

painaustralia

Survey Report

Impact of opioid regulatory
reforms on people
living with chronic pain



April 2022

Contents

Page	1	Executive summary
Page	3	Background
page	5	Survey findings
page	8	The impacts when opioid medication was reduced or ceased
page	10	Difficulties accessing treatment and a lack of alternative services
page	15	Support provided by health professionals
page	17	Lack of education and communication
page	19	Opioid reforms - the impact on consumers
page	21	Perpetuating stigma
page	23	Increased anxiety and distress
page	25	The impact on consumers before and after the opioid reforms
Page	27	Solutions
Page	29	Conclusion
Page	30	Endnotes

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Executive summary

This report provides an analysis of a survey conducted by Painaustralia to determine how people with chronic pain have been impacted by the Australian Government's opioid regulatory reforms which were introduced in June 2020.

Painaustralia received an overwhelming response to the survey with more than 1800 respondents, and more than 25,000 consumers were reached on our social media platforms. The survey was also shared by other health organisations, several of whom have more than 15,000 followers.

Our survey has again highlighted the consequences of the reforms which have resulted in additional challenges for consumers to manage their pain. The reforms have focused solely on regulation rather than alternative policies being developed for multidisciplinary, non-medication based treatments.

The survey demonstrates the urgent need for alternative support and the significant mental health consequences for chronic pain consumers who are increasingly distressed and anxious when seeking medication, or other treatment services for their conditions.



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MAIN THEMES

Lack of access to alternative support and treatment in place of medication.

Difficulties in accessing medication for chronic pain.

Increased GP and health professional visits resulting in increased costs to consumers.

Feelings of stigma and judgement.

Decreased quality of life.

Greater feelings of distress and anxiety significantly impacting mental health.

Need for greater information, awareness and education of health professionals and consumers about the reforms and alternative treatments and support.

Recommendations

The survey findings clearly outline the urgent need for greater alternative services and treatments and mental health support for consumers who live with chronic pain. Greater education and awareness for both consumers and health professionals is a high priority. To address these issues, Painaustralia recommends:

01

Continuous and additional education and awareness campaigns addressing stigma, the reasons behind the reforms and alternative treatment options for both consumers and health professionals

02

Increased support for people living with chronic pain including a dedicated helpline to address mental health issues and provide referral to alternative pathways and support groups.

03

Funding for new item numbers under the Medicare Benefits Scheme to provide greater access to multidisciplinary pain management, allied health visits and group pain management programs

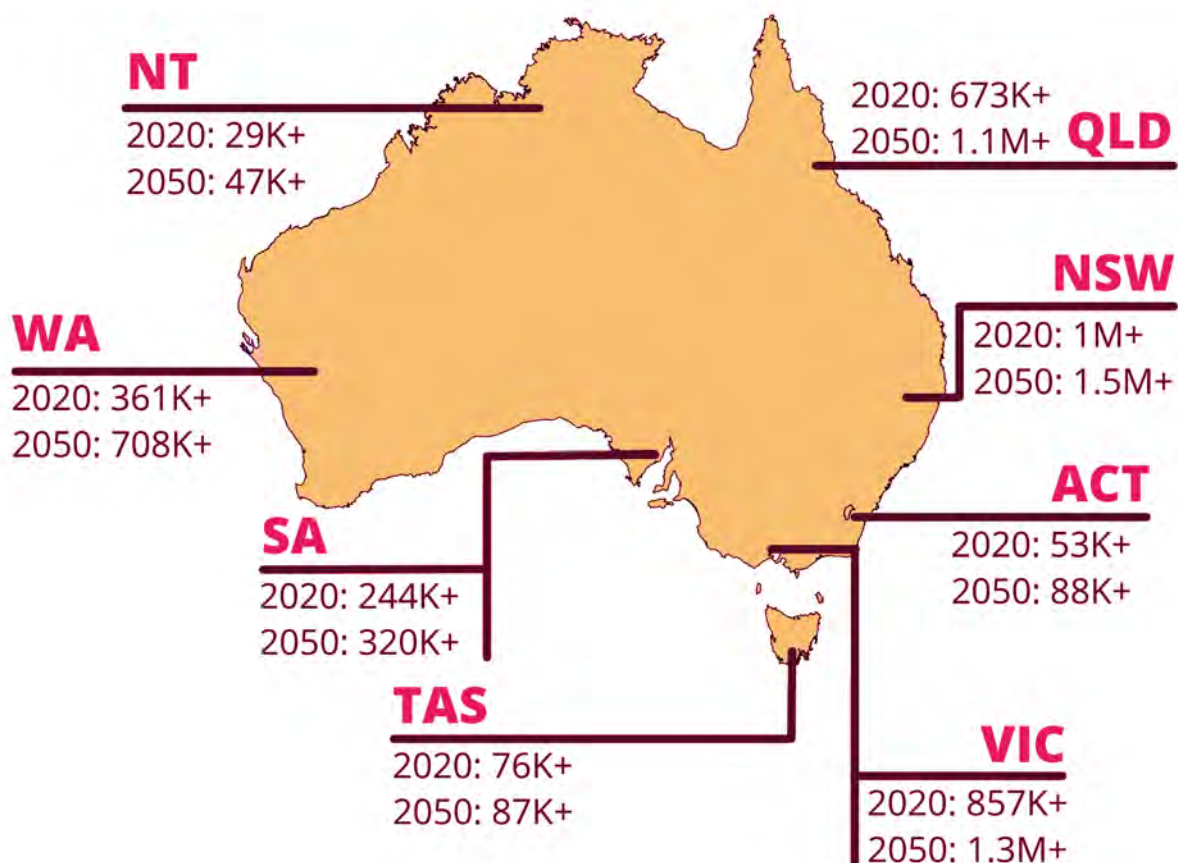


Background

Chronic pain is complex and each person experiences it differently. In Australia, chronic pain affects the quality of life of more than 3.4 million individuals (infographic 1) and carries a significant economic burden in lost production and health costs - estimated to be \$144.1 billion in 2020.¹ In the absence of any changes to health system treatments or prevalence rates, these figures are expected to grow exponentially to 5.2 million people living with chronic pain by 2050, costing the Australian economy \$215.6 billion dollars.²

Due to a lack of services and extremely long wait times across the country for pain specialist treatment, medicines are often the mainstay of treatment for people living with chronic pain. Some medicines such as paracetamol and non-steroidal anti-inflammatories can play a role within a multidisciplinary, best-practice approach to managing chronic pain for many consumers. Analgesics such as pregabalin, opioids, aspirin, paracetamol and paracetamol with codeine are among the most prescribed drugs in Australia, all of which are for pain relief.

**3.4 million Australians lived with chronic pain in 2020.
If no action is taken this number will rise to 5.2 million in 2050.**



Infographic 1: Pain prevalence in Australia¹

In Australia, more people die from opioid related causes than the national road toll.² In an effort to reduce this harm, the Australian Government introduced regulatory changes to the prescription of opioids as well as access to Modified Release Paracetamol for the management of pain. These changes came into effect from 1 June 2020 and were part of a suite of measures intended to support appropriate use of opioids and other pain medications, changes to clinical guidelines and ongoing prescription and compliance monitoring.

A Painaustralia survey conducted shortly after the introduction of the opioid reforms and several months into the pandemic in August 2020 showed consumers were finding it difficult to access their usual medications or alternative treatments, were being isolated and were facing additional barriers to accessing treatments.

Painaustralia supports the need to address harm from opioid use and acknowledges the need for regulation and oversight. However these changes coincided with the pandemic and the national rollout of Real Time Prescription Monitoring (RTPM) programs. All of these factors combined have contributed to limiting consumer access to medications in the absence of readily accessible and affordable alternative treatment options. While there is a need to be conscious of the harm that can result from opioid use, consumers should not be inappropriately denied access to the necessary pain management options they need.

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Survey findings

The Painaustralia survey, promoted via social media, was conducted over eight weeks from late December 2021 until the first week of February 2022. It received a total of 1808 responses and an additional 1920 social media engagements that included posts, reactions, shares, retweets and comments.

Overwhelmingly, consumers reported the reforms had had a significant negative impact on their quality of life. Consumers relayed stories of having their medications ceased immediately and being left with little or no alternative for treatment. They reported increased feelings of anxiety and isolation while having to cope with additional costs due to increased medical visits and inadequate funding for alternative treatment.

Overwhelmingly, consumers reported the reforms had had a significant negative impact on their quality of life. Consumers relayed stories of having their medications ceased immediately and being left with little or no alternative for treatment.



Participant profile

The majority of the participants in the survey were women (79.7 per cent), (table 1) and tended to be of working age with back pain and arthritis being the predominant chronic pain conditions (figures A and B). 95.6 per cent of respondents have used an opioid medication to manage their chronic pain (table 2), and 75.1 per cent are currently using opioid medications for their chronic pain (table 3).

Your gender	Percentage of respondents
Female	79.7 %
Male	18.9 %
Non-binary	0.3 %
Prefer not to say	0.4 %
Non-respondent	0.7 %

Table 1: Gender

Have you ever used an opioid medication to manage your chronic pain?	Percentage of respondents
Yes	95.6 %
No	3.3 %
Non-respondent	1.1 %

Table 2: Previous opioid medication usage

Do you currently use opioid medication for your chronic pain?	Percentage of respondents
Yes	75.1 %
No	24.1 %
Non-respondent	0.8 %

Table 3: Currently using opioid medications

79.7 per cent of participants were women

95.6 per cent of respondents have used an opioid medication to manage their chronic pain

75.1 per cent are currently using opioid medications for their chronic pain



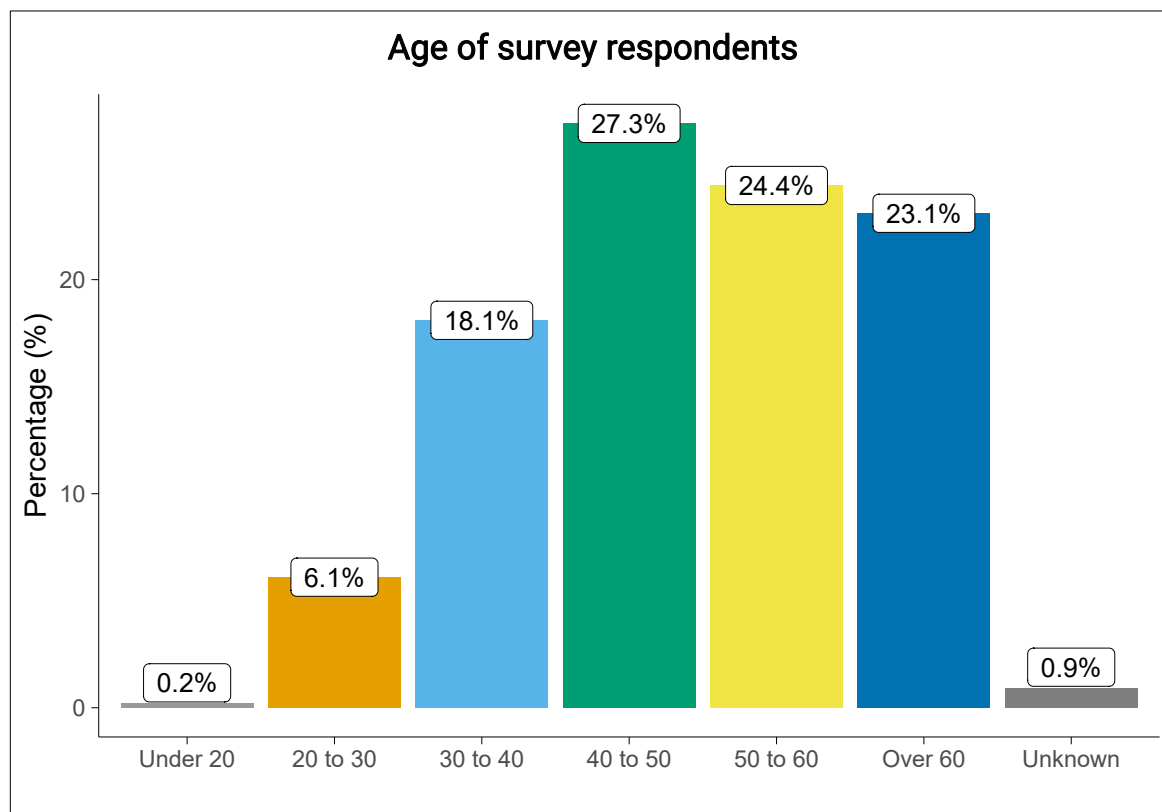


Figure A: Age of survey respondents

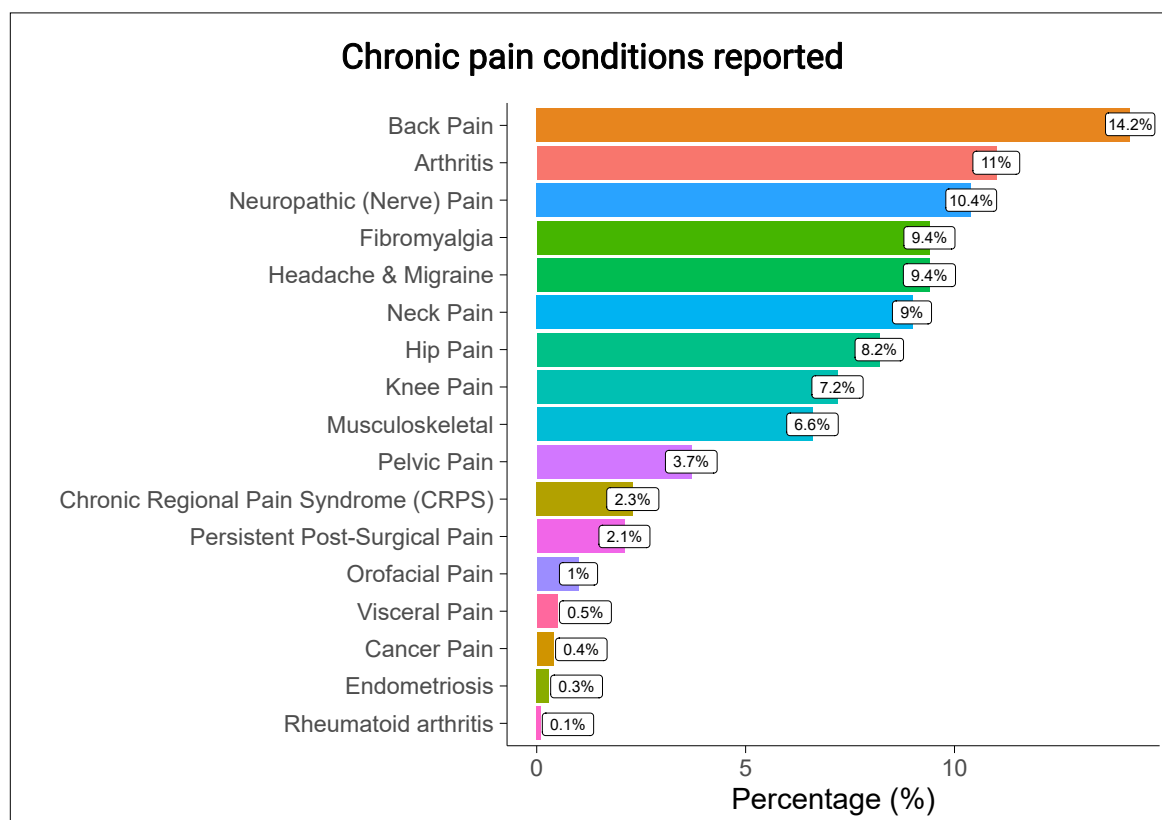


Figure B: Top 17 Chronic pain conditions reported



The impacts when opioid medication was reduced or ceased

Since the reforms were introduced, a total of 37.7 per cent of respondents said their opioid medication had been reduced by a health professional and total of 18.5 per cent had their medication ceased (table 4). 61 per cent of respondents who had their medication ceased or reduced said they would like to be more involved in the decision regarding their medication. (table 5)

Many respondents were concerned that their medications had been stopped or were reluctant to go to a GP in case their medication was ceased immediately. There were also reports of rapid opioid tapering with a lack of support or guidance from their prescribing health professionals. Rapid opioid dose reduction is a concern as it can pose risks such as more severe pain and neuro-psychological effects.

After the opioid reforms were introduced in June 2020, did your health care professional reduce or cease your opioid medication?	Percentage of respondents
No change in your opioid medication	37.9 %
Reduce your opioid medication	31.5 %
Cease your opioid medication	16.1 %
Refer you to a specialist who reduced your opioid medication	6.2 %
Non-respondent	5.9 %
Refer you to a specialist who ceased your opioid medication	2.4 %

Table 4: Reduced or ceased your opioid medication

If medications are required for managing your pain, would you like to be more involved in the decision regarding which medications you are prescribed?	Percentage of respondents
Yes	61.0 %
No, my GP already involves me in decisions around my medications	23.8 %
No, I trust my GP to make decisions in my best interest	4.9 %
Non-respondent	10.3 %

Table 5: Involvement in decision making regarding medication prescription

Consumer comments included:

*"At first, I wasn't given a choice the dosages were just cut, and some medications ceased completely. Now I have more say on my daily meds, but a restriction has been put in place for flare up meds."*³

*"I wasn't aware there was a reform. The next time I went to see a GP for opioid pain relief I was told this can only be prescribed to patients who are dying from cancer and I should be able to manage my pain with paracetamol. I would have appreciated knowing changes to prescribing practices so that so could discuss alternate treatment options rather than being brushed off and made to feel as though I was doing something wrong by asking for help to manage my severe pain."*⁴

*"As a carer I have seen some GPs suddenly refuse to prescribe opioid analgesics to patients they have been caring for, many for several years."*⁵

*"I had no say in the matter, I was simply told that my medications were to be reduced and that the doctor's hands were tied. The doctor cut my medications in half and made me withdraw cold turkey, no tapering, and just said that it was part of the new guidelines. I think I should have been given the opportunity to present my case as to my quality of life has been enhanced/improved with the addition of pain medication, rather than just the doctor making the decision for me and hence making my life worse."*⁶

*"An incredible amount of distrust in the system from the pain community. Each doctor visit was filled with apprehension 'is today the day I get cut off?'"*⁷

*"GPs need to have access to resources to assist with tapering off opioids. Wait times too long to get this knowledge from specialists when the assistance is needed immediately at the time, not in months' time."*⁸

*"Ceased prescription with no warning and no pain management plan in place."*⁹

*"I wasn't given a choice my doctor just said she would be reducing me until I was off it. She said I could see a occupational therapist but the waiting lists for pain specialists was too long."*¹⁰

*"I was told that I had to start reducing dose until I was weaned off. Regardless of pain levels. Regardless of quality of life."*¹¹

*"I was just told they were halving my dose and had no other options presented to me."*¹²

*"The decision was made for me with disregard to the impact it would have on my ability to work and care for my family."*¹³

Difficulties accessing treatment and a lack of alternative services

A majority of respondents (59.6 per cent) reported difficulties in accessing any treatment options for their pain management (table 6). The lack of alternative treatments and services is a reoccurring theme with 43.1 per cent reporting that their health professional did not offer an alternative treatment or support for them to manage their pain (table 7). Consumers from rural and regional areas told of their difficulty in accessing services and the need for travel and associated costs. In addition, the pandemic has created more barriers to accessing other treatment options. In some instances, consumers told us they had turned to medicinal cannabis in the absence of medications to help them manage their chronic pain.

Did you experience any difficulties in accessing any treatment options for your pain management?	Percentage of respondents
Yes	59.6%
No	25%
Non-respondent	15.4%

Table 6: Difficulties in accessing treatment options

Did your health professional offer an alternative treatment or support to manage your pain in another way?	Percentage of respondents
Yes	46.5 %
No	43.1 %
Non-respondent	10.5 %

Table 7: Alternative treatment or support offered

59.6%

of respondents reported difficulties in accessing any treatment options for their pain management.



Consumer comments included:

"Explained that they could not give me scripts but gave no alternative." ¹⁴

"Drs have advised me that they are too scared to provide my normal amount that they know works for me in case they get in trouble " ¹⁵

"Between the removal of medication and covid. I feel extremely let down. Been waiting over 18 months for an initial appointment at a specialist clinic." ¹⁶

"Having to change pain specialists I've been left on an inadequate dose and cannot see another pain specialist for another 7 months. Covid means I cannot access hospital treatment I need." ¹⁷

"My GP/practice doctors do not like opioids and are not as willing to prescribe them even though my Orthopaedic doctor required them pre and post operative. However they do not offer alternatives." ¹⁸

"access to pain specialist is a problem due to demand." ¹⁹

"I wish I had other options besides opioids when I'm in flare ups." ²⁰

"I decided to self-medicate with cannabis." ²¹

"Yes and no, covid has made a huge impact on pain management due to restricted exercise, restrictions to access to mental health, restrictions to accessing medical facilities, as someone who lives rather rurally and without local family support this impact has been felt massively on my behalf and while the reduction in pain medication has been an issue it is only due to high stress levels that pain had increased significantly along with usual pain management techniques being restricted." ²²

"Absolutely YES for support from my Pain Specialist but when it comes to my rural GP it's a resounding NO, ...patients are driving as far as 100km away to access another GP." ²³

"Living rural, waiting times for specialists are long." ²⁴

"I changed my dr & switched to medical cannabis due to his unwillingness to help with my pain management." ²⁵

"I've been in pain 35 years I've tried everything including trial meds I just need to be able to manage my pain so I can live and not be isolated and in pain" ²⁶

“

Nothing was offered that I hadn't already tried and almost all alternative medications caused adverse reactions. ²⁷

”

Common alternative treatments recommended

For those consumers who were offered alternative treatments (46.5 per cent), (table 7) the most common were allied health services (figure C) such as physiotherapy and psychology support. (table 8).

However, many consumers reported that they were unable to access these alternatives due to costs.

“Cost is prohibitive. 5 allied health sessions per year doesn’t cover half of what I need.”²⁸

Consumer comments included:

“Can’t afford constant physio and nothing else was offered.”²⁹

“...but is limited and so many are now trying to access things like physio, psychology, dietician, pain clinics etc that the wait times and costs are unbearable.”³⁰

“Can’t afford hydrotherapy and if I could it takes months to get in.”³¹

“Making it harder for people who suffer with chronic pain to get opioids is not helping our situations. We can’t afford constant physio, specialist visits, psychologically appointments etc so until the government makes it easier for chronic pain sufferers to afford to live with this illness then they need to make opioids readily available as it’s our only option before we want to kill ourselves. It takes lawyers and money to even be considered for any insurances or disability payments which still don’t even cover basic human needs.”³²



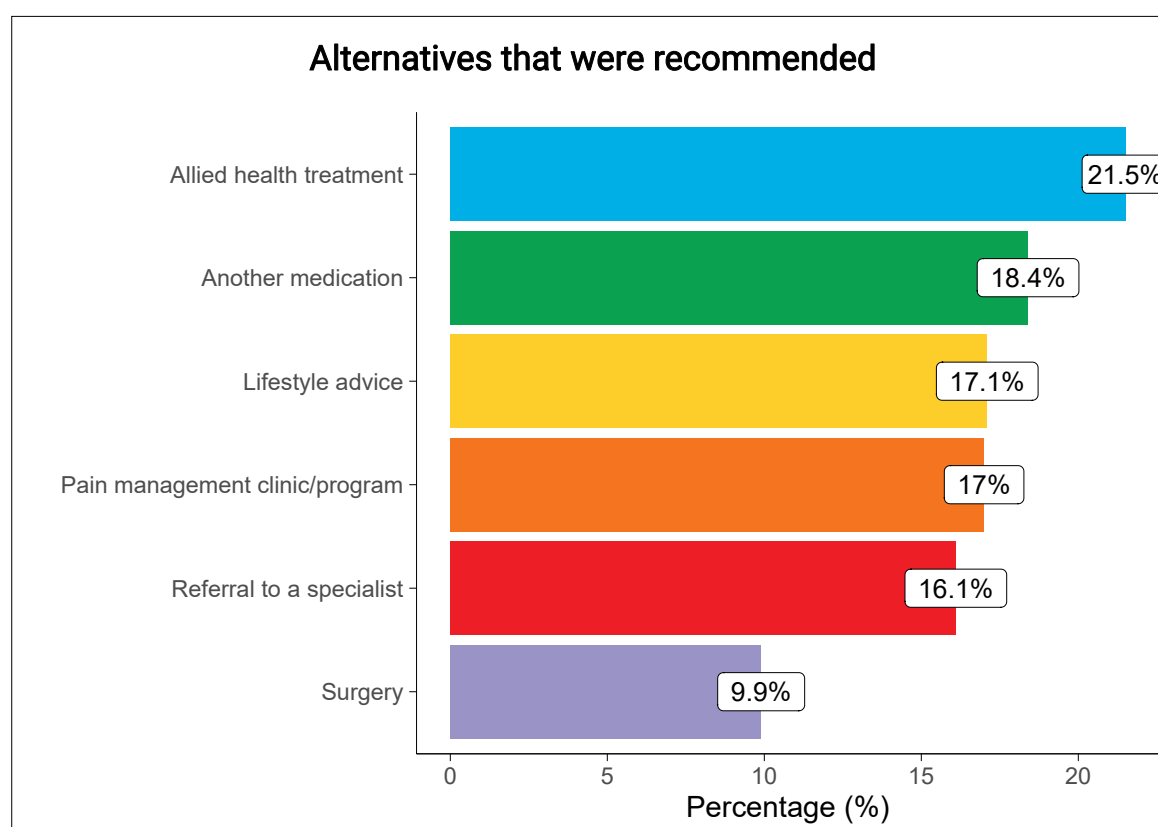


Figure C: Alternatives that were recommended

Alternative treatment offered	Percentage of people that were offered alternatives
Physiotherapist	41.4 %
Psychologist	26.7 %
Chiropractor	6.2 %
Massage therapist	5.2 %
Exercise Physiologist	4.6 %
Osteopath	4.3 %
Hydrotherapy	4.1 %
Acupuncture	3.1 %
Occupational Therapist	2.7 %
Podiatrist	1.4 %

Table 8: Alternative treatment or support offered

59.6 per cent reported difficulties in accessing any treatment options for their pain management.

43.1 per cent reported that their health professional did not offer an alternative treatment or support for them to manage their pain

46.5 per cent were offered alternative treatments most commonly physiotherapy and psychology



Support provided by health professionals

48.6 per cent of respondents said they felt supported by their healthcare professional in managing their chronic pain (table 9).

Have you felt supported by your healthcare professional in managing your chronic pain?	Percentage of respondents
Yes	48.6 %
No	34.3 %
Non-respondent	17.1 %

Table 9: Supported by healthcare professional

Consumer comments included:

"My GP is amazing and discusses everything with me, so I make an informed decision. It's frustrating that she is not deemed trustworthy enough to give a chronic pain patient the same meds I've been on for 10+ years." ³³

"Both GP and Neurologist work together. Really great approach to ongoing management. GP bulk bills as migraine is chronic and severe." ³⁴

"I'm saying yes because some have been great. I've always tried to keep the same doctor at the same clinic I've gone to for the past 40 plus years but unfortunately, they up and leave after two or three years and you have to start all over again. I do think some look at you and think you look ok so you must be ok and that is very frustrating." ³⁵

"Currently my GP is helpful in managing my chronic pain and I feel much less anxious about asking for and talking about pain relief." ³⁶

"Finding a decent GP that I can continue to work with has been vital. Now I have him I'll follow him to almost anywhere. He does his best with the constraints he's working with." ³⁷

"Yes, but there are real limitations due to lack of time, lack of familiarity of alternative options or new treatments/clinical trials." ³⁸

"I take multiple medications, at least 5 x different pain meds & I would love to take less but there is no one medication that treats all my issues. My GP always listens to me & helps me, but he is also worried about the changes as he doesn't want to get in trouble for over prescribing & then having to get multiple specialists to also sign off my medications." ³⁹



Of the 34.3 per cent that did not feel supported, many expressed their frustrations, commenting that they believed their health professional was either constrained in being able to help them or did not understand the reforms or have enough knowledge about chronic pain.

Consumer comments included:

"Certainly not since the new government rules. Doctor's hands are tied. Frightened of being shut down." ⁴⁰

"Yes and no, my Dr tries but, his options are also limited." ²²

"As a GP they try, but I don't think they have the time or specialised knowledge." ⁴¹

"When you advise them, you are in constant pain and you need solutions, they say the govt rules prevent them from assisting." ⁴²

"I found a doctor who helped me and prescribed me opioids again for relief, however she has since retired and now the new doctors I have been to see refuse to prescribe them or cut scripts in half. I am very sensible with my pain relief and only take it as needed (I cannot afford to take it when I don't being on a carers pension!) ...It is incredibly frustrating and upsetting." ⁴³

"A doctor wants to be able to help their patients, chronic pain is a tough problem for doctors as they really do not know enough about the condition at present. It is extremely difficult for patients to deal with on a daily basis, government interference, inability to access the disability pension, being unable to function, let alone work only compounds the stress of the pain and fatigue. People need medication and treatment that works, you cannot expect people to work without access to effective treatments." ⁴⁴



Lack of education and communication

A resounding 69.4 per cent of respondents told us there was not enough information and communication provided to patients when the opioid reforms were rolled out (table 10, figure D).

Do you think the information and communication provided to patients when the opioid reforms were rolled out was adequate?	
No	69.4 %
Yes	12.1 %
Unknown	18.5 %

Table 10: Adequacy of communication

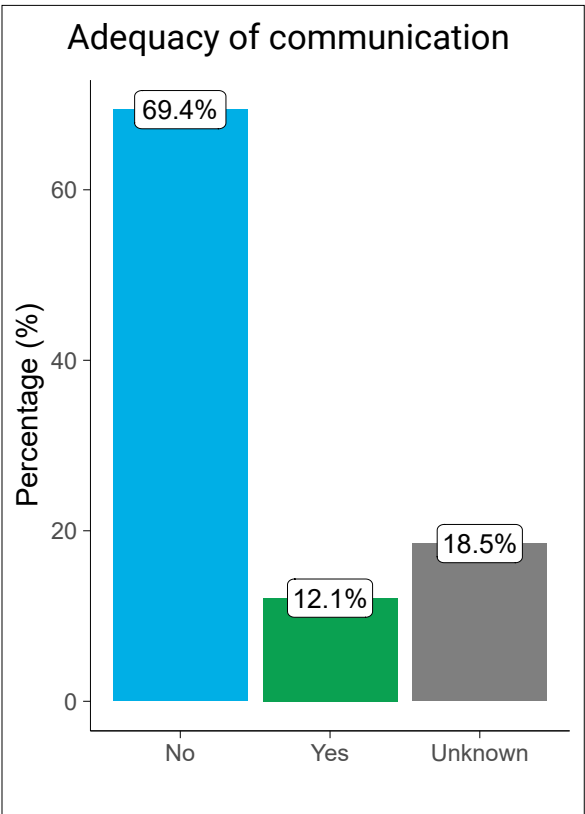


Figure D: Adequacy of communication



Consumer comments included:

"Absolutely not. It was cruel and reprehensible. The public messaging painted those who benefited from opioids as addicts. It did not distinguish patients on long term often low dose opioids...Chronic pain is usually an invisible condition, meaning that patients can be misunderstood and marginalised even before the opioid "reforms". Publicly suggesting patients who use prescribed opioids are addicts is one of the most divisive and destructive policy campaigns I have ever seen. Pain management is complex, and patients and their doctors need the full array of options available to them to find the best approach to pain management for EACH patient. There is a need to be much more nuanced than the current blunt approach has been." ⁴⁵

"Almost no information was provided to patients when this reform happened." ⁴⁶

"As a member of a national chronic pain advisory group I am in a privileged position to gain info on changes. I am aware that most others are far less fortunate and have been affected by the changes and needlessly poorly served." ⁴⁷

"Even different doctors told me different things it was extremely confusing. Even my dr was not clear on the process. A real mess". ⁴⁸

"I was given no warning at all and I can still tell you there are people in Australia today who don't even know that changes were made, people still go to their GP's in pain thinking they will be able to prescribe adequate pain medication." ⁴⁹

"I was lucky. I am a retired RN, so had knowledge of medications. But in a very busy practice, I did not receive adequate communication." ⁵⁰

"It confused doctors and gave them mixed messages and made them think they had to cut their patients off completely. Some doctors still think that." ⁶

"It was hopeless - I'm on a Chronic Pain Facebook group and a number of people were suicidal after their doctors just pulled their opioids and didn't give them anything else. My doctor first said I might need to stop then changed his mind. It was awful. The whole thing was very badly done." ⁵¹

"It was not adequately explained how access was to be granted, under what conditions, or what restrictions Drs had ie second dr recommendations etc". ⁵²

"It was pathetic and left us with so many questions that no one knew the answers too." ⁵³

"Advice for patients needed to be clear, consistent and easily accessible. It wasn't. The result was vulnerable patients who were unsure, stressed and afraid." ⁴⁸

Opioid Reforms - The impact on consumers

Out-of-pocket costs

Out-of-pocket costs for alternative treatments, and increased visits to GPs, allied health and pain specialists, were significant issues cited by consumers in the survey. Often people with chronic pain are unable to work, with 40 per cent of early retirement due to chronic pain, which impacts on consumers ability to pay for treatment and services.¹ A report from the Grattan Institute⁵⁴ found that in 2020-21 nearly half a million Australians decided not to see a specialist because they could not afford it. Many more did not fill a prescription because of the cost. This situation was reflected by many respondents to our survey. Furthermore, people in rural areas face additional costs associated with travel and lack of access to services.

Consumer comments included:

*"I had to pay for MRI and specialist privately because the public system was too slow to get appointment. I had to pay for extra prescriptions because they reduced size of prescriptions. I have been so distressed about potentially losing the only medication that works for me it's been terrible."*⁵⁵

*"I can no longer get my breakthrough pain medication and although my main pain management medication dosage was not changed, I was only able to get 2 weeks' worth instead of the usual 1 months' worth. The increased travel, stress, aggravation to injuries and costs associated was very distressing."*⁵⁶

*"only real help was referral to specialist but that was really expensive."*⁵⁷

*"can still get the prescription but have to go more often (and my gp does not bulk bill and has a considerable gap - so it costs me more)."*⁵⁸



*Since the change I have increased anxiety about being able to manage my pain and access services to continue treatment. Also the cost of these supplementary medications and treatments is far higher.*⁵⁹



Consumer comments included:

"Although my doctor is great the stigma around opioid use means I have to constantly rebook for fresh prescriptions, which is extremely costly." ⁶⁰

"it is now significantly more difficult and more expensive to get the medication i need, which adds to the stress of living with a chronic condition." ⁶¹

"Since the change I have increased anxiety about being able to manage my pain and access services to continue treatment. Also the cost of these supplementary medications and treatments is far higher." ⁵⁹

"Associated costs and no funding mean most are inaccessible." ⁶²

"I can no longer get my break through pain medication and although my main pain management medication dosage was not changed I was only able to get 2 weeks worth instead of the usual 1 months worth. The increased travel, stress, aggravation to injuries and costs associated was very distressing and for the first time in over 10 years I ran out of my buprenorphine patches and was twice left with no pain medication." ⁵⁶



\$22,500

Per person a year

Financial Cost of Pain in 2020



\$12.64 billion

health system costs



\$49.74 billion

lost in productivity



\$13.09 billion

other financial costs



\$68.63 billion

reduction in quality of life

If no action is taken, the annual cost of chronic pain in Australia will rise from \$144.1 billion in 2020 to an estimated \$215.6 billion by 2050

Infographic 2: Financial cost of pain in 2020¹

Perpetuating stigma

One of the major themes that emerged from the thousands of comments made by consumers related to stigma. Patients reported being judged, punished and treated like a drug addict. Painaustralia often hears from consumers with chronic pain detailing their stories of not being believed or experiencing stigma.

Consumer comments included:

"Constant feeling that doctors think I'm drug seeking when I'm regularly scheduling appointments for prescription renewal because I can only get one month of opioids at a time." ⁶³

"had to request pain relief, and was often made to feel like i was drug-seeking." ⁶⁴

"I moved house and my new Dr refused to prescribe panadeine, which I had previously used rarely, only when needed. I am too embarrassed to ask again so I suffer." ⁶⁵

"I moved from Sydney to a regional area and my new GP was very reluctant to prescribe Codeine. I went without good pain relief for a year, and now she prescribes very small amounts. I have been living with chronic pain for 30 years and have demonstrated I am not a drug addict; but doctors always seem to think that anyone with chronic pain just isn't trying hard enough to live with it. If only they lived in my shoes!" ⁶⁶

"Any person with chronic pain is treated like they are a drug user more now than ever." ⁶⁸

"I'm embarrassed to ask for assistance as I'm treated like an addict." ⁶⁷

"chemist staff judgement and assume misuse." ⁶⁹

"A great deal of fear and stigma is put on those of us who are genuinely using the medicine to control / ease our pain levels. Both Pharmacy staff and Doctors have been rather cruel and judgemental and have made us feel as if we are misusing the medicine." ⁷⁰

"At times it's been very difficult, and made to feel like an addict rather than a patient." ⁷¹

"I feel like they treat me like a junkie when in fact I am just trying to live with purpose, manage a business and household effectively." ⁷²



“It’s hard at times to feel you’re not being judged. The feeling of shame is a hard one to bear at times.”⁷³

Consumer comments included:

“As a woman the number of GPs that suggested I was depressed or it was in my head has been ridiculous. Took 10 years to get diagnosed as 8 GPs did not test for RA and chose to push me to antidepressants. This treatment of women as if we are emotional instead of actually looking carefully has to stop.”⁷⁴

“Feel like a criminal for asking, generally avoid the doctor if possible.”⁷⁵

“Been constantly accused of being a drug addict... starting to seriously consider illegal drugs because I can’t get relief.”⁷⁶

“Any person with chronic pain is treated like they are a drug user more now than ever.”⁶⁸

“I do not ask for opioid medication. I feel profiled & judged - made to feel like a junkie when asking for help to manage pain. Only seek help when it is unmanageable and all other coping strategies no longer work only to be told “there’s nothing we can do”. Poorly managed pain leads to depression & wanting to end life to end suffering.”⁷⁷

“The stigma attached with the use of opioids is hard. Especially at my age, I feel people/medicos jump to conclusions quickly. The research into TN indicates it’s mostly in women over 50, but I was 15 when it started. That isn’t well documented so met with a lot of resistance.”⁷⁸

Increased anxiety and distress

We know there is a significant interrelationship between people who live with chronic pain and consequential mental health issues, particularly depression and anxiety.

Painaustralia's *Cost of Pain in Australia* report found that chronic pain and depression or anxiety co-occur in 44.6 per cent of patients.¹ Major depression is the most common mental health condition associated with chronic pain. Between 30%-40% of people with a diagnosed mental health condition also present for treatment for chronic pain.⁷⁹ Almost 1.45 million people in pain also live with depression and anxiety.

Chronic pain is also a significant risk factor for suicidal behaviour. People living with chronic pain are two to three times more likely to experience suicidal behaviours compared to the general population.⁸⁰ Many respondents commented on the increase in stress and anxiety they have felt since the opioid regulations have come into effect.

Consumer comments included:

*"I have multiple diseases that cause pain. Fibromyalgia, Arthritis, Brain injury & Pernicious Anaemia has damaged nerves. Finding a doctor who is trained in all of those is impossible so have to see different doctors for each disease & at times the expense is beyond my budget & waiting times are lengthy. I am also waiting on my 2nd knee replacement which has been postponed indefinitely due to the Covid Pandemic which has caused me a lot more pain & affected my mental health."*⁸¹

“

*There has also not been additional options added to pain management meaning I have to live with a much lower quality of life with greater experiences of suicidal ideation.*⁸²

”

*"Access to opioids like oxycodone during intermittent flare ups was a literal life-saver. It meant I could live my life and avoid dangerous suicidal ideations. There has also not been additional options added to pain management meaning I have to live with a much lower quality of life with greater experiences of suicidal ideation."*⁸²

*"Doctors are too scared to offer any opioids even when in severe pain and I was left suffering and very distressed."*⁸³

*"Made to feel bad & anxious about trying to get help."*⁸⁴

Consumer comments included:

"I had my first injury over 5 years ago, it had settled and I was back working full time. Had a re-injury just over a year, and because I've been through it all everyone expects me to know everything (that and I'm also a nurse), so don't really check in on my mental health. Or understand how frustrating it is to go through it all again." ⁸⁵

"being treated as though I am drug seeking and having to ration any opioids I am able to obtain is very difficult in managing my pain. I am determined to keep my job (nurse/midwife) and do not feel I should need to reduce my hours any more than I have (I already only work 24 hours a week due to my chronic conditions). I don't need a huge amount of pain relief but it's almost impossible to get any. I have had significantly worse mental health since being unable to obtain the pain relief I need, and I see the reforms as being extreme and unnecessary." ¹⁴

"I understand WHY they were done but not everyone is a junkie who needs their medication controlled for them...now i feel suicidal when I'm in a flare as nothing brings relief." ⁶¹

44.6%

of people who live with chronic pain also report living with depression and anxiety.



The impact on consumers before and after the opioid reforms

Overwhelmingly, respondents reported they were worse off since the introduction of the opioid reforms (figure E). When asked to compare their chronic pain condition in the 12 months before the opioid reforms (June 2019 to June 2020) and the 12 months after the reforms (June 2020-2021), over half of the respondents (52.5 per cent) said the management of their chronic pain had worsened in some way. Only 5.6 per cent said it had improved. A majority 53.3 per cent attributed their worsening pain to the opioid reforms negatively impacting on their quality of life (figure F).

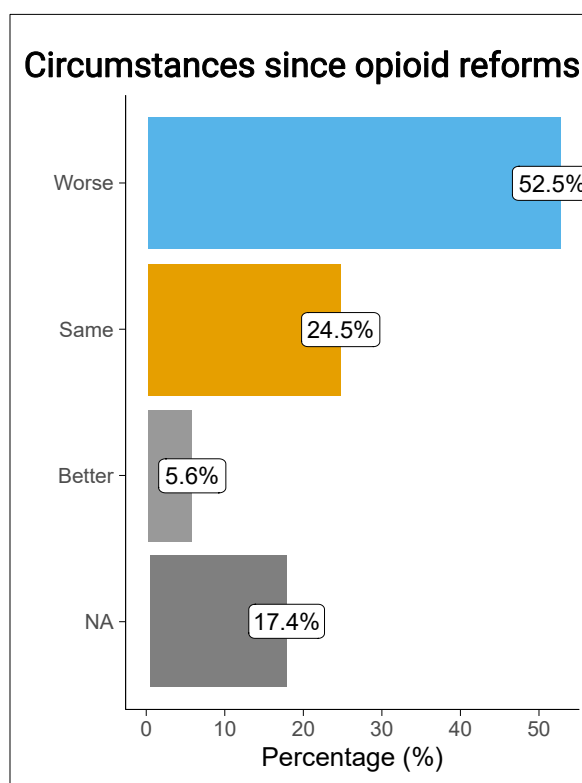


Figure E: Circumstances since opioid reforms

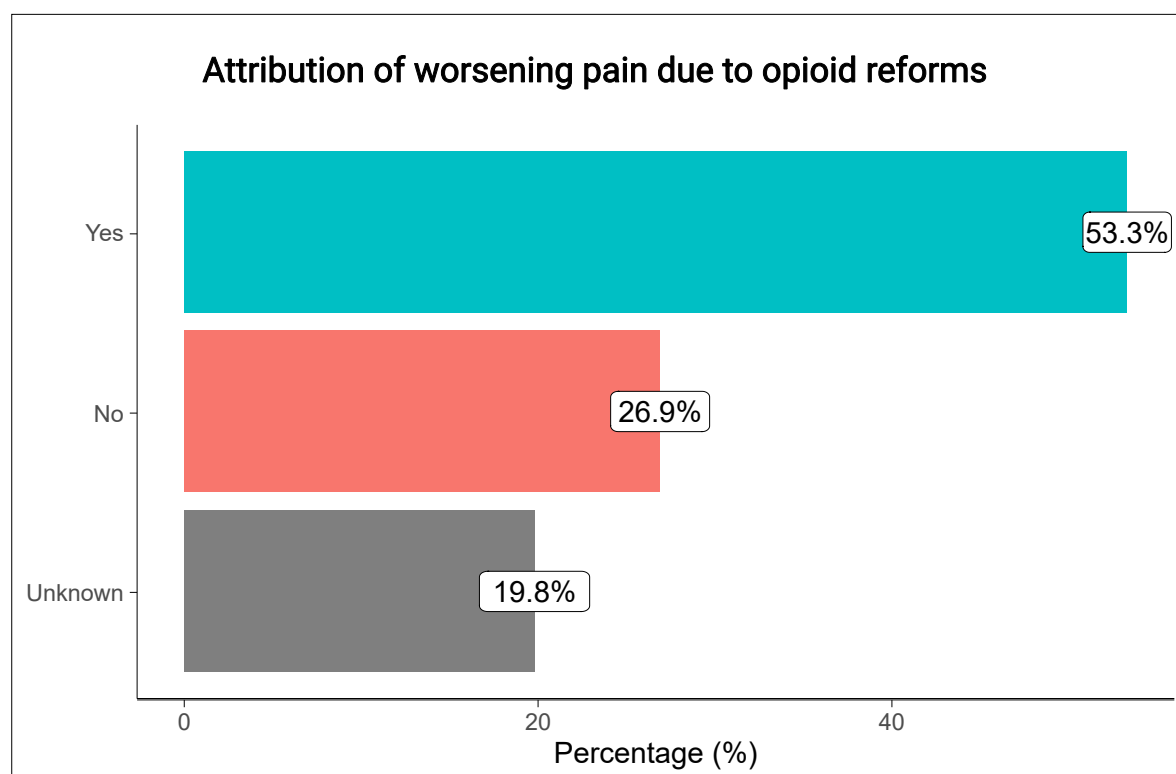


Figure F: Attribution of worsening pain due to opioid reforms

Consumer comments included:

*"If I get a flare up now I use ice packs and cry myself to sleep as there is no amount of panadol that will reduce that kind of pain."*⁸⁶

*"Reduced dose means I take more paracetamol because it's not working which will obviously damage over time, loss of will to live, loss of motivation to try anymore, no future, no options."*⁸⁷

*"Limitation on pain medications available leaving me in increasing chronic pain and lower quality of life."*⁸²

*"The halving of my medication has stolen so much of my life. My ability to function has been significantly reduced in many aspects, including; my ability to exercise, my ability to cook and bake for my family, my ability to participate in activities with my family, my ability to maintain my home, my ability to enjoy leisure activities and hobbies, my ability to socialise with friends and more."*⁸⁸

*"I don't have options for managing flares except to pause my entire life until its over."*⁸⁹

“

*I have been force tapered to a dose that no longer controls my pain... I used to jog 4 times a week, go to gym and work. Now I am disabled by pain.*⁹⁰

”



Solutions

Painaustralia supports the intention of the reforms to reduce opioid-related harm. However, it is clear from our survey that many of the challenges that existed for people with chronic pain before the introduction of the regulations have been exacerbated. The introduction of the reforms during the Covid-19 pandemic have left consumers with chronic pain increasingly isolated, distressed and at a loss when seeking access to, and affordable alternative treatments.

The survey results demonstrate that regulation cannot be the only solution to the growing opioid problem and over-reliance on opioids to treat chronic pain. We have to balance access to medications, where and when it is safe and clinically needed, while providing and funding other multidisciplinary best-practice interventions that can help people to live as well as they can with their chronic pain.

The **National Strategic Action Plan for Pain Management** was endorsed by the Australian Government and all State and Territory governments last year. It provides a pathway to address the alarming lack of alternatives for multidisciplinary and non-prescription treatment options for people living with chronic pain.⁹¹ It is now critical that all levels of government accelerate and fund the key activities that were outlined and agreed to in the plan.



To read the National Strategic Action Plan for Pain Management go to
www.painaustralia.org.au



Funding is urgently needed for

Continuous and additional education and awareness for both consumers and health professionals -

this includes education in the rationale for the opioid changes for consumers, more guidance for health professionals around the opioid regulations and awareness of alternative pathways and support for consumers.



Increased support for people living with chronic pain including a dedicated helpline -

based on similar successful services operated by organisations such as Dementia Australia, Breast Cancer Network Australia and the Heart Foundation. Since the reforms, Painaustralia has received calls and messages from thousands of people in the community, seeking information and advice about their pain issues. Many are experiencing distress. They are in need of more information about the rationale for the changes, and about non-pharmaceutical strategies for managing their pain. A dedicated and funded helpline would assist people living with pain to address their mental health and understand the ongoing reforms to prescribing and dispensing of opioid medications. Such a helpline could provide referral and access to other pain management options and support groups.



Changes to the Medicare Benefits Scheme to provide greater access to multidisciplinary pain management programs -

Painaustralia urges the Australian Government to fund the recommendations from the pain management clinical committee as part of the work of the Medicare Benefits Schedule Review Taskforce. In particular funding is required for the committee's recommendations 26 and 27 which relate to the areas of access to multidisciplinary pain management, allied health visits and group pain management reforms. This would help to provide much needed access to treatments other than medication.



Conclusion

This very important survey highlights the extent of the challenges and barriers people living with chronic pain constantly face. Their daily challenges have been amplified through the combination of the pandemic, the opioid regulation reforms, and the introduction of real time prescription monitoring programs.

The survey demonstrates there is no 'one size fits all' solution for chronic pain and no single policy reform that will fix the enormous toll chronic pain exacts on our communities.

We must work together, recognise chronic pain as a significant national health priority, fund alternative treatments and support and educate health professionals. We must raise awareness for consumers, and address the obstacles faced by millions of Australians and their families and carers.



The survey demonstrates there is no 'one size fits all' solution for chronic pain and no single policy reform that will fix the enormous toll chronic pain exacts on our communities.

~Painaustralia



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