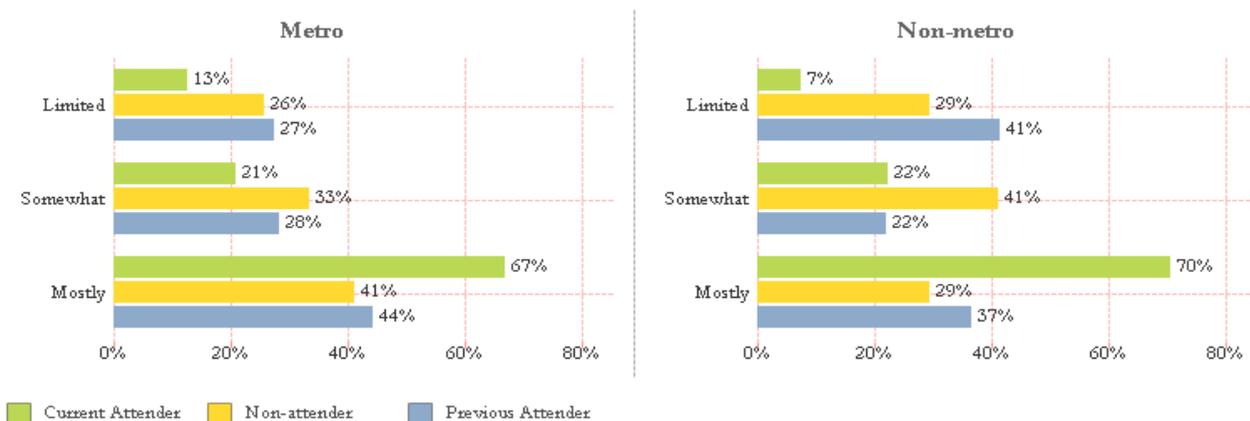
Source: Patient PMP survey 2016. Scale = 0 “not at all” to 10 “completely” where 0-3 = limited; 4-7= “somewhat” and 8-10 =”mostly”. Metropolitan patient N = 191 non-metropolitan patient N = 86. Note that the red coloured bar (“attender unknown”) describes patients who did not provide their clinic attendance status in their survey responses.

**F28: Majority (61%) of patients surveyed reported to have ‘somewhat’ to ‘mostly’ more skills to manage their pain now compared to six months ago.**

#### 5.4 COMMUNICATION WITH PAIN MANAGEMENT SERVICE PROVIDERS

The evaluation patient survey asked patients “to what extent they feel they can communicate meaningfully with their pain management service provider”. Figure 5.6 shows that the majority of current pain clinic attenders in both metropolitan (>87%) and non-metropolitan areas (>92%) reported that they can communicate meaningfully with their pain management service providers. A larger proportion of patients that never attended or previously attended clinics reported to have limited ability to communicate meaningfully with their pain management service provider.

Figure 5.6: Extent to which patients feel they can communicate meaningfully with their pain management service provider



Source: Patient PMP survey 2016. Scale = 0 “not at all” to 10 “completely” where 0-3 = limited; 4-7= “somewhat” and 8-10 =”mostly”. Metropolitan patient N = 193, non-metropolitan patient N = 85. Note that the red coloured bar (“attender unknown”) describes patients who did not provide their clinic attendance status in their survey responses.

**F29: Majority of current pain clinic attenders reported being able to have meaningful conversations with pain management service providers.**

## Impact on use of opioids to manage chronic pain

This Chapter presents information gathered to assess the impact of the PMP, if any, whether there has been any changes in use of opioids to manage patients' chronic pain; and whether patients report any changes in medication use to support them in managing their pain. The data in this Chapter uses the data sources as per the provided ACI Data Plan which includes ePPOC data and PBS data.

### 6.1 MEDICATION USE BY PATIENTS WITH CHRONIC PAIN

Pain management services collect information about the medications their patients take and the frequency of their use. This information is provided to ePPOC as three variables, describing:

- whether or not a patient uses opioid medication on more than two days per week;
- the patient's daily oral morphine equivalent (using a standardised conversion table);
- the number of major drug groups the patient's medications fall within. The major drug groups are opioids, paracetamol, NSAIDs, antidepressants, anticonvulsants and benzodiazepines.

Table 6.1 presents, for those patients taking opioid medication, changes in the indicators at referral compared to episode end. Analysis suggests there have been reductions in opioid use for the NSW population included in the ePPOC dataset. Overall, the data suggests a 36.2% reduction in patients using opioids more than 2 days per week and a 42.2% reduction in average daily morphine equivalent dose. The change in the average number of major drug groups is too small to be considered an actual change.

**Table 6.1: Medication use of patients attending pain management clinics**

Indicator	Referral	Episode end	Change
% patients using opioids >2 days/week (n=398)	57.8%	36.9%	-36.2%
Average daily morphine equivalent for patients taking opioid medication (n=207)	84.6 mg	48.9 mg	-42.2%
Average number of major drug groups (n=393)	2.6	2.8	+7.7

Source: ePPOC.

**F30: The ePPOC data suggests that there has been a 36.2% reduction in patients using opioids more than 2 days per week; and a 42.2% reduction in average daily morphine equivalent dose for patients taking opioid medication.**

### 6.2 CHANGES IN MORPHINE EQUIVALENT DOSE RATES

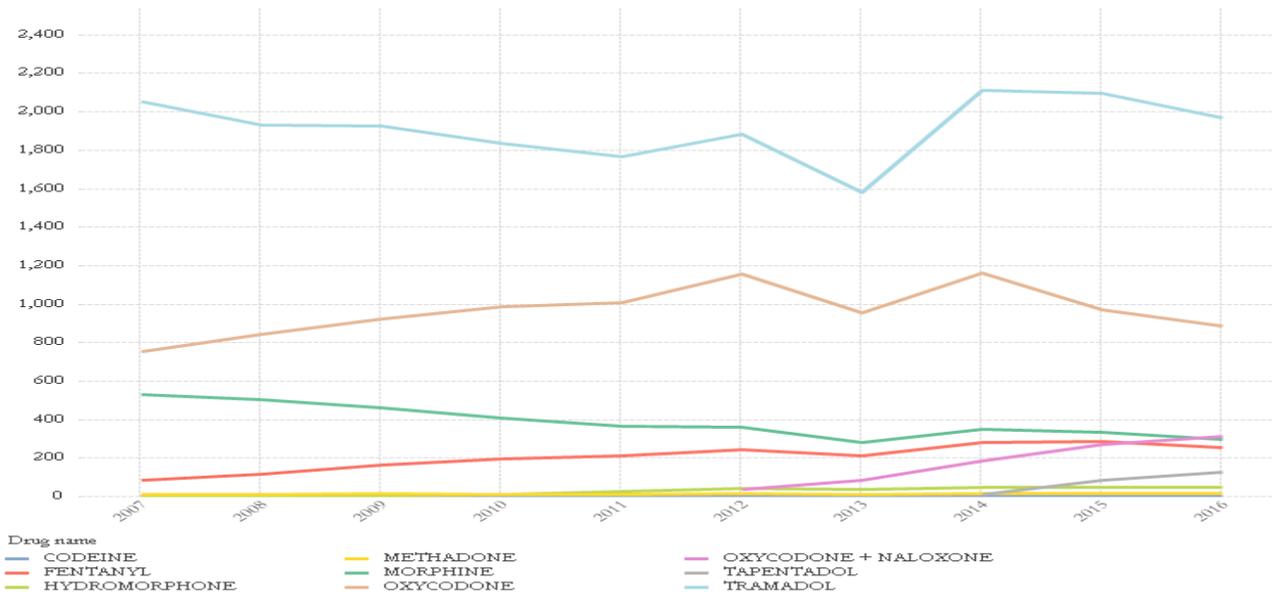
PBS data was extracted to determine any changes in morphine equivalent dose rates. Specifically, we extracted service volumes by calendar year for NSW in the date range 2007 to 2016. We then applied oral Morphine Equivalent Daily Dose (oMEDD) conversion factors<sup>5</sup> to these PBS service volume data. The PBS drugs used in this analysis was aligned to the baseline data specification. We then calculated oMEDD for each of the PBS listed items agreed with the ACI.<sup>6</sup>

<sup>5</sup> This oMEDD conversion factors is intended for comparison of different opioid regimens in individual patients or in patient cohorts.

<sup>6</sup> The oMEDD was calculated for each item based upon the ANZCA Faculty of Pain Medicine's conversion factors (see <http://fpm.anzca.edu.au/documents/opioid-dose-equivalence.pdf>). With the exception of pregabalin (items 2335X, 2348N, 2355Y and 2363J) since these

Figure 6.1 shows that total annual supply of opioids increased from 3,442 kg in 2007 to 4,110 kg in 2015. This is an increase of 668 Kgs or 19.4%. All drugs of interest have experienced increases with the exception of morphine, suggesting that patients have either switched to alternatives and/or that new patients are initiating to alternatives. Note: 2015 data was used in this analysis since 2016 data was only complete to October 2016.

Figure 6.1: NSW total annual supply 2007-2016 - oral morphine equivalent kilograms by drug

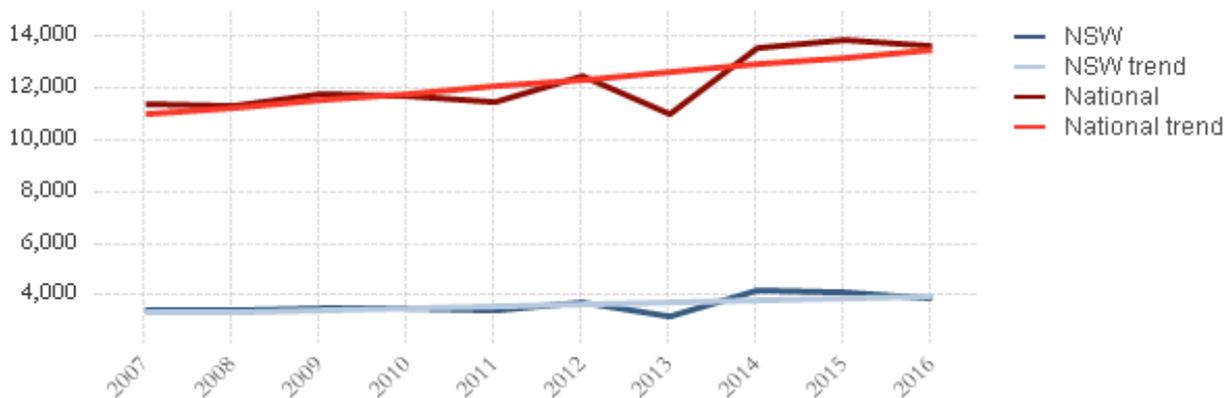


Source: [http://medicarestatistics.humanservices.gov.au/statistics/pbs\\_item.jsp](http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp)

Figure 6.2 shows that there was a drop in total supply in 2013 both nationally and within NSW. The reason for this change in supply is unknown (e.g. could relate to overstatement for 2014 rather than understatement for 2013 or just an anomaly).

Figure 6.2: Total annual supply 2007-2016 – oral morphine equivalent (Kgs)

Total Equivalent Morphine Kilograms Supplied

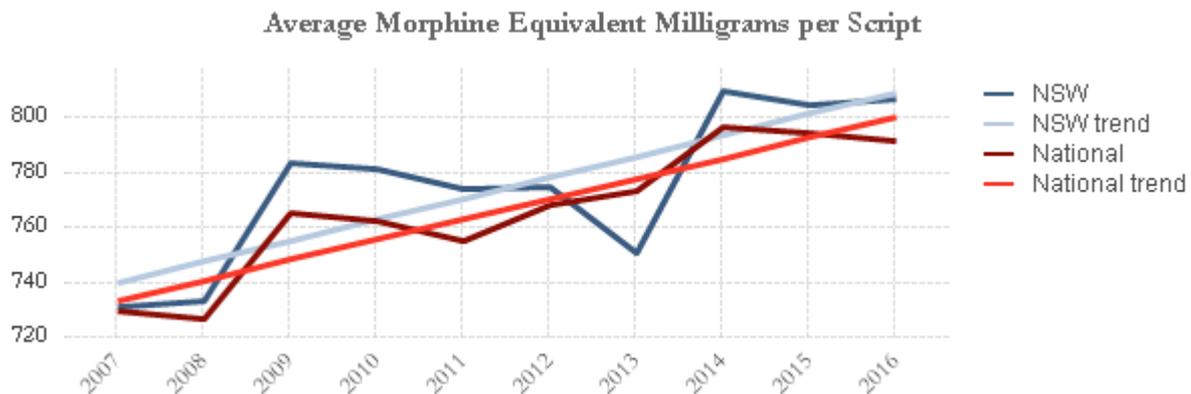


Source: [http://medicarestatistics.humanservices.gov.au/statistics/pbs\\_item.jsp](http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp)

are not opioid medicines and equivalence factors are unavailable. Conversion factors for oxycodone + naloxone and methadone were retrieved from: Eastern Metropolitan Region Palliative Care Consortium (Victoria) - Clinical Working Party - Opioid Conversion Ratios – Guide to Practice 2010.

Figure 6.3 shows that the oral Morphine Equivalent milligrams per script has increased over the period 2007 to 2016 from 731 mg in 2007 to 807 mg in 2016 both nationally and in NSW. For NSW, assuming that each script is intended to cover 30 days, this equates to an oMEDD of 24.4 mg and 26.9 mg respectively, which is an increase of 10.4%.

Figure 6.3: Average milligrams per script 2007-2016 oral morphine equivalent daily dose



Source: [http://medicarestatistics.humanservices.gov.au/statistics/pbs\\_item.jsp](http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp)

Our extrapolated oMEDD measures indicate that the oMEDD for each filled script has increased over the period. We found the overall opioid supply has increased over the period 2007 to 2016 in NSW.

- F31: PBS data suggests generally increasing rates of opioid use in NSW between 2007 and 2015. Tramadol and oxycodone prescriptions increased most markedly, particularly during 2013-14. Further, we identified variation in the pattern of year to year rates of opioid use in NSW between 2007 and 2016 as measured by oMEDD extracted from selected PBS data.**
- F32: The oral Morphine Equivalent milligrams per script has increased over the period 2007 to 2016 from 731 mg in 2007 to 807 mg (i.e. 10.4%) in 2016. The total supply of opioids in NSW has grown at a higher rate at 19.4%, indicating an increase in per capita use.**
- F33: Taking together the ePPOC data showing a reduction in opioid use in the pain clinic population and the PBS data showing an increase in oMEDD suggests that the increase in opioid prescription is driven by an increase in opioid prescriptions outside the pain clinics.**

## Impact of PMP on health services

This Chapter presents information gathered to support the assessment of the impact of the PMP, if any, on health service utilisation, costs, efficiency and funding models. Two data sources were used to assess this: MBS data describing selected chronic pain related attendances and therapeutic procedures in NSW between 2007 and 2015 calendar years; and ePPOC data. It was originally intended to complement these data sources with NSW Health Administrative Datasets. The NSW Health administrative datasets may have provided the numbers, nature and duration of emergency department presentations and hospital admissions for a “chronic pain” patient cohort. However this dataset was not available, and excluded from this evaluation in consultation with the ACI.

### 7.1 CHANGES IN HEALTH SERVICE UTILISATION

Information about health service use is collected from patients as an outcome measure as part of the ePPOC data collection. Specifically the ePPOC dataset gathers data on the number of times patients have used a health service (including seeing a GP or allied health professional, attending an emergency department etc.) in the last 3 months from returned referral and episode end. Table 7.1 shows that there has been a reduction in both the mean and median number of visits from referral to episode end with GP, medical specialist visits and allied health professionals. There has been no change in the median number of visits to emergency department, admissions to hospital or diagnostic tests, however the mean number of visits have decreased. At first glance, a reduction in health service use may appear to be a positive outcome, however, increased health service use may in fact reflect more appropriate use of services, for example a patient seeking regular sessions with allied health providers to assist in managing their pain<sup>7</sup>.

Table 7.1: Changes in health service utilisation

Health Service	Referral (median/mean)	Episode end (median/mean)
General practitioner	3.5 / 4.6	3.0 / 3.3
Medical specialist	1.0 / 1.4	0.0 / 0.8
Allied health professionals	3.0 / 4.9	1.0 / 2.9
Hospital emergency department	0.0 / 0.3	0.0 / 0.2
Admitted to hospital	0.0 / 0.2	0.0 / 0.1
Diagnostic tests	0.0 / 1.2	0.0 / 0.6

Source: ePPOC.

**F34: The ePPOC data shows a decrease in the mean number of health service visits (to GPs, medical specialists and allied health professionals) of patients attending pain clinics between referral to episode end.**

<sup>7</sup> ePPOC (2016) patient Outcomes in pain Management – 2016 Mid Year Report. P 25

## 7.2 CHANGES IN PAIN RELATED PROFESSIONAL ATTENDANCES AND THERAPEUTIC PROCEDURES

Table 7.2 shows the number of MBS claims for case conferences; pain medicine attendances; and neurosurgical pain relief from 2007 and 2015. Analysis of the data suggests an increase in the number of claims across all subgroups. The largest proportion of MBS claims occur in the MBS subgroups of Pain Medicine Attendances and Case Conferences. These two subgroups accounted for 92% of attendances in 2015. Total attendances for all MBS subgroups increased from 18,025 in 2007 to 48,123 in 2015, increasing 166% in the period. There were increases in several of the MBS pain related professional attendances and therapeutic procedures (2007 to 2015). Other therapeutic procedures declined by 44% between 2007 and 2016 (n=1267 to n=713). A breakdown of individual MBS numbers which make up the subgroup analysis is provided in Appendix B.

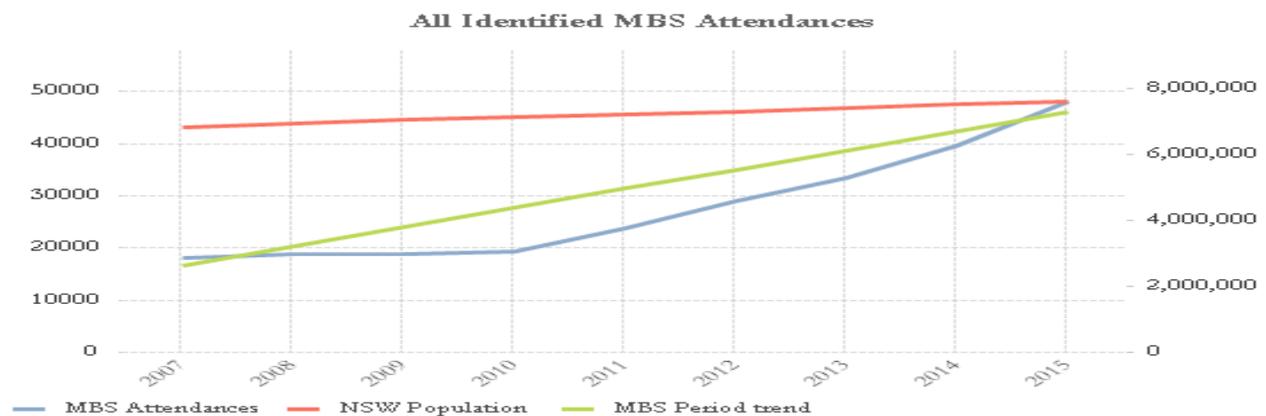
**Table 7.2: Volume of attendances by MBS Subgroup**

MBS Subgroup	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
Case Conferences	6,571	7,305	7,874	7,931	11,070	14,471	15,352	18,595	20,012	-
Neurosurgical Pain Relief	284	452	527	729	839	1,065	1,352	1,613	1,811	-
Other Therapeutic Procedures	1,267	1,305	1,304	1,250	1,024	881	847	736	742	713
Pain Medicine Case Conferences	-	-	-	-	-	-	-	-	1,288	-
Pain Medicine Attendances	9,903	9,873	9,245	9,318	10,780	12,571	15,867	18,692	24,270	-
<b>Total</b>	<b>18,025</b>	<b>18,935</b>	<b>18,950</b>	<b>19,228</b>	<b>23,713</b>	<b>28,988</b>	<b>33,418</b>	<b>39,636</b>	<b>48,123</b>	<b>713</b>

Source: [http://medicarestatistics.humanservices.gov.au/statistics/pbs\\_item.jsp](http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp)

Figure 7.1 shows that the rate of all MBS attendances for pain management services grew at a faster rate than that of NSW population growth between 2007-2015. This is by contrast with PBS services where PBS prescriptions grew at a similar rate to NSW population during this period.

**Figure 7.1: Volume of attendances vs NSW population 2007-2016**



Source: [http://medicarestatistics.humanservices.gov.au/statistics/pbs\\_item.jsp](http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp)

MBS claims for case conferences; pain medicine attendances; and neurosurgical pain relief increased consistently between calendar years 2007 and 2015. We were not able to make any inferences about improved efficiencies in health care utilisation based on MBS claims data.

**F35: Analysis of MBS data shows that the number of claims for case conferences; pain medicine attendances; and neurosurgical pain relief increased between 2007 and 2015.**

It is important to note that the MBS data represents claims made by privately referred patients seen by non-admitted services of public hospitals and/or patients seen in private rooms. Therefore it is only reflective of the work being undertaken in the public pain clinics for privately referred patients.

## Impact of PMP on primary care sector

This Chapter presents information gathered to assess the impact of the PMP, if any, on the primary sector's capacity and practice for managing patients with chronic pain.

### 8.1 AWARENESS AMONGST PRIMARY SECTOR PRACTITIONERS

For this indicator we used two data sources including interviews and surveys with GP and non-GP primary care clinicians across NSW conducted by HealthConsult during November 2016.

#### 8.1.1 Information to inform clinician understanding and management approaches

We interviewed clinicians about their preferred sources of information about chronic pain management. Table 8.1 summarises the gathered qualitative data obtained from GPs compared to non-GPs. Overall, our interviews suggested GPs and non-GPs were broadly similar in their sources for information about chronic pain. However non-GPs reported to make direct contact with the pain clinics particularly to answer specific questions whereas GPs engaged with the pain clinics largely through continuing professional development (CPD) activities.

**Table 8.1: Information sources about chronic pain for primary care clinicians (interview results)**

GPs	Percent	Non- GPs	Percent
Internet (e.g. NPS, Uptodate.com, Medscape)	100%	Direct contact with pain clinics	63%
Conferences and CPD (e.g. PHN, pain clinics)	63%	Internet (e.g. ACI, HIPS, Pain Australia)	56
Journals	50%	Conferences and CPD	44%
Colleagues (e.g. specialists, fellow GPs, pain clinics)	50%	Professional associations	31%
RACGP and ACCRM	25%	Journals	25%
Textbooks (e.g. Australian Medicines Handbook)	25%	Formal postgraduate study	25%
		Own formal research.	6%

Source: HealthConsult clinician interviews 2016.

We also surveyed primary care clinicians to determine where they obtained their information about management approaches for chronic pain. Table 8.2 shows that CPD activities were the most common sources of information about chronic pain management for both GPs and non- GPs. Other sources of information were professional journals; workshops and colleagues conferences; ongoing professional training and the ACI Pain Management Network website.

**Table 8.2. Information sources about chronic pain for primary care clinicians**

Information source	GP		Non-GP		Total	
	N	%	N	%	N	%
ACI Pain Management Network website	5	6%	7	10%	12	8%
Colleagues	8	9%	9	13%	17	11%
Conferences	8	9%	5	7%	13	8%
Continuing professional development	19	22%	12	18%	31	20%
Journals/Professional publications	12	14%	9	13%	21	14%
Original professional training	6	7%	7	10%	13	8%
Other	3	4%	5	7%	8	5%
Pain Australia and/or Chronic Pain Australia website	4	5%	5	7%	9	6%

Information source	GP		Non-GP		Total	
	N	%	N	%	N	%
Pharmaceutical reps	7	8%	3	4%	10	7%
Workshops	13	15%	6	9%	19	12%

Source: PMP Clinician survey 2016.

**F36:** Both the primary clinician interviews and clinician survey suggest that GP and non-GPs obtain information about chronic pain from similar sources (e.g. continuing professional development activities, publications and colleagues). However through interviews with primary care professionals we found that non-GPs are more likely to make direct contact with the pain clinics compared to GPs for information about managing patients with chronic pain.

**F37:** The most common source of chronic pain information for primary health professionals identified through the clinician survey was from profession-specific CPD. Other common sources included: journals, workshops and colleagues.

### 8.1.2 Awareness of National Pain Strategy and the NSW Pain Management Plan

Primary care clinicians were asked during the interviews how aware were they of the National Pain Strategy; NSW Pain Management Plan and ACI Pain Management website. Most GP were not aware of any of the sources (88%). For those GPs aware of the sources it was because they were involved in their development (12%). A larger proportion of non-GPs were aware of the sources with 38% reporting they had superficial knowledge of them; 19% saying reporting they were involved in their development and 44% reporting to have no knowledge of any of the sources.

We also surveyed primary care clinicians to ascertain which of the sources (i.e. National Pain Strategy and the National Pain Strategy; NSW Pain Management Plan and ACI Pain Management internet site) they were aware of. Table 8.2 shows that about 50% of primary care clinicians are aware of all three information sources. Compared to GPs, a higher proportion of non-GPs were aware of the NSW PMP and ACI website to the National Pain Strategy.

Table 8.2: Awareness of ACI website, National Pain Strategy and NSW PMP

Information source	Discipline of survey respondent	No		Yes		Total	
		N	%	N	%	N	%
ACI Pain Management Network website	GP	14	64%	8	36%	22	100%
	Non-GP	4	29%	10	71%	14	100%
	<b>Total</b>	<b>18</b>	<b>50%</b>	<b>18</b>	<b>50%</b>	<b>36</b>	<b>100%</b>
National Pain Strategy	GP	14	64%	8	36%	22	100%
	Non-GP	7	50%	7	50%	14	100%
	<b>Total</b>	<b>21</b>	<b>58%</b>	<b>15</b>	<b>42%</b>	<b>36</b>	<b>100%</b>
NSW Pain Management Plan	GP	15	68%	7	32%	22	100%
	Non-GP	4	29%	10	71%	14	100%
	<b>Total</b>	<b>19</b>	<b>53%</b>	<b>17</b>	<b>47%</b>	<b>36</b>	<b>100%</b>

Source: Clinician PMP survey 2016

**F38:** Less than a third of surveyed and/or interviewed GPs were aware of the National Pain Strategy; NSW PMP and ACI Pain Management website. However at least 50% of non-GPs that were surveyed and/or interviewed were aware of the ACI NSW PMP, ACI Pain Management website and the National Pain Strategy.

### 8.1.3 Perceived usefulness of ACI pain management website among clinicians

We interviewed primary care clinicians in order to ascertain the perceived usefulness of the ACI pain management website. GPs were unable to provide a response to this question due to their lack of awareness of the website. However of the non-GPs that have awareness of the website, they report to have superficial knowledge only (25%); use it frequently (25%); provide the URL to patients (19%); and do not use it (31%). Overall the interview analysis suggests that non-GPs have greater awareness of the ACI pain management website, and use it more frequently. However, GPs have limited awareness of the ACI pain management website and therefore do not use it.

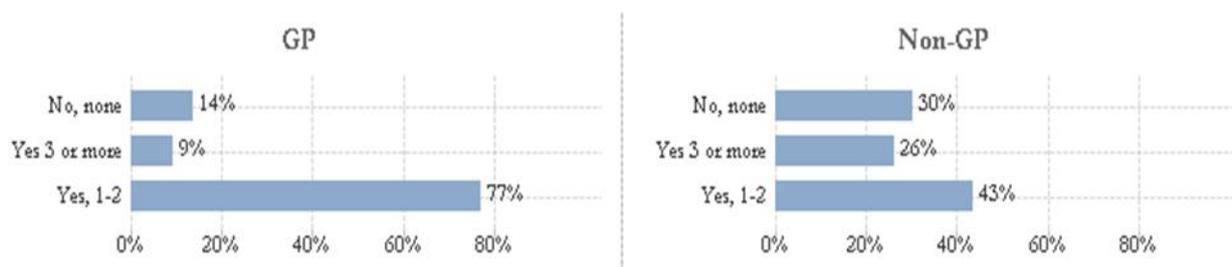
**F39: GPs were largely unaware of the ACI pain management website and therefore do not use it. Whereas non-GP clinicians were more aware of the ACI website, and therefore use the website for their information and some provided the URL to patients.**

### 8.1.4 Attendance at pain management updates in the last three years

We interviewed primary care clinicians in order to ascertain their attendance at pain management updates in the last three years. About 50% of GPs reported to have attended the updates at hospital and pain clinics; PHN and local CPD events (38%); drug company events (12.5%); RACGP or ACCRM events (25%); and/or through formal study (12.5%). There were only eight GPs that reported to not have attended any pain management specific updates in the last three years. For non-GP clinicians, again about 50% reported to have received the updates through attendance at hospital and pain clinics; professional association events (25%); formal study (25%); PHN and local CPD events (13%). There were 16 non-GP clinicians that reported to not have attended any pain management specific updates in the last three years (19%). In summary, we found hospital and pain clinic events were the most important source of pain management information over the last three years for both GPs and non-GPs.

Through the survey, primary care clinicians were asked if they had attended any pain management updates in the preceding three years. Figure 8.1 shows that a higher proportion of GPs (85%) reported to attend pain management updates than non-GPs (70%) over the last three years. Overall a large proportion of primary care clinician’s surveys had attended pain management updates in the preceding three years. This suggests that both GPs and non-GPs are engaged with maintaining and updating their professional pain-specific knowledge.

**Figure 8.1: Primary care clinician attendance at pain management updates last three years**



Source: Clinician PMP survey 2016. N (GP) = 22 N (non-GP) = 23

**F40: Majority of primary care clinicians surveyed and/or interviewed have attended pain management updates over the preceding three years.**

### 8.1.5 Future pain management updates

The primary care clinician asked “how would you prefer to receive future updates about pain management?” Table 8.3 shows that all GPs are interested in receiving updates and their preferred method for updates is from online resources (46%) followed by attending face to face seminars/workshops (43%). For non-GPs there was an equal preference for receiving updates from online resources (44%) and by attending face to face seminars/workshops (44%). Through interviews with primary care clinician we learnt that the reasons clinicians prefer online resources is due to their limited time and to reduce travel.

**Table 8.3: Preferred format for future pain management updates**

Mode for updates	GP		Non-GP		Total	
	N	%	N	%	N	%
Attending face-to-face seminars/workshops	12	43%	11	44%	23	43%
From online sources	13	46%	11	44%	24	45%
Not interested	-	-	1	4%	1	2%
Other	3	11%	2	8%	5	9%

Source: Primary care clinician PMP survey 2016

**F41: Majority of primary care clinicians reported to be interested in receiving pain management updates. Both GPs and non-GPs preferred methods for receiving updates is from online resources and by attending face-to-face seminars/workshops.**

We interviewed primary care clinicians in order to ascertain their preferred format for future pain management updates. All interviewed clinicians expressed an interest in further updates about pain management. The most preferred modality to receive updates reported by GPs was face-to-face (75%) followed by online (25%). Most GPs preferred that the face-to-face updates were in the form of complex case presentations. For non-GPs, face-to-face as again the preferred modality to receive the updates.

## 8.2 SATISFACTION WITH SUPPORT PROVIDED FROM PAIN CLINICS

The survey asked primary care clinicians “what type of support they had received from pain clinics”. There was a low response rate to this question. However, Table 8.4 shows that the most common support received by both GPs and non-GPs was assessment and management within the pain clinic. The data also shows that non-GPs had received assistance via the telephone, telehealth and in-practice education.

**Table 8.4: Types of support provided by pain clinics to primary care clinicians**

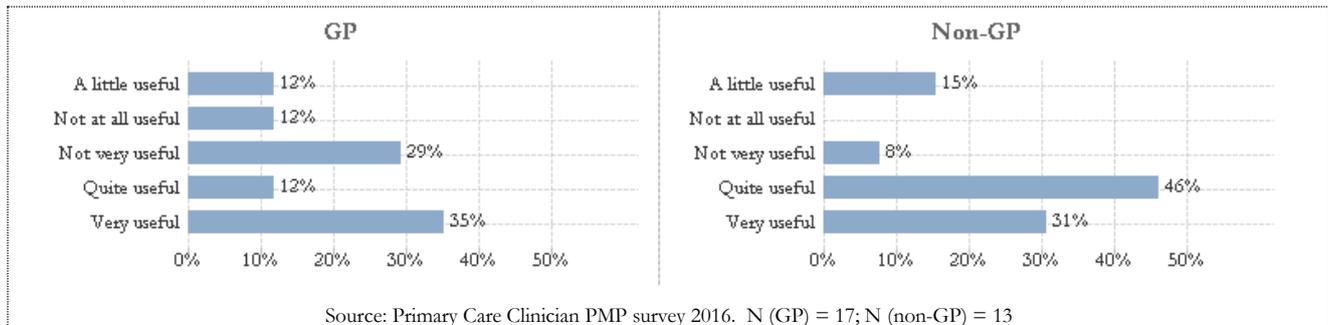
Types of support received	GP		Non-GP		Total	
	N	%	N	%	N	%
Assessment and management within the pain clinic, with letters	13	43%	5	24%	18	35%
In practice education	3	10%	3	14%	6	12%
No support	3	10%	2	10%	5	10%
Other	3	10%	2	10%	5	10%
Seminars/workshops	4	13%	2	10%	6	12%
Telehealth consultations	-	-	3	14%	3	6%
Telephone support	4	13%	4	19%	8	16%

Source: Primary care clinician PMP survey 2016

**F42: The most common support received by primary care clinicians from pain management clinics has been “assessment and management within the pain clinic, with letters”.**

The clinician survey also asked “how useful they have found support from local pain clinics”. Figure 8.2 shows that 47% GPs reported pain clinics were “quite useful” to “very useful”. By comparison, 75% of non-GPs reported that pain clinics were “quite useful” to “very useful”. Limited access to pain clinics was consistently reported by GPs.

**Figure 8.2: Usefulness of support provided by local pain clinic**



Through the interviews with GPs we learnt that most reported a lack of access to pain clinics and demands of travel on patients (75%); lack of access to specialists and multidisciplinary care in rural areas (38%). One GP commented “GPs are expected to pick up patients where there are inadequate services.” From the non-GPs we interviewed we learnt that there is limited access to government funded pain clinics (46%); limited access to GPs (19%); limited access to specialists (6%), whereas about 33% reported that they felt supported by the pain clinics).

**F43: Majority of primary care clinicians that have received support from pain management clinics have reported that the support has been ‘quite useful’ to ‘very useful’. However a theme identified from the GP interviews suggested that although pain clinics are a useful source of support they experience difficulty in accessing the service for their patients.**

Through interviews with primary care clinicians we gained insight into the dynamics of the relationship between local hospitals, GPs, allied health, opiate misuse, and access to pain clinics. This systems- level interaction data is potentially very valuable, however such questions were not captured by the structured survey. In future evaluations, at least a case study level analysis of these interactions would be useful in identifying barriers and enablers to ensuring the primary care, secondary and tertiary sectors are working together to better support each other and those suffering with chronic pain.

### 8.3 UNDERSTANDING OF BEST PRACTICE PAIN MANAGEMENT APPROACHES AMONG PRIMARY CARE CLINICIANS

We interpreted “contemporary chronic pain management approaches” as clinical interventions consistent with the Desirable Characteristics of National Pain Strategies. Recommendations by the International Association for the Study of Pain (IASP). Specific domains covered by the IASP include:

- education for both professionals and the public (including assessment of the needs of a person in pain and best practice management of pain);
- models of care (biopsychosocial, multidisciplinary, timely, emphasis on self-care, and provision for special populations);
- quality standards (access times, patient feedback, measurement of quality of life, and measure of economic burden); and

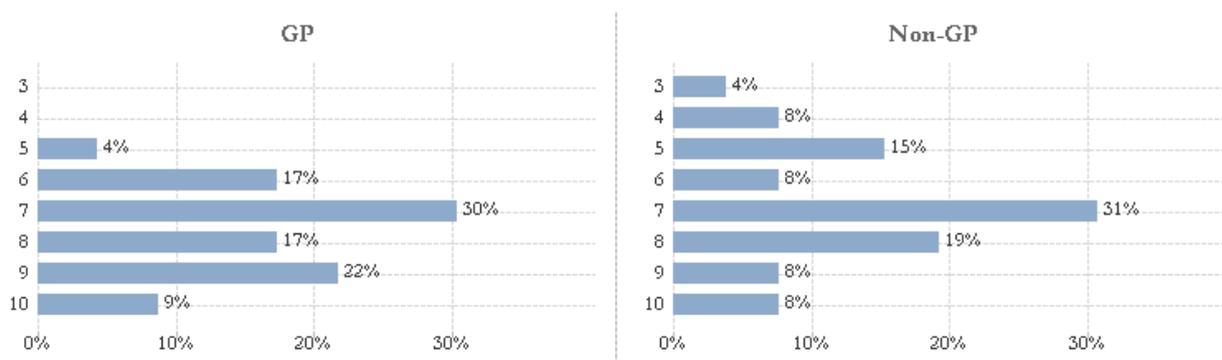
- research<sup>8</sup>.

### 8.3.1 Level of understanding of best practice approaches for managing chronic pain

During the interviews with primary care clinicians, they were asked to describe their level of understanding of best management approaches for managing chronic pain. Of the GPs that responded (n=8), 50% responded “competent” and 50% responded “good”. Of the non-GPs that responded; 13% responded “could be better” 38% “competent” and 50% “confident/good” (n=16). In addition, all respondents suggested their knowledge could be further improved and that there was often insufficient time to implement pain management guidelines fully.

The clinician survey also asked them to rate their level of understanding of best practice approaches for managing chronic pain. Figure 8.3 shows that majority of GPs and non-GPs rated their current understanding of chronic pain management as ‘7’ which is suggestive them believe they are above average but there is still scope for further learning improvement.

Figure 8.3: Level of understanding about best practice approaches to managing chronic pain



Source: PMP survey 2016. Scale: 0=no understanding and 10 = excellent understanding. N (GP) = 23; N (non-GP) = 26

**F44: Both GPs and non-GPs generally rated their current understanding of chronic pain management strategies as competent. This indicator does not offer any insight about the specific impact of the PMP on the primary care sector.**

### 8.3.2 Changed clinician understanding of managing chronic pain

We interviewed primary care clinicians in order to ascertain how their understanding of managing chronic pain had changed over the last few years. GP responses included:

- improved understanding of the effective use of multidisciplinary teams (75%);
- as I have gained experience I approach chronic pain with a more tailored approach (62.5%);
- improved understanding of new drugs (37.5%);
- less reliance on pharmaceuticals (25%).

The non-GP clinician responses included:

- improved understanding of the effective use of multidisciplinary teams (44%);
- improved understanding of the use of behavioural and psychological approaches including self-management, health literacy, and education (38%)
- specific training e.g. Butler, Nicholas (6%); and

<sup>8</sup> IASP (2016) Desirable Characteristics of National Pain Strategies. Recommendations by the International Association for the Study of Pain. Retrieved from <http://www.iasp-pain.org/DC/NPS?navItemNumber=655>

- increased focus on functional approaches (6%, (n=16).

We also surveyed primary care clinicians in order to ascertain how their understanding of managing chronic pain had changed over the last few years. The survey asked “have you changed any of the strategies you suggest/use in managing your patients chronic pain over the last few years?” Only 11 responses were provided. The free text responses were coded and include:

- cognitive approaches and education (n =11);
- multidisciplinary teams (n =7);
- reduced reliance on pharmaceuticals (n =5);
- access difficulties to pain clinics (n =2);
- Vitamin D (n=1).

**F45: The most common changes reported by primary care clinicians about how their understanding of managing chronic pain had changed over the last few years included an improved understanding of the effective use of multidisciplinary teams and incorporation of pain education and cognitive approaches.**

## 8.4 PRIMARY CARE CLINICIANS' MANAGEMENT STRATEGIES

We interpreted “current best practice approaches” as clinical interventions consistent with the Desirable Characteristics of National Pain Strategies. For this indicator we used two data sources including interviews with primary care clinicians and primary care clinician surveys.

### *8.4.1 Usual approaches to supporting patients experiencing chronic pain*

The primary care clinician survey asked clinicians, “to what extent do they feel the following chronic pain management strategies are effective for patients living with pain”. Clinicians could select multiple approaches. Table 8.5 shows that most GPs reported that no one strategy was completely effective. However GPs reported that the most effective strategies were: maintaining a healthy weight (78%); participating in relaxation activities (70%); seeing an exercise physiologist (70%); attending support groups (70%); and attending psychology sessions (66%). In comparison, non-GPs reported that the most effective strategies for managing chronic pain were: maintaining a healthy weight (83%); attending the gym or other fitness service (74%); attending psychology sessions (70%); or participating in relaxation activities (65%) and educational information from health professionals (65%). The most ineffective management strategy reported by both GPs and non-GPs was “taking nutritional or dietary supplements” (87%, 78% respectively). Overall, we found GP and non-GP strategies were broadly consistent with IASP and NSW PMP recommendations for managing chronic pain in a primary care clinical setting.

**F46: Primary care clinicians reported that the most effective chronic pain management strategies for patients living with pain was maintaining a healthy weight (>78%); participating in psychology sessions (>66%) and participating in relaxation activities (>65%). The most ineffective management strategy reported by both GPs and non-GPs was “taking nutritional or dietary supplements” (87%, 78% respectively). Overall, we found GP and non-GP strategies were broadly consistent with IASP and NSW PMP recommendations for managing chronic pain in a primary care clinical setting.**

Table 8.5: Extent to which primary care clinicians' management strategies reflect current best practice approaches to pain management

To what extent do you feel the following are effective for patients living with pain?	GP						Non-GP					
	0	1-4	5	6-9	10	Total	0	1-4	5	6-9	10	Total
Attending pain management clinics		38%	5%	52%	5%	100%	4%	13%	17%	48%	17%	100%
Participating in physiotherapy sessions		32%	14%	55%		100%		22%	17%	39%	22%	100%
Participating in psychology sessions		19%	14%	52%	14%	100%	4%	17%	9%	48%	22%	100%
Participating in other allied health sessions	9%	27%		64%		100%		22%	26%	44%	9%	100%
Attending support groups	10%	15%	5%	70%		100%	9%	17%	17%	52%	4%	100%
Receiving educational information from health professionals		29%	19%	43%	10%	100%	9%	17%	9%	52%	13%	100%
Accessing educational information from online websites		37%	16%	37%	11%	100%	9%	17%	13%	52%	9%	100%
Participating in relaxation activities		25%	5%	65%	5%	100%	9%	13%	13%	61%	4%	100%
Attending the gym or other fitness services		33%	10%	57%		100%	4%	17%	4%	61%	13%	100%
Undertaking self-driven exercise regimes		46%	9%	41%	5%	100%		39%	9%	44%	9%	100%
Seeing an exercise physiologist		25%	5%	65%	5%	100%	9%	18%	9%	50%	14%	100%
Receiving telephone support from pain clinics	23%	23%	8%	46%		100%	9%	18%	14%	41%	18%	100%
Taking nutritional or dietary supplements	23%	64%	5%	9%		100%	14%	64%	14%	9%		100%
Eating a healthy diet	5%	14%	23%	55%	5%	100%		30%	13%	48%	9%	100%
Maintaining a healthy weight		18%	5%	73%	5%	100%		17%		61%	22%	100%
Referring to/receiving complementary therapies	25%	40%	25%	10%		100%	4%	48%	4%	44%		100%
Having a pain management program	25%	40%	25%	10%		100%	4%	48%	4%	44%		100%

Source: Primary Care Clinician PMP Survey 2016. Scale = 0 "not at all" to 10 "completely"

We interviewed GPs and non-GPs in order to evaluate their perceptions of effective strategies for managing chronic pain. The interview responses reflected the scope of professional practice of individual respondents, and were consistent with contemporary approaches to chronic pain management. All GP respondents described a pattern of: 1) histories to exclude other causes; 2) work with patients to develop goals; 3) use of MDT; 4) titration of opioids with specialists if appropriate; and 5) ongoing patient coordination role for GPs. Non GP respondents reported a similar pattern of approaches to managing chronic pain including 1) histories to exclude other causes 2) work with patients to develop goals 3) use of MDT; and 4) coordination of patient care with GPs and specialists. Overall, we found GP and non-GP strategies were broadly consistent with IASP and NSW PMP recommendations for managing chronic pain in a primary care clinical setting.

#### ***8.4.2 Other approaches to supporting patients experiencing chronic pain***

We surveyed primary care clinicians in order to ascertain other approaches they used to support patients experiencing chronic pain. We coded the free text responses and found that, other strategies being used by clinicians included:

- cognitive and education approaches (n=8);
- indeterminate (n=4);
- reduced reliance on pharmaceuticals and alcohol (n=3);
- listening to patients (n=3);
- exercise (n=2);
- continuity of services (n=1);
- goal setting (n=1); and
- pet therapy (n=1).

We also interviewed primary care clinicians about other approaches they adopted to managing chronic pain. We found both GPs and non-GPs were not able to provide additional information beyond responses described in section 8.4.1, and consistently referred to their earlier responses.

**F47: Other approaches used by primary care clinicians that they believe were effective in supporting people living with chronic pain included: cognitive and education approaches; reduced reliance on pharmaceuticals and alcohol; listening to patients; exercise; continuity of services; goal setting; and pet therapy. These complementary strategies were broadly consistent with IASP and NSW PMP recommendations for managing chronic pain.**

## Conclusion and Recommendations

This Chapter draws on the information and findings documented in Chapters 4 to 8 to present the conclusions and associated recommendations of our evaluation of the PMP 2012-2016 against the objectives of the evaluation.

### 9.1 IMPACT OF PMP ON PATIENT EXPERIENCE AND WELL BEING

Most patients surveyed as part of the evaluation, regardless of their geographic location, reported to be able to access services to manage their pain and to access the best possible treatment and care. However, the evaluation found that the perception of primary care clinicians (including GPs) in regards to the wait time for their patients to access pain services is problematic with most quoting wait times between 12 to 18 months. Review of ePPOC data suggests this is only true for about 3% of patients. This difference in perception compared to reality suggests that there is further need for education and communication with primary care clinicians about the actual wait times that their patients would experience if referred to a pain management clinic. In addition, the evaluation found through thematic analysis of clinician interviews, that some pain clinics see all referred patients within 30 days of referral to undertake an assessment and triage them appropriately. This information was never reported by primary care clinicians and promoting this information to them may assist in changing their perceptions of accessing pain management services.

**R1: We recommend that the key findings from the evaluation are promoted to primary care clinicians so that they become more aware of the impact the PMP has had on improving access to pain management services, as well as the improvements achieved in patients' wellbeing through attendance at these services.**

The evaluation found that the ePPOC data supports that there have been improvement in patients' health and wellbeing outcomes. Specifically, it shows that there have been improvements in patients experiencing a reduction in pain frequency and pain in less regions; improvements in pain severity rating and interference subscales; improvements in their depression, anxiety and stress levels and in their confidence and ability to undertake daily tasks despite the presence of pain. This was found to be consistent with the data from the evaluation patient survey which showed that majority (61%) of patients understand their pain better and have more skills to manage their pain now compared to six months ago.

For those patients that have had accessed pain clinics in NSW, the evaluation found that health professionals (including GP, other health professional and specialist) were the main referrers to pain management clinics. The most common types of support and treatment being provided to patients by the pain clinics was "medication" and least common was "spinal cord stimulator implant". Overall 56% of survey respondents felt that the treatment and support being provided by pain clinics was either "quite useful" or "very useful" however non-metropolitan based patients felt the clinics were more useful (63%) compared to metropolitan based patients (52%).

The evaluation also found that most patients with chronic pain are able to find and understand information to help manage their chronic pain. The evaluation also found that for those patients attending pain clinics they reported to be able to have meaningful conversations with their pain service providers. This was not the experience of those not attending pain clinics. There could be lessons

learnt by exploring the experiences of patients with pain clinics, particularly understanding how pain services engage with their patients to make them feel the communication is meaningful, and then sharing these lessons in the education and communication sessions with primary care clinicians. This may improve the experiences of patients not attending pain clinics.

## 9.2 IMPACT OF PMP ON PATIENT RELIANCE ON OPIOIDS

The evaluation found that the data describing changes to patient reliance on opioids during the term of the PMP was mixed. While several measures in ePPOC indicate large decreases in opioid use in people attending pain management services in NSW, other data sources (e.g. PBS, oMEDD measures) show increases in opioid use in the NSW population as a whole. These data together with thematic analysis from interviews with primary care clinicians, which showed opioids are being overprescribed by GPs, suggests that although pain clinics are achieving a reduction in opioid use in the chronic pain population, the opioid prescribing practice outside pain clinics is escalating. There are several possibilities to tackling this issue including (1) increasing the population that attend pain management clinics or (2) further education and promotion provided to the primary care sector to address opioid misuse and non-medication strategies for managing patients suffering from chronic pain. Both suggestions have resourcing needs. For example to increase the population attending pain management clinics, resourcing including more staff, would be required for the clinics to take this on. Further whether the existing clinic resources are enhanced or whether new clinics are opened in different areas would need investigation. Also if promotion and education was to be considered, funding would also need to be provided to resource this activity.

**R2: As pain clinics have been shown to be able to reduce opioid use in individuals who have undergone treatment, increasing the proportion of patients who attend pain clinics is likely to reduce opioid use in NSW. Therefore strategies to increase numbers of patients attending pain clinics should be explored, noting there will be resource implications to be considered. In addition, if a decision is made to increase the resourcing of pain clinics, we recommend investigation into whether existing clinics are best placed to deliver the additional services or whether new clinics need to be established.**

**R3: We recommend that the ACI continue to support the provision of GP education to address opioid misuse and educate them further on non-medication strategies for managing patients suffering from chronic pain.**

## 9.3 IMPACT OF PMP ON HEALTH SERVICE UTILISATION, COSTS, EFFICIENCY AND FUNDING MODELS

The ePPOC data suggests a reduction in the mean and median number of visits patients suffering from chronic pain have with a GP, medical specialist visits and allied health professionals from referral to episode end. A reduction in health service use equates to a reduction in health service costs. However, whether a reduction in health service use and cost is resulting in the same, worse or better patient outcomes is unknown. For this type of analysis to be conducted a comparator group analysis would be required. This data was not available for the evaluation. The provided data did not enable an assessment of the impact of the PMP on health service efficiency and/or funding models.

In addition, the data used to assess the impact of the PMP on health service utilisation (including ePPOC and MBS) was problematic in that the data was only available for analysis at the level of NSW as a state. Also the ePPOC data provided to the evaluators consisted of a three year window as opposed to annual data where changes per year could be assessed. It is understood that the length of

an episode varies and that they cross calendar and financial years, however annual analysis would have enabled a better assessment of the impact of the PMP by year. Also as the PMP investment in pain clinics was tiered (i.e. different levels of support and funding provided to each pain clinic), and there are different arrangements and services models across each Local Health District (LHD), a more disaggregated level of analysis would have been useful. Future analysis would be more beneficial at the level of the LHD and/or clinic. Comparisons can then be done at the state level, LHD level and clinics level and appropriate comparators at each level could be used to assess the impact of the PMP where different service models and/or funding models are being used.

**R4: Future analysis of the impact of the PMP on health services should be done using annual ePPOC data. The analysis should be done at multiple levels including State, LHD and clinic levels. Appropriate comparators should then be used at each level to enable an assessment of the impact of PMP where different service and/or funding models are being used.**

#### **9.4 IMPACT OF PMP ON PRIMARY CARE SECTOR CAPACITY**

The evaluation found that majority of GPs surveyed and/or interviewed were unaware of the National Pain Strategy; NSW PMP and ACI Pain Management website. Hence GPs were found not to be utilising the resources available on the ACI Pain Management website. Instead the majority of GPs were found to be obtaining the information they require to help them manage their patients that suffer from chronic pain by searching online and through attending conferences and other continuing professional development activities, including those hosted by pain clinics. Majority (86%) of GPs had attended pain management updates within the last three years and all were interested in continuing to attend future updates preferably in the format of a face-to-face workshop or online resource.

In contrast, a large proportion of non-GP clinicians (e.g. allied health, nurses) that were surveyed and/or interviewed were aware of the National Pain Strategy; NSW Pain Management Plan and ACI Pain Management website. In addition, non-GPs reported to utilise the ACI Pain Management website and some even reported providing the URL to patients as an information source. Most non-GPs (70%) had attended pain management updates within the last three years and majority (96%) were interested in continuing to attend future updates again in the format of a face-to-face workshop or online resource.

**R5: We recommend that the ACI continue to work with the PHNs and/or profession-specific education bodies (e.g. RACGP; Australian Physiotherapy Association) to deliver pain management update seminars/chronic pain management education that is promoted and available to primary care clinicians. In particular, we recommend exploring the best ways to increase GP awareness of the National Pain Strategy, NSW PMP and resources available on the NSW ACI website.**

The evaluation found that most surveyed primary care clinicians had been provided with some type of support from pain management clinics. However less than 50% of GPs found this support to be useful, whereas 75% of non-GPs found the provided support to be 'quite useful' to 'very useful'.

The evaluation found that GPs are experiencing challenges in getting their patients access to pain clinics and with the level of support provided by pain clinic to assist them in managing their patients suffering from chronic pain. Specifically through the primary care clinician interviews we gained insights into the dynamics of the relationship between local hospitals, GPs, allied health staff and in issues associated with opiate misuse and accessing pain clinics. This systems-level interaction data is potentially very valuable, however such questions were not captured by the structured survey. An

analysis of these interactions would be useful in identifying barriers and enablers that could be used to ensure that the primary, secondary and tertiary services are working together effectively to better support each other and those suffering from chronic pain.

**R6: In order to further understand the challenges being experienced by primary care clinicians in supporting their patients who suffer from chronic pain, we recommend the ACI explore the issues identified in the evaluation with health professionals working in primary, secondary and tertiary services that support patients with chronic pain. Such exploration would examine the dynamics of the relationships, the referral patterns, opiate misuse, and access to pain clinics. This information could then be analysed to identify barriers and enablers which could be used to ensure that primary, secondary and tertiary health services are working together to better support each other and those suffering with chronic pain.**

The evaluation found that the chronic pain management strategies that were considered effective for patients living with pain was similar amongst GPs and non-GPs in that most reported that “maintaining a healthy weight” was most effective and the least effective was “taking nutritional or dietary supplements”. Although there were differences between what GPs and non-GPs considered to be the most and least effective chronic pain management strategies, overall we found GP and non-GP strategies were broadly consistent with IASP and NSW PMP recommendations for managing chronic pain in a primary care clinical setting.

## 9.5 FUTURE EVALUATION OF THE PMP

Although HealthConsult did not design the data collection tools used in the Phase 3 evaluation, as the implementers, we have some suggestions that could be considered when designing future evaluations of the PMP.

### 9.5.1 ACI Pain Management Website

The ACI Pain Management website is designed so different segments of the website are targeted to different populations: “for everyone”; “for youth: PainBytes”; “spinal cord injury pain” and “health professionals”. There is currently no capacity for differentiating users of the website (e.g. people living with chronic pain from other users of the site). One way to address this issue is to have a registration page and ask which category a visitor belongs to (e.g. pain sufferer, carer/parent of pain sufferer, health professional etc.). Registration of users would allow enhanced tracking of patients and other site users through Google Analytics. However, in our opinion, user registration would decrease the usability of the site, and raise potential privacy issues. We suggest that the ACI consider conducting an annual pop up survey that asks one or two questions about who the website users are. This data can be used in any future evaluations and extrapolated to understand the types of users and the frequency by which they use the website. In addition, as a means of understanding what aspects of the website could be enhanced, a more in-depth survey could be conducted annually to understand which features of the website users like, what they don’t and what information they feel is missing.

**R7: In order to have a greater capacity to understand the types of users accessing the information and resources on the ACI Pain Management website, we recommend that an annual ‘pop-up’ survey is conducted asking users to identify themselves by a short selection of categories (e.g. person suffering from chronic pain, parent/carer of a person suffering from chronic pain etc.). In addition, as a means of understanding what aspects of the website could be enhanced, ACI could conduct a more**

**comprehensive survey annually to understand which features of the website users like, what they don't and what information they feel is missing.**

### **9.5.2 Analysis of the NSW ePPOC data**

The ePPOC data included in the evaluation was limited in that aggregate data, for three years, at state level was only provided. We recognise that these limitations are the consequence of potential identification issues of clinics in the ePPOC dataset. However by obtaining the required consent and support from the contributing services, the ePPOC dataset could be used as a valuable decision making aid for ACI. This data does not need to be publicly published but could be used to inform service model development opportunities. We recommend that the ACI continue their collaboration with ePPOC and work with the University of Wollongong to support the contributing services to build up the dataset so that more disaggregate level analysis can be conducted in future evaluations of the PMP.

**R8: We recommend that the ACI continue their collaboration with ePPOC and work with the University of Wollongong and pain clinic services to enable subsequent analysis of the data to be at a more disaggregate level in future evaluations of the PMP.**

It is also important to recognise that the evaluation data analysis was limited in its ability to triangulate the data sources and have more confidence in the findings. This was due to not only the aggregation of the provided ePPOC data, the low number of survey responses but also due to the difference in time periods by which the data was gathered (e.g. three year window of data for ePPOC compared to end November/December 2016 snapshot only for survey data). The provision of more granular data and larger survey responses will enable future evaluations to triangulate the survey results from clinicians, parents/carers, and individuals living with chronic pain with the ePPOC data. This will enable stakeholders to have more confidence in the evaluation findings and provide insights into why there may be variations in some of the data sources.

### **9.5.3 Survey design and dissemination techniques**

The chosen survey dissemination method, which included selecting only five pain clinics as the survey distributors for all three survey types, was problematic. This was partly impacted by the timeframe in which the evaluation was conducted and the distribution of surveys was hurried so that data collection was completed prior to Christmas. More time for planning by the evaluation team together with more time for working with the sites to decide the best strategy for dissemination would have helped. However, for future evaluation we recommend either targeting fewer sites and concentrate on increasing the survey responses at those sites so that more granular data is obtained and actionable recommendations very specific to sites is provided. Or include all pain clinics (which may result in fewer survey responses per site) but will represent the views of a broader target population. The applicability of the data and recommendations will be of a more generalised nature possibly relevant to more sites.

**R9: Future evaluations of the PMP that involve both patient and parent/carer surveys should ensure dissemination does not happen concurrently to minimise confusion of the survey responders. We suggest separate dissemination and stronger differentiation between patient and parent/carer surveys during future evaluations of the PMP.**

The interpretation of the patient and parent/carer survey data was also problematic in that there was no other data source by which the findings could be explored and/or triangulated with. This was unlike the primary care clinician data where both survey and interview data was available. Future evaluations should consider the use of at least a subset of patient and/or parent/carer interviews, of sufficient size

to achieve thematic saturation, to enable thematic analysis of interview data to assist in the interpretation of the survey data.

Also the patient survey suffered from a high dropout rate as the survey progressed through the included questions. This suggests that the survey was too long and/or too complicated. We suggest that future evaluations of the PMP that involve a patient survey include focus testing the survey prior to ensure the dissemination of a simple and clear survey which will assist in encouraging the completion and decrease the dropout numbers as the survey progresses.

**R10: For future evaluations of the PMP that involve target population surveys, we recommend including testing of the survey with a sample (e.g. n=3 is sufficient) of the intended target audience in advance of survey release as an aid to decreasing the dropout rates.**

#### ***9.5.4 Use of national data collections***

As previously discussed, like the ePPOC data, the PBS and MBS data could not be disaggregated below NSW State level. Should future evaluations of the PMP take up our suggestion of analysing the data at multiple levels including State, PHN or LHD and clinic level, we recommend that a data request is made to the Department of Human Services to obtain the required MBS and PBS data at a more disaggregated level. This will enable, for example, the rates of opioid prescription by specific opiates to be analysed at the PHN level, which may identify areas where further education could be targeted particularly at the GP population of prescribers.

**R11: For future evaluations of the PMP, we recommend a formal data request is made to the Department of Human Services to obtain PBS and MBS data at the LHD or PHN level, annually from 2012, by opiates. Such analysis, for example, may identify areas that need targeted education and/or show reduction in opiate prescription rates following a targeted education intervention.**

## Appendix A : Vimeo video analytics

Table A.1: Vimeo video analytics

Video Title	Total loads	Total plays	Total finishes	% of videos loaded that are played	% of videos that are played that are played to the end
Introduction to Pain	28,721	7,666	2,232	27%	29%
Pain and Physical Activity	12993	3029	621	23%	21%
Episode 1 - Introduction to Chronic Pain	9,175	2,731	1,432	30%	52%
Getting help from your Healthcare Team	10316	2186	507	21%	23%
Pain: Lifestyle and Nutrition	9,143	2,172	420	24%	19%
Pain and Sleep	9789	2013	349	21%	17%
Pain and Role of Medications	9,980	1,967	304	20%	15%
Welcome to PainBytes	20598	1940	947	9%	49%
Pain and Thoughts	9,188	1,875	272	20%	15%
Episode 1 - Segment 1 - How do we feel pain?	2992	1215	560	41%	46%
Episode 1 - Segment 3 - How can I manage Chronic Pain	3,036	1,035	503	34%	49%
Episode 1 - Segment 2 - What is Acute and Chronic Pain	3670	988	525	27%	53%
Episode 2 - Introduction to Pain and Physical Activity	4,100	987	492	24%	50%
Episode 1: Introduction to Spinal Cord Injury and Chronic Pain	3208	808	137	25%	17%
Episode 3 - Introduction to Pain and Feelings	2,874	762	408	27%	54%
Episode 4 - Introduction to Pain and Mind Body Connection	3528	750	345	21%	46%
Episode 1 Segment 5 - How can I take Responsibility for my Pain	2,355	639	350	27%	55%
Episode 1 - Segment 4 - Who can help me manage chronic pain	2064	610	349	30%	57%
E5 - Intro Pain and School	3,082	577	362	19%	63%
Episode 6: Medications for Spinal Cord Injury Pain	2924	489	85	17%	17%
Episode 2: Understanding Pain after Spinal Cord Injury	1,588	477	115	30%	24%
Episode 5 Segment 3 - What Will I Do When I Get Pain At School	1608	442	197	27%	45%
Episode 2 - Segment 1 - Why Is Nutrition Important When You Have Pain?	1,203	408	196	34%	48%
Episode 3 Segment 1 - Stress And Anxiety Personal Experience	1084	369	194	34%	53%
Episode 6 - Introduction to Pain and Family	1,586	356	182	22%	51%
Episode 2 - Segment 4 - How Can I Make My Goals SMART	2210	356	169	16%	47%
Episode 2 - Segment 2 - What Are The Benefits Of Physical Activity	1,237	353	198	29%	56%
Episode 3 Segment 3 - How Are Feelings Thoughts And Actions Connected	2237	316	128	14%	41%
Episode 4 Segment 5 - Relaxation Techniques and Mindfulness	2,862	306	186	11%	61%
Episode 4: Spinal Cord Injury Pain, Physical Activity and Exercise	1352	291	63	22%	22%
Episode 2 - Segment 5 - What Is An Upgrade and Flare Up Plan	1,253	290	149	23%	51%
Episode 2 - Segment 3 - What Are My Current Levels Of Physical Activity	1243	289	181	23%	63%

Video Title	Total loads	Total plays	Total finishes	% of videos loaded that are played	% of videos that are played that are played to the end
Episode 3 - Segment 2 - How Can Feelings Affect Your Pain	959	283	165	30%	58%
Episode 4 Segment 4 - How Can Distraction Be Used To Manage Pain	4690	273	114	6%	42%
Episode 7 - Introduction to Staying on Track	1,145	264	187	23%	71%
Episode 4 Segment 3 - What Are Unhelpful Thoughts	1042	244	146	23%	60%
Episode 5 Segment 2 - Why Do I Need To Go To School When I'm In Pain	1,206	228	141	19%	62%
Episode 7: Spinal Cord Injury Pain: Thoughts and Feelings	1118	224	51	20%	23%
Episode 4 Segment 1- Who Am I	673	212	129	32%	61%
Episode 4 Segment 2 - Are You Avoiding Certain Activities	784	197	104	25%	53%
Episode 5 Segment 7 - Explaining Pain To Teachers And Friends	978	188	79	19%	42%
Episode 4 Segment 6 - Using Techniques In Everyday Life	876	170	103	19%	61%
Episode 5 Segment 4 - How Will I Be Able To Concentrate At School	677	153	95	23%	62%
Episode 6 Segment 5 - Tips For Siblings And Families	645	119	48	18%	40%
Episode 6 Segment 4 - How Can I Communicate With My Family About My Pain	659	115	65	17%	57%
Episode 5 Segment 6 - How Will I Get Around School	536	109	66	20%	61%
Episode 7 Segment 1 - How Can You Plan For Challenging Situations	942	109	50	12%	46%
Episode 6 Segment 1- You're Not Alone In Coping With Pain	531	107	58	20%	54%
Episode 7 Segment 2 - Why Is It Important To Have Support	1,499	106	53	7%	50%
Episode 6 Segment 3 - What Are Some Challenges That A Family Can Experience	724	104	56	14%	54%
Episode 6 Segment 2 - What Are The Strengths Of My Family	453	81	58	18%	72%
Episode 7 Segment 3 - Where To From Here	323	27	27	8%	100%
<b>Total</b>	<b>193,659</b>	<b>42,005</b>	<b>14,953</b>	<b>22%</b>	<b>36%</b>

Source: vimeo-stats.docx provided by ACI for the period March 2014 to October 2016

## Appendix B : MBS Data

MBS SubGroup	ItemNum	2007	2008	2009	2010	2011	2012	2013	2014	2015
CASE CONFERENCES	735	1,865	2,188	2,646	2,486	2,910	3,627	3,549	5,323	6,755
CASE CONFERENCES	739	1640	1884	1269	1922	2,796	4,728	4,985	5,242	4,745
CASE CONFERENCES	743	1,385	1,226	1,157	1,213	1647	2008	2045	2507	2727
CASE CONFERENCES	747	1072	1460	1934	1481	1986	1985	2610	3,221	3,650
CASE CONFERENCES	750	285	283	414	476	1,048	1,051	1,130	1,287	1,047
CASE CONFERENCES	758	324	264	454	353	683	1072	1033	1,015	1,088
NEUROSURGICAL PAIN RELIEF	39125	9	8	13	3	2	11	6	5	4
NEUROSURGICAL PAIN RELIEF	39126	34	45	36	10	12	22	15	12	20
NEUROSURGICAL PAIN RELIEF	39127	2	-	2	2	6	8	9	2	4
NEUROSURGICAL PAIN RELIEF	39128	18	17	21	11	15	15	18	18	13
NEUROSURGICAL PAIN RELIEF	39130	49	90	85	152	198	186	391	620	673
NEUROSURGICAL PAIN RELIEF	39131	28	49	92	109	126	164	194	191	284
NEUROSURGICAL PAIN RELIEF	39133	18	22	17	24	17	26	24	7	15
NEUROSURGICAL PAIN RELIEF	39134	49	77	74	111	120	155	172	188	230
NEUROSURGICAL PAIN RELIEF	39135	18	25	26	33	29	47	56	62	74
NEUROSURGICAL PAIN RELIEF	39136	17	32	41	88	95	120	147	162	153
NEUROSURGICAL PAIN RELIEF	39137	2	7	13	15	26	42	29	31	22
NEUROSURGICAL PAIN RELIEF	39138	30	70	98	164	183	256	287	304	307
NEUROSURGICAL PAIN RELIEF	39139	10	10	9	7	10	13	4	11	12
OTHER THERAPEUTIC PROCEDURES	14218	1267	1305	1304	1250	1024	881	847	736	742
PAIN MEDICINE CASE CONFERENCES	2946	-	-	-	-	-	-	-	-	476
PAIN MEDICINE CASE CONFERENCES	2949	-	-	-	-	-	-	-	-	180
PAIN MEDICINE CASE CONFERENCES	2954	-	-	-	-	-	-	-	-	30
PAIN MEDICINE CASE CONFERENCES	2958	-	-	-	-	-	-	-	-	503
PAIN MEDICINE CASE CONFERENCES	2972	-	-	-	-	-	-	-	-	62
PAIN MEDICINE CASE CONFERENCES	2974	-	-	-	-	-	-	-	-	35
PAIN MEDICINE CASE CONFERENCES	2978	-	-	-	-	-	-	-	-	1

MBS SubGroup	ItemNum	2007	2008	2009	2010	2011	2012	2013	2014	2015
PAIN MEDICINE CASE CONFERENCES	2992	-	-	-	-	-	-	-	-	1
PAIN MEDICINE ATTENDANCES	2801	2,842	2,792	2,678	2,952	3,482	4,314	5,250	5,876	7,846
PAIN MEDICINE ATTENDANCES	2806	6880	6806	6381	6181	7076	8040	10326	12,428	15,843
PAIN MEDICINE ATTENDANCES	2814	181	265	184	163	200	190	142	161	320
PAIN MEDICINE ATTENDANCES	2820	-	-	-	-	-	21	71	99	95
PAIN MEDICINE ATTENDANCES	2824	-	-	-	6	-	2	18	6	22
PAIN MEDICINE ATTENDANCES	2832	-	4	2	16	16	4	60	122	144
PAIN MEDICINE ATTENDANCES	2840	-	6	-	-	6	-	-	-	-
<b>Total</b>		<b>18,025</b>	<b>18,935</b>	<b>18,950</b>	<b>19,228</b>	<b>23,713</b>	<b>28,988</b>	<b>33,418</b>	<b>39,636</b>	<b>48,123</b>

Source: MBS Data

## Appendix C : Analysis of parents/carers survey

### IMPACT OF PARENT/CARERS LIVES

Figure C.1 shows the gathered data from parents/carers of adults about how caring for someone with chronic pain has restricted their life.

Figure C.1: Parent/carers experiences of caring for adults: their pain has restricted your life

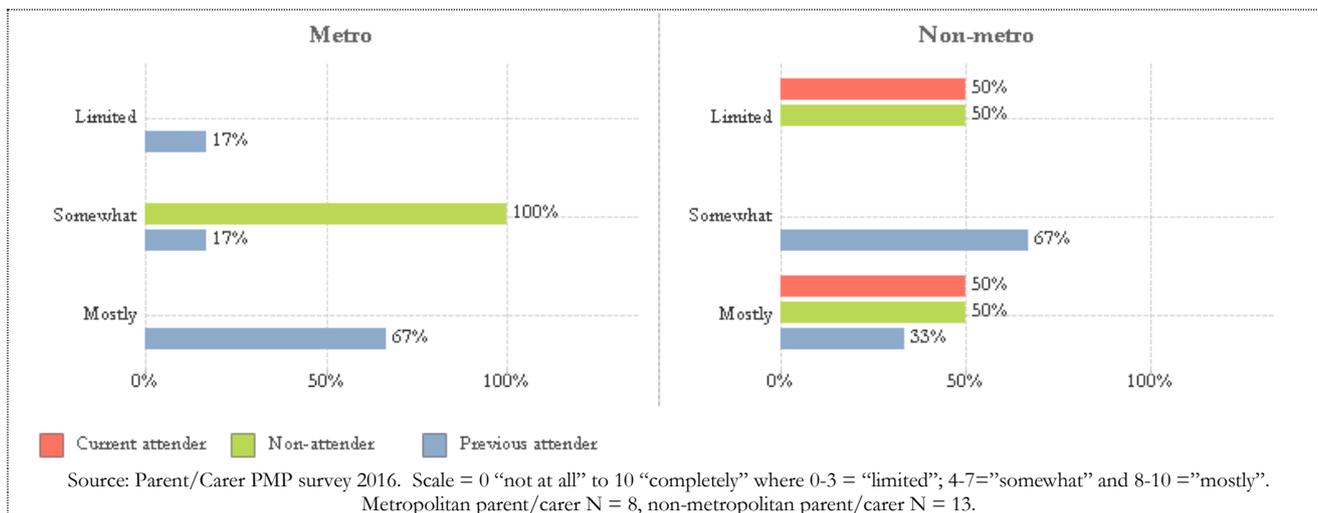
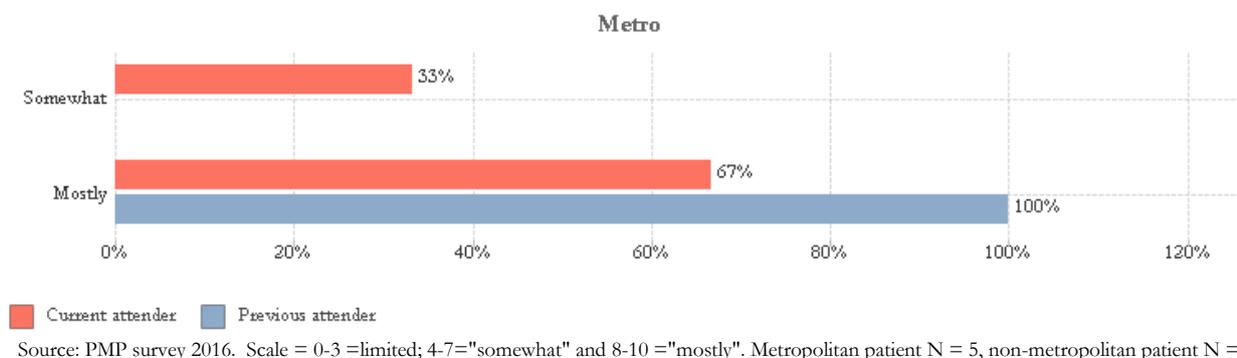


Figure C.2 shows the gathered data from parents/carers of children about how caring for someone with chronic pain has restricted their life.

Figure C.2: Parent/carers experiences of caring for <19 year old: has pain restricted your life?



### IMPACT ON PARENT/CARERS HEALTH

Figure C.3 shows the gathered data from parents/carers of adults about how caring for someone with chronic pain has affected their health.

**Figure C.3: Parent/carers experiences of caring for adult: their pain has affected your health**

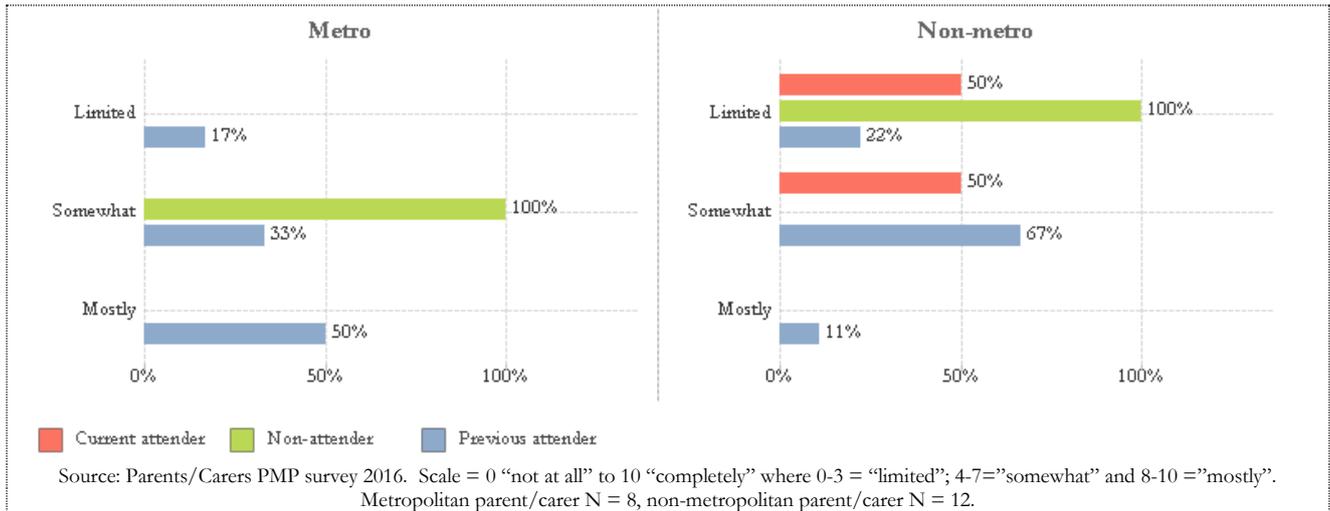
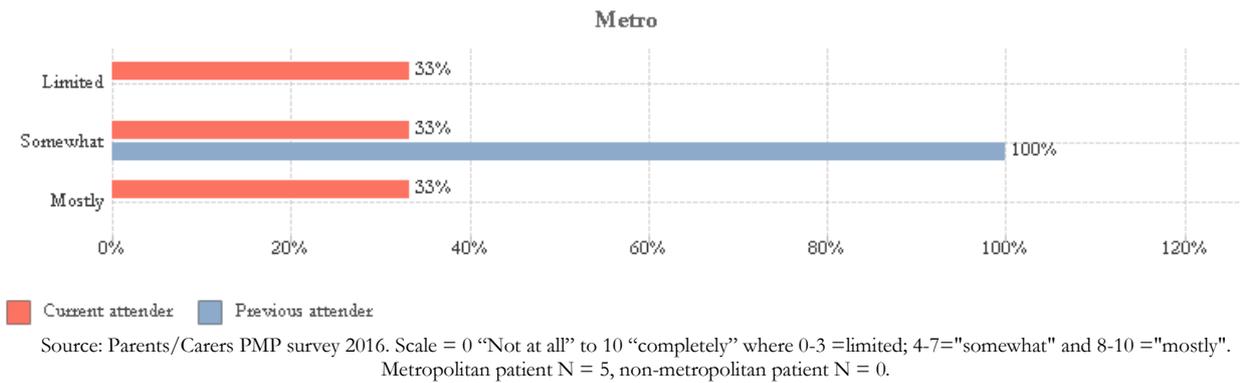


Figure C.4 shows the gathered data from parents/carers of children about how caring for someone with chronic pain has restricted their life.

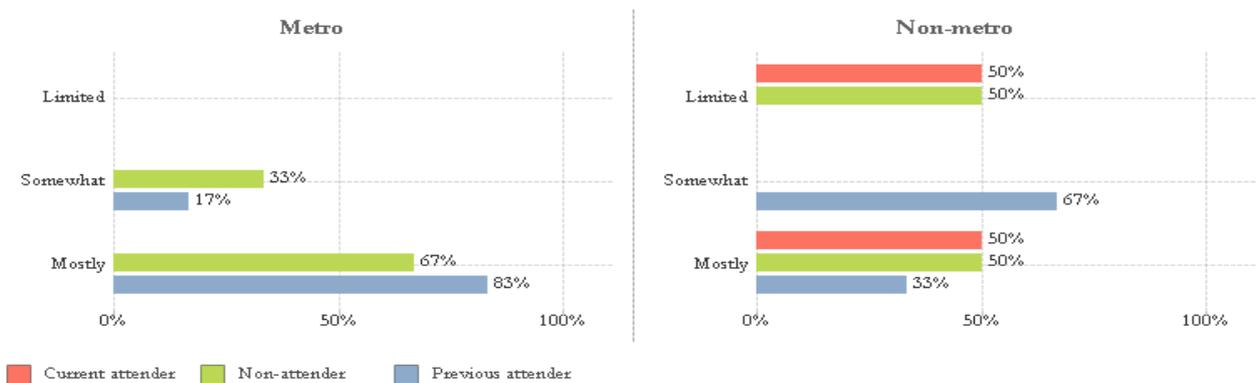
**Figure C.4: Parent/carers experiences of caring for <19 year old: has pain restricted your life?**



**UNDERSTANDING WHY PEOPLE HAVE PAIN**

Figure C.5 shows the gathered data from parents/carers of adults about whether they understand why the person they care for has pain.

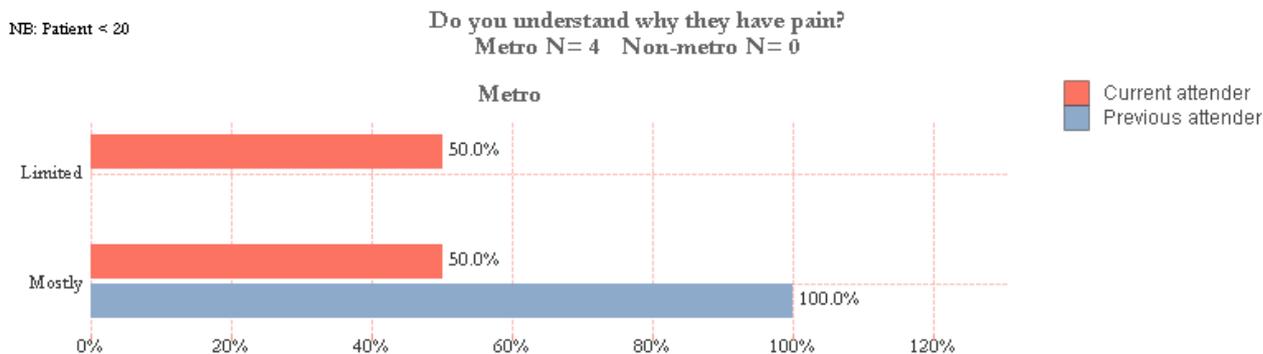
**Figure C.5: Parent/carers experiences of caring for adult: you understand why they have pain**



Source: Parents/Carers PMP survey 2016. Scale = 0 “not at all” to 10 “completely” where 0-3 = “limited”; 4-7=“somewhat” and 8-10 =”mostly”.  
Metropolitan parent/carer N = 8, non-metropolitan parent/carer N = 12.

Figure C.6 shows the gathered data from parents/carers of children about whether they understand why the person they care for has pain.

**Figure C.6: Parent/carers experiences of caring for <19 year old: do you understand why they have pain?**



Source: Parents/Carers PMP survey 2016. Scale = 0 “Not at all” to 10 “completely”

### UNDERSTANDING THE INFORMATION ABOUT PAIN

Figure C.7 shows the gathered data from parents/carers of adults about whether they understand the information they have been given about chronic pain.

**Figure C.7: Parent/carers experiences of caring for adult: You understand their information about pain**

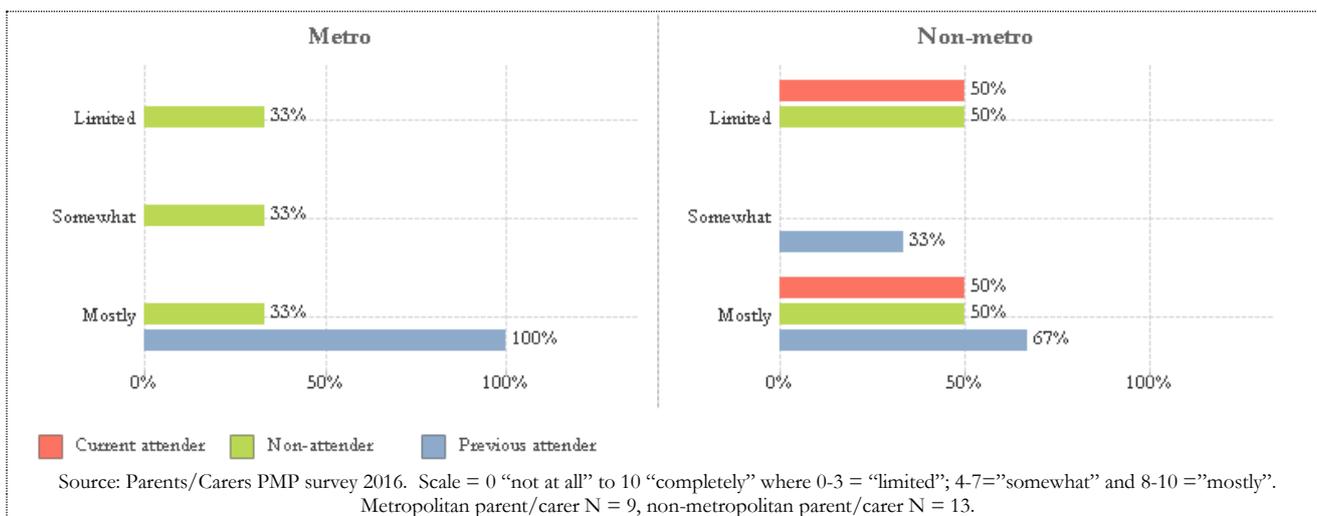
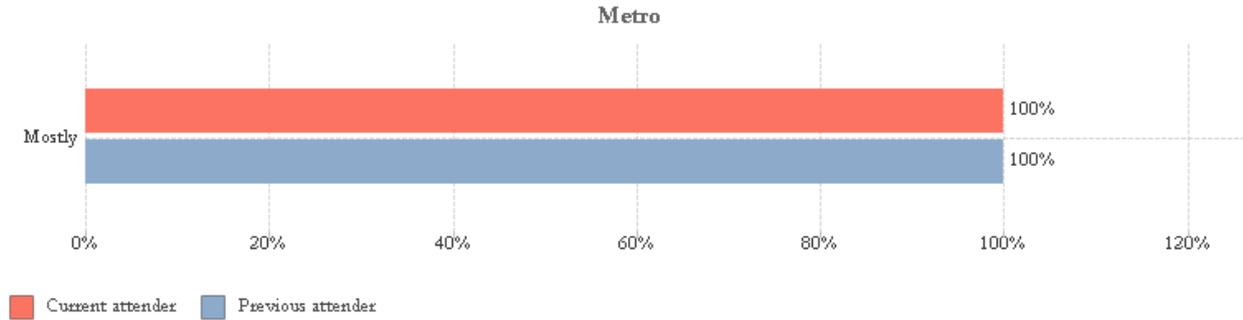


Figure C.8 shows the gathered data from parents/carers of children about whether they understand the information they have been given about chronic pain.

**Figure C.8: Parent/carers experiences of caring for <19 year old: understanding information about pain**

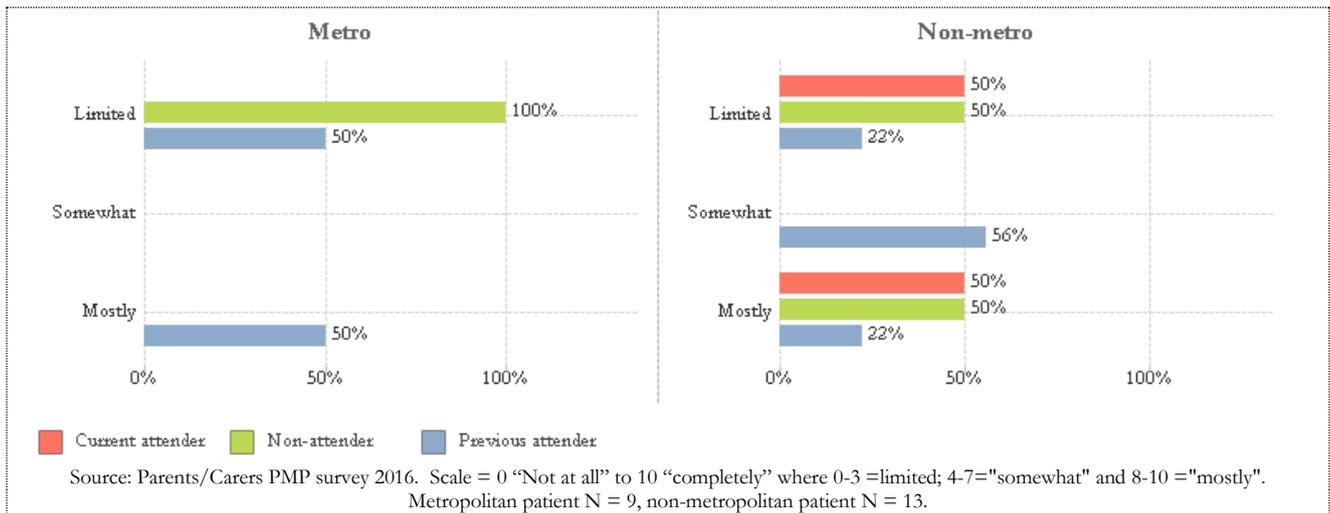


Source: Parents/Carers PMP survey 2016. Scale = 0 “Not at all” to 10 “completely” where 0-3 =limited; 4-7=“somewhat” and 8-10 =“mostly”.  
Metropolitan patient N = 5, non-metropolitan patient N = 0.

**SUPPORT PROVIDED TO PARENTS/CARERS**

Figure C.9 shows the gathered data from parents/carers of adult about whether they feel supported to help with the pain of the individual for whom they were caring.

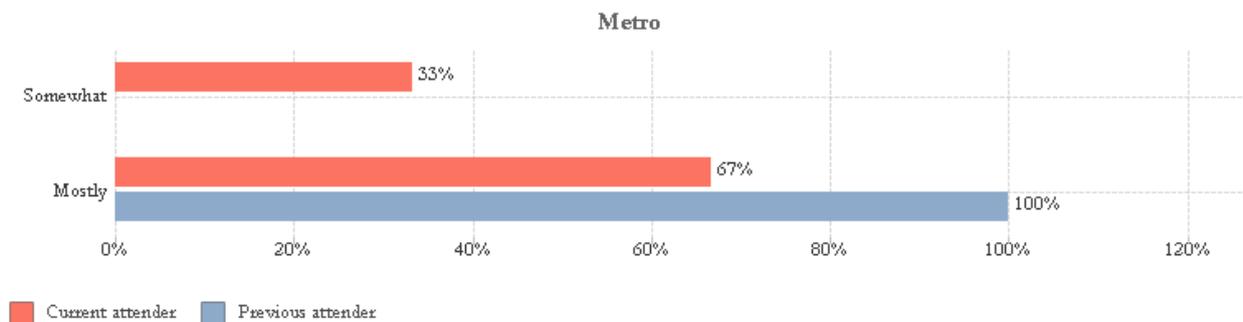
**Figure C.9: Parent/carers experiences of caring for adult: Feel supported to help with their pain**



Source: Parents/Carers PMP survey 2016. Scale = 0 “Not at all” to 10 “completely” where 0-3 =limited; 4-7=“somewhat” and 8-10 =“mostly”.  
Metropolitan patient N = 9, non-metropolitan patient N = 13.

Figure C.10 shows the gathered data from parents/carers of children about whether they feel supported to help with the pain of the individual for whom they were caring.

**Figure C.10: Parent/carers of people < 19 year old: Feel supported to help with their pain**

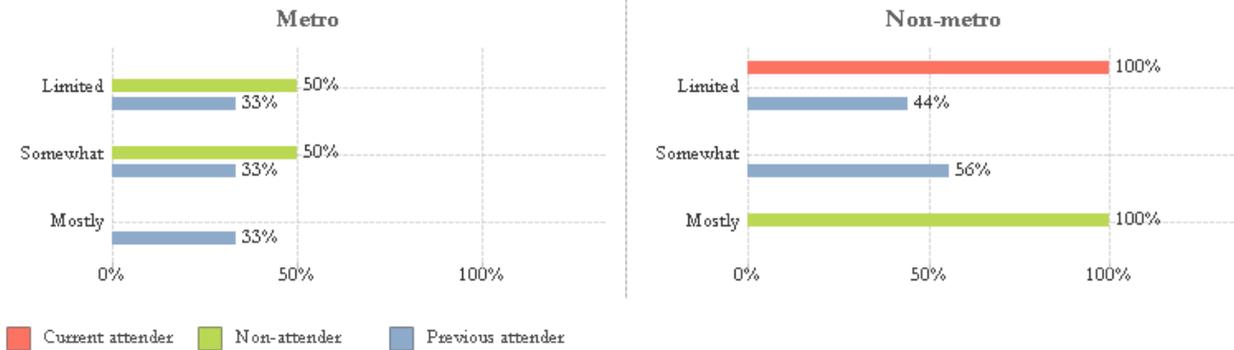


Source: Parents/Carers PMP survey 2016. Scale = 0 “Not at all” to 10 “completely” where 0-3 =limited; 4-7=“somewhat” and 8-10 =“mostly”.  
Metropolitan patient N = 9, non-metropolitan patient N = 13.

## CHANGES TO SUPPORT PROVIDED TO CARERS/PARENTS

Figure C.11 presents the gathered data of parents/carers of adults with chronic pain in regards to their perceptions of changes to the support they received to assist people living with chronic pain over the preceding six months.

**Figure C.11: Compared to six months ago - have more confidence in their future**



Source: Parents/Carers PMP survey 2016 Adults (greater than 20 years). Metropolitan N = 13, non-metropolitan N = 13

Figure C.12 presents the gathered data of parents/carers of adults with chronic pain in regards to their perceptions of changes to their skills in assisting people living with chronic pain over the preceding six months.

**Figure C.12: Compared to six months ago - have more skills to help manage chronic pain**

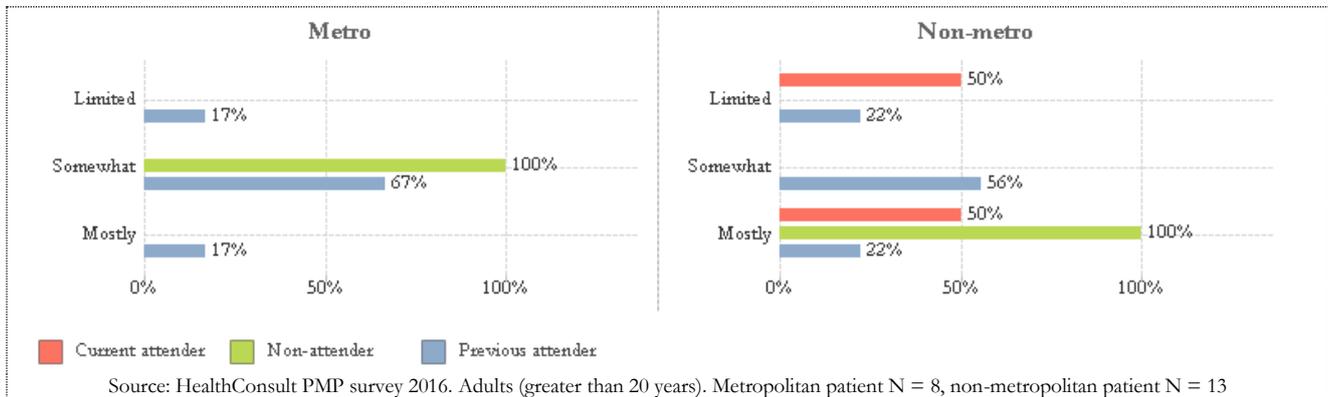
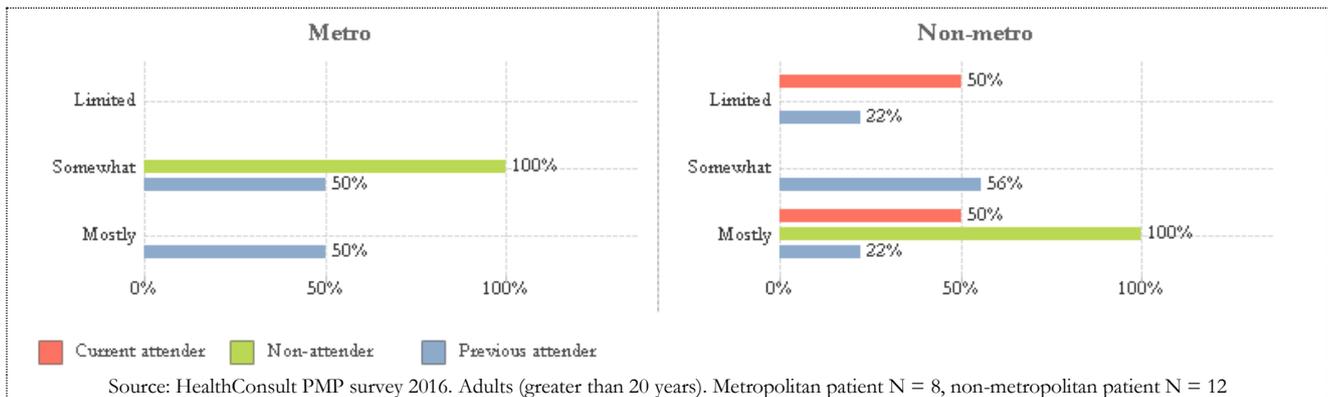


Figure C.13 presents the gathered data of parents/carers of adults with chronic pain in regards to changes in their understanding of chronic pain over the preceding six months.

**Figure C.13: Compared to six months ago – have better understanding of chronic pain**



## Appendix D : Free text patient survey data

Patient survey respondents were offered the opportunity to provide free text responses to several optional questions. The three free text questions were:

- (1) What new information, management strategies or skills did you learn at the Chronic Pain Clinic;
- (2) How could the Chronic Pain Clinic have been more helpful for you; and
- (3) Is there anything more you would like to say about your pain, how you've tried to manage it, and ways in which you may be better supported?

Their responses to these questions were coded by the evaluation team. We conducted an analysis of the free text themes using a grounded approach. That is, we grouped like responses into clusters that emerged from the patient responses, rather than defining categories in advance. We also examined the population of patient respondents to these optional questions. These results are described in Table E.4. We found current and previous pain clinic attenders, and non-attenders from both metropolitan and non-metropolitan regions were strongly represented.

We found mixed responses to each of the three questions. Negative or equivocal responses overall outweighed positive responses. However, this weighting towards negative responses should not be interpreted as necessarily reflecting generalised public sentiment towards the PMP. We believe these free text responses provided an avenue for people living with chronic pain to make their voices heard. So respondents used this available avenue to voice their frustration and to voice their concerns. In summary, chronic pain is clearly the source of a great deal of distress for individuals and their families and challenging for health professionals to manage. These free text responses thus also reflect the unfortunate reality that in some cases, chronic pain is an intractable clinical problem.

### PATIENT PERCEPTIONS OF NEW INFORMATION, STRATEGIES AND SKILLS ACQUIRED AT A CHRONIC PAIN CLINIC

Table D.1: What new information, management strategies or skills did you learn at the chronic pain clinic?

Category	Percentage	Raw number
Cognitive approaches to pain management (including CBT, counselling, individual reframing of experience)	36.7%	58
Physical self-management (includes pacing, activities of daily living [ADL], and exercise)	20.9%	33
Appropriate use of medications (including addiction, AOD)	19.0%	30
Understanding the range of available non-pharmaceutical treatments (e.g. surgery, implants)	11.4%	18
Other (including: just started, can't say, uncertain; and not elsewhere categorised.)	12.0%	19
<b>Total</b>	<b>100%</b>	<b>139</b>

Source: Patient PMP Survey (2016). Note totals may not add to 100 due to rounding

**Figure D.2: Representative free text responses: How could the Chronic Pain Clinic have been more helpful for you?**

How could the Chronic Pain Clinic have been more helpful for you?
"How to pace myself, but it is not always possible."
"Pin should not hinder your life. Medications are not the answer and can cause addiction"
"Health Professionals are learning more about chronic pain treatments but they are few and far between. Took me 3 years to find appropriate treatment and correct diagnosis of pudendal nerve entrapment. More resources at the pain clinic would go a long way into helping people cope and deal with chronic pain."
"none really but I haven't gone regularly as distance is an issue and the cost of going up"
"They taught me a lot but due to my recent circumstances that I do not wish to explain I need to work things out for myself. They were a great help and I wish to keep receiving info from the Pain Management Clinic, hopefully in the future I will be able to help someone else out"

Source: Patient PMP Survey (2016).

**PATIENT PERCEPTIONS OF HOW CHRONIC PAIN CLINICS MAY HAVE BEEN MORE HELPFUL****Table D.3: Thematic analysis: how could the Chronic Pain Clinic have been more helpful for you?**

Category	Percentage	Raw number
Negative experience (includes lack of empathy from health professionals and perceived poor diagnosis and treatment)	44%	80
Positive experience (including they did the best they could)	30%	55
Access ( including geography, cost, waiting time and health literacy)	9%	16
Other (including: limited GP liaison; unsure; provision of temporary accommodation; and not elsewhere categorised.)	9%	16
Ongoing engagement and follow up (includes follow up calls and appointments to monitor progress; provision of information about updates in pain science)	8%	15
<b>TOTAL</b>	<b>100%</b>	<b>182*</b>

Source: Patient PMP Survey (2016). \* Several responses were coded for more than one category. Note totals may not add to 100 due to rounding

**Table D.4: Representative free text responses: How could the Chronic Pain Clinic have been more helpful for you?**

<b>How could the Chronic Pain Clinic have been more helpful for you?</b>
"Less focus on 'back pain' (mine isn't back pain) and a broader acceptance of the multiplicity of causes of pain; development of an individual pain management plan for each participant. Printouts of exercise, etc. for later referral."
"I felt very supported and have stopped using medication."
"Course a little too short! 3 weeks only! 3 hours twice a week, Manage your Pain book by Dr Nicholas a "must" for all chronic pain sufferers. The training was an excellent experience, that largely freed me of the chronic pain."
"I really don't think there is much more they can do except keep me abreast of any new medications etc that may be of assistance to my ongoing pain"
"Just by understanding that because you don't turn up sometimes it isn't anything to do with them, but when you are trying to keep work and have to take time off for appointments it is sometimes hard to explain to your employer"
"Listening to the patients, rather than immediately label them. Treat them more individually. Not all treatments work for every patient. Show more empathy!! My experience was not great, frustrating. But have learned a lot about doctors, psychologists (etc.) and myself/pain."

**ADDITIONAL OPEN COMMENTS FROM PATIENTS ABOUT THEIR PAIN MANAGEMENT AND SUGGESTIONS FOR IMPROVED SUPPORT****Table D.5: Is there anything else you would like to say, about your pain, how you've tried to manage it and/or any ways you could be better supported?**

<b>Category</b>	<b>Percentage</b>	<b>Raw number</b>
Stable situation (includes feel helpless, managing day to day; acceptance; maintenance with little change)	33%	64
Negative experience of health service (includes GPs, specialists, allied health and pain clinics)	23%	45
Access issues ( including geography, cost, waiting time and health literacy)	17%	33
Positive experience of health services (including GPs, pain clinics; and all other mainstream and alternative providers)	16%	32
Other (including no; N/A; and not elsewhere categorised.)	11%	21
<b>TOTAL</b>	<b>100%</b>	<b>195 *</b>

Source: Patient PMP Survey (2016). \* Several responses were coded for more than one category. Note totals may not add to 100 due to rounding

**Table D.6: Representative free text responses: is there anything else you'd like to say?**

<b>Is there anything else you would like to say about your pain, how you've tried to manage it and/or any ways you could be better supported.</b>
"I am very lucky to have a specialist pain management doctor who has prescribed medication to relieve both acute and chronic pain. However the pain management course called reboot gave me confidence not to let the pain take over my life! I now continue to swim, walk exercise during acute attacks and they no longer cause panic as they used to do. I now continue whatever I am doing even during the worst attacks of pain. Thank you Reboot!!"
"I couldn't be any less supported. I'm disgusted in the whole system."
"Every day is a challenge and I can only do my best to cope"
"To suffer chronic pain has been extremely challenging but I am not alone. I have accepted it as part of the human condition."
"I tried to get into a pain clinic -- could not get in. They said I was managing quite well. I was VERY upset. I knew I needed help. And medications were not helping. Those of us suffering from neuropathic pain -almost impossible to manage -need MORE help than others."
"I absolutely hate being dependent on medication. I hate the fact that friends and family don't take on my struggle with my every day pain. Thankfully my GP is so caring and understanding. I am improved than years ago and feel that in my case other than my ailments causing the pain its how I handle stress in my life as to how I then can handle the pain."

**PROFILE OF PATIENT RESPONDENTS TO OPEN QUESTIONS****Table D.7: Profile of patient respondents to open questions**

Question	Clinic attender status	Metro		Non-metro		Total	
		n	% of respondents	n	% of respondents	n	% of all survey respondents
What new information, management strategies or skills did you learn at the Chronic Pain Clinic?	Current Attender	36	11%	16	5%	52	17%
	Previous Attender	59	19%	28	9%	87	28%
	<b>Total</b>	<b>95</b>	<b>30%</b>	<b>44</b>	<b>14%</b>	<b>139</b>	<b>44%</b>
How could the Chronic Pain Clinic have been more helpful for you?	Current Attender	37	12%	17	5%	54	17%
	Previous Attender	91	29%	35	11%	126	40%
	<b>Total</b>	<b>128</b>	<b>41%</b>	<b>52</b>	<b>17%</b>	<b>180</b>	<b>57%</b>
Is there anything else you would like to say? - about your pain, how you've tried to manage it and/or any ways you could be better supported.	Current Attender	28	9%	13	4%	41	13%
	Non-attender	29	9%	10	3%	39	12%
	Previous Attender	81	26%	31	10%	112	36%
	<b>Total</b>	<b>138</b>	<b>44%</b>	<b>54</b>	<b>17%</b>	<b>192</b>	<b>61%</b>