



# painaustralia

## SURVEY REPORT

AUGUST 2020

**IMPACT OF 2020  
OPIOID REFORMS  
ON PEOPLE LIVING  
WITH CHRONIC PAIN**

# EXECUTIVE SUMMARY

This report provides an analysis of a survey conducted by Painaustralia to gauge how people with chronic pain have been impacted by the opioid reforms implemented on 1 June 2020.

Painaustralia received an overwhelming response to the survey, which had nearly 600 responses over the course of 10 days. The survey also drew commentary from consumers on social media platforms, with nearly 300 comments on the original post. Overwhelmingly, consumers have reported further creation of additional and significant barriers to pain management for an already vulnerable cohort.

As Painaustralia has reported to the Opioid Regulatory Advisory Group and the Opioid Reform Communications Committee, the chronic pain community had already been reporting adverse health outcomes from the impact of the bushfires. The subsequent pandemic and correlated challenges in accessing primary and preventative care services have had a major effect on the chronic pain community. The rollout of significant reforms on 1 June have exacerbated challenges faced by people living with chronic pain, as has been demonstrated by the several calls from distressed consumers, many who mention suicidal ideation.

The four main themes identified by the survey are that overarchingly the 1 June Reforms:

- Created an additional layer of complexity
- Led to loss in function and autonomy
- Perpetrated stigma and isolation; and
- Significantly impacted mental health.

These findings clearly outline the lack of co-ordinated communication to support the significant reforms. The findings also highlight the lack of accessible, and affordable options for the management of chronic pain.

To address these gaps, Painaustralia recommends:

- Targeted educational and awareness campaign to support the new reforms and emphasise informed decision-making support for consumers; and
- Expedited implementation of action items from the National Strategic Action Plan for Pain Management.
- Targeted mental health support for people living with chronic pain be considered as an important strategy to support the reforms.

# BACKGROUND

From 1 June 2020, several regulatory changes took place that had a major impact on the prescribing of opioids for the management of pain. Broadly, these changes saw smaller quantities, changes to the 'indications' that will be funded, and changes to the authority process required for opioids to be subsidised.

These changes were recommended by the Pharmaceutical Benefits Advisory Committee (PBAC), an independent expert body, which advises the Australian Government about Pharmaceutical Benefits (PBS) matters.

The PBAC recommended a number of amendments to the PBS listings for opioid medicines. These PBS listed medicines include codeine, codeine + paracetamol, immediate release oxycodone, tramadol, immediate release hydromorphone and immediate release morphine. The changes apply to these opioids when prescribed for patients with acute severe pain and chronic severe pain (non-cancer and cancer).

More information about the opioid reforms can be found [here](#).

# SURVEY REPORT

Painaustralia had 595 participants in the survey, which ran for 10 days. Overwhelmingly, consumers report that these reforms have created an additional and significant barrier to pain management for an already vulnerable cohort.

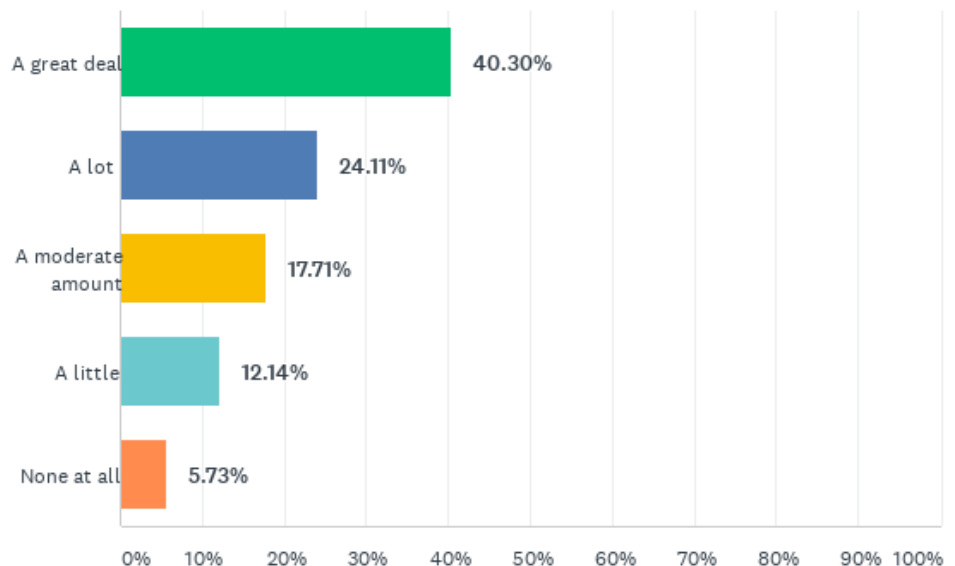
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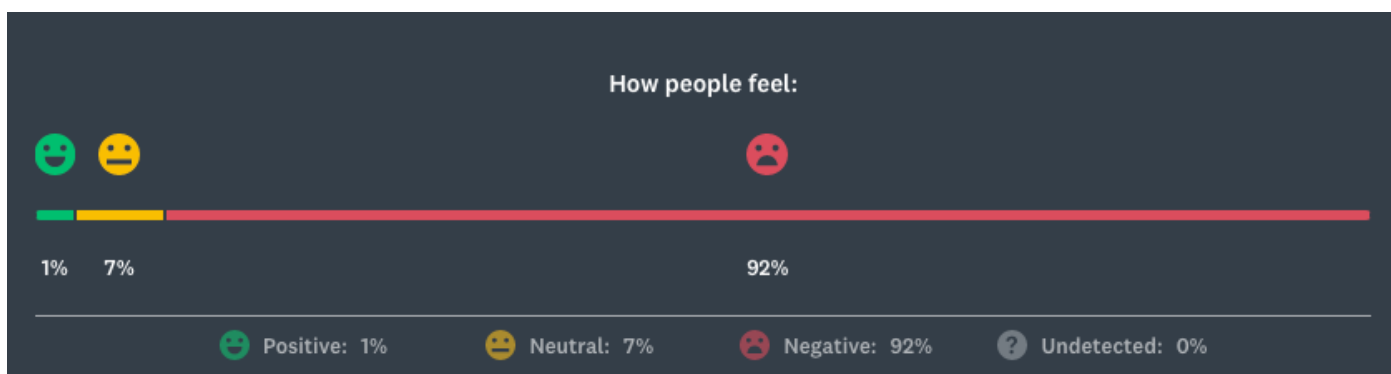
## 1. An additional layer of complexity

A majority of respondents (65%) indicated that the changes have impacted them significantly.

### Has your chronic pain management been impacted by the opioid reforms?



An overwhelming majority of respondents (92%) indicated that the reforms have negatively impacted them, with only 1 percent indicating that the opioid reforms had a positive effect on their pain management.



*I don't understand why these reforms keep taking place. It keeps getting harder to get what used to be basic pain relief medication. I had to take and will continue to have to take heavily regulated medication and justify it continuously despite every medico involved saying it will be years before my nerve injury improves enough to stop taking it. I guess those who don't experience it themselves don't care about those who need it.*

### **Increase in frequency of GP visits:**



*now need to see my GP once a month to get a prescription. This reform is clogging up doctors with patients who only need a prescription. It also makes it very expensive as I don't have a health card, so I have to pay when I see my doctor.*

Consumers report a massive increase in the number of health practitioner visits, particularly to GP's and pharmacists. The direct impact this has had on out-of-pocket costs for consumers, as well as the additional anxiety of seeking healthcare during the pandemic, have created a lot of stress and concern for the chronic pain community.



*No more repeat prescriptions. Need to go back to Dr every month plus a second Dr for another option twice a year. I'm worried if I can't control my pain, I won't be able to work.*

A particular issue has been accessing repeat prescriptions. While Painaustralia understands that new reduced pack sizes have not replaced standard pack sizes, there appears to be a breakdown in communication of these important facts to both consumers and prescribers.



*Changes mean accessing my 3monthly scripts is a nightmare & I have to reconfigure work schedule every 28 days to obtain scripts for the same meds I've been on for years just adds to the inconvenience of quality of life*

The out of pocket costs and the frequency of health practitioner visits has seen consumers face significant concerns around their ongoing ability to access appropriate care.



*I have to schedule regular visits to my GP to get prescriptions. My total bills to see my GP have doubled. I'm terrified of running out of medication.*

*I am unable to get repeat scripts of my usual medications meaning I need to attend the GP multiple times per month which impacts on my capacity to work my FT job.*

## **2. Loss in function and autonomy**

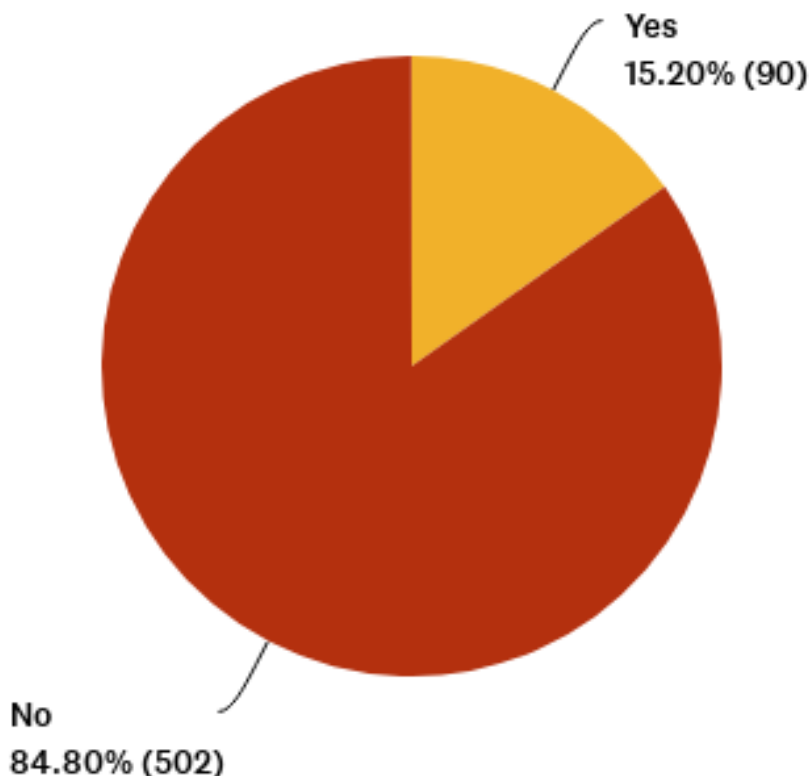


*I have been left in limbo, I have no idea when I will get help, what help I am entitled too, by who or what options I have anymore. I've failed many medications with various side effects and am currently having to self-taper as I was told two weeks ago my current script won't work (thank god it did! Or I would have had no medication for the past week. you don't stop taking 4 panadeine fort a day cold turkey!) and I needed a second opinion. Despite seeing the pain management team, I still don't know what my outcome is or will be. I've been in high pain and feeling suicidal for the past 6 weeks. I don't feel safe to tell the medical professionals this as I feel they see me as a "drug seeker". I don't feel safe, I'm scared, I'm in pain and they don't care, I don't matter.*

Overwhelmingly, consumers report not feeling confident about their pain management strategies post the reforms.

## Do you feel confident and supported about your pain management strategies after the reforms?

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One of the most concerning impacts has been several reports from consumers of forced/rapid opioid tapering. This is a dangerous trend as rapid opioid dose reduction also poses risks including more severe pain and neuro-psychological effects. In the US, [the Food and Drug Administration \(FDA\) recently alerted health care professionals to avoid rapid opioid dose tapering](#) among physically dependent patients because of [potential hazards of serious withdrawal symptoms, uncontrolled pain, psychological distress, and suicide](#).



*I have been cut off one of my medications.*

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*I am now needing to see a pain management specialist in order to continue to receive the medication that I am taking. My doctor has been given a grace period for me to see the specialist but after that time they will not be able to prescribe me my medication*

Evidence has also highlighted the potential for [misapplication of poor communication](#) of these policies on populations outside the scope, as has been reported in the Opioid Regulatory Communications Committee which heard several instances of misapplication reported for patients needing palliative care pain relief. Painaustralia has had consumer reports where they have received inadequate relief even in instances of acute, post-surgical pain.



*I recently had my 4th Brain Surgery and was discharged on Panadol. Which wasn't suffice for the firsts 3-5 days. I was also out of state for my surgery, so had no GP to access. I can't believe I couldn't get any help after Brain Surgery. I do use alternate forms of pain management such an acupuncture, psychology, Physiology, walking etc.... so I think if people did complementary programs alongside the use of opioids helps more than just giving opioids. If someone is not increasing their dose but managing their pain it doesn't mean it should be reduced either.*

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*I need a hip replacement- I have been managing with 4 panadeine forte a day = 120 tablets a month. My specialist was prescribing it - now he can't prescribe it. So now I have to pay to see my GP because she gave me a script for only 50 tablets at a time. Due to pain - I have gone from full time work to working 3 days per week.*

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*The reforms take away all rights to self-determination, the ability to manage best pain management practice and has created new mental health issues where a sense of unworthiness and uselessness eats away any self-esteem present.*

**Painaustralia recommends the urgent implementation of a targeted educational and awareness campaign to support the new reforms. Such a campaign must emphasise informed decision-making support for consumers.**

### 3. Perpetrates stigma and isolation



*There is always such a stigma around Opioid use. Not many people including Health Professionals ever really acknowledge that you may actually need this medication as part of your Health Care Plan to manage and function each day!*

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*As I am 22years old it is hard to get a GP to take my pain seriously even though I have a diagnosed disability. I am in pain 24/7 and have to be in tears at an appointment to get pain relief I use to be able to get over the counter. I use it sparingly and only when it's extremely needed.*

Many consumers have reported rationing medications to ensure they have sufficient medications to manage their pain.



*my opioid painkiller 'allowance' has been reduced by two thirds each fortnight as my prescription now have no repeats, where previously I was given two repeats. so now I must carefully ration my pain medicine, decide on which days I will have no painkillers and so therefore be unable to function effectively, or to function at all. I had no other pain killer replacement given. my pain levels have been very high since this change. having a medicine review by a previous specialist will cost me time, money and energy.*

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*"Some days I need to take 1 extra tablet to manage pain. That control has been taken away - if I have an extra pill once a week the pharmacist will not dispense until fixed date. Loss of patient control.*

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*I suffer extreme nerve pain. I don't sleep at night at all. I need this pain medication, or I would not be here. Sometimes I finish my pain meds a few days early due to severe flare ups, so I have to wait for a few days with nothing.*



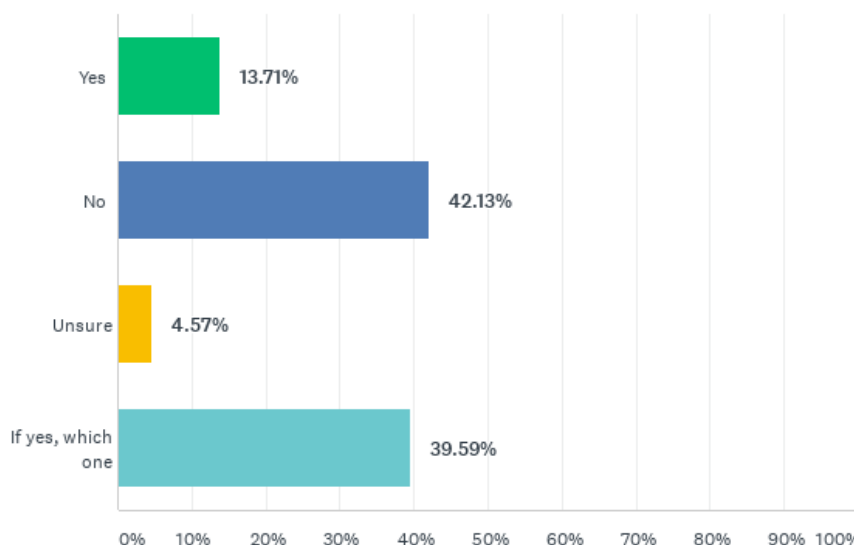
Stigma—shaming and shunning—continue to be perpetrated through these reforms and patients with chronic pain report their frustrations in accessing alternative and appropriate care. As [research has shown us in the US](#), the national conversation surrounding opioid therapy for chronic non cancer pain has become confusing, disjointed and, most unfortunately blameful even when patients appropriately take opioids for chronic noncancer pain.

People also reported not feeling supported in their pain management journey with options that met their needs, with only 13 percent reporting that their health professional shared alternate strategies.



*My specialist sent me to Active health clinic in Melbourne. It was good but was disrupted due to Covid-19. & very expensive. I got good things from it but it's not the whole answer.*

## Has your GP or health care professional shared alternative pain management strategies with you?



time refuse none every tens machine unfortunately walking attend one m don t work well  
 always manage pain management specialist psychology told long term day counseling  
 USE Paracetamol VE year need referred pain relief surgery  
 pain management clinic good mindfulness opiates work current help  
 Swimming go stretching see osteo take Lyrica exercise everything  
 tried referral pain Yes physio things medication diet  
 alternative suggested therapy much pain management  
 chiropractor Pain clinic topical Physiotherapy yet pain specialist  
 effective heat packs increased many yoga massage meds don t specialist  
 mindfulness meditation Panadol doctors different mediation GP pain levels already given  
 acupuncture reduce also hydrotherapy keep etc will bad Changed creams discuss



*I've had all the treatment offered to me and it hasn't worked so it's not like pain meds was my 1st go to, I tried all recommendations and procedures without success. So, what now? Do they really think mindfulness is the be all and end all?*

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*I already use mindfulness, CBT, exercise, physiotherapy, heat packs, and topical treatments. I've had healthcare professionals recommend these options and some disbelieve me when I say I already use them because I happen to take low dose opioid medication infrequently to manage flare ups when the pain is too much to handle.*

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*a mild antidepressant, losing weight, exercise... the same old tune and same old selling points... which are pointless if I am unable to physically function.*

As noted in the [National Strategic Action Plan for Pain Management \(the Action Plan\)](#), untreated and poorly managed pain devastates the lives of individuals who live with it and impacts their relationships and ability to participate in work, education and the community.

The need to implement the Action Plan comes at a critical time: pain management finds itself at the intersection of key global public health challenges of the 21st century including the safe and effective use of medications (particularly opioids), the urgent need to stem the rise of chronic conditions and the rise in chronic pain stemming from the pandemic.

Understanding the complexity and individuality of pain is the essence of the Action Plan. There is no one solution that should be imposed on everyone experiencing pain. The Action Plan sets out over 50 evidence based implementable recommendations that will help change the way pain is managed.

In light of the far-reaching impact of the PBS reforms, Painaustralia recommends the expedited implementation of some of the action items as outlined in the Action Plan.

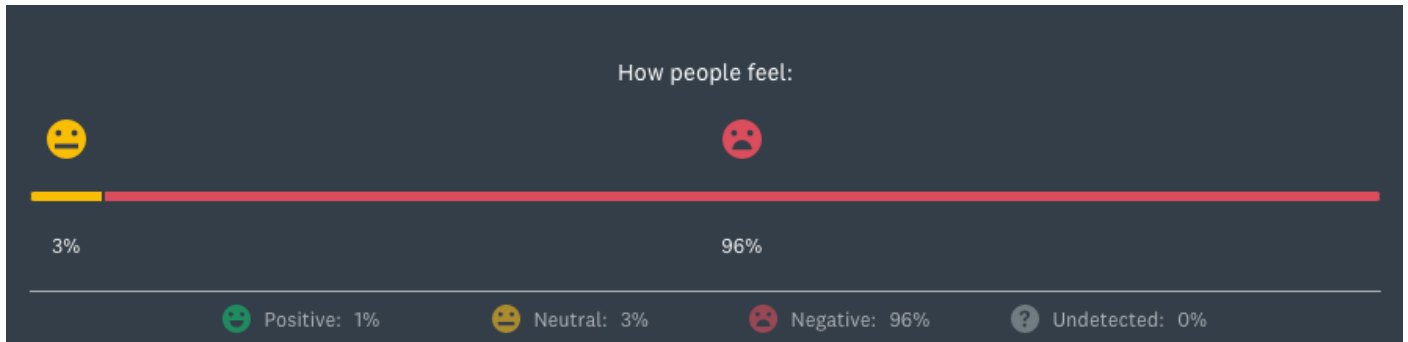
In particular, there are goals and linked action items that meet consumer need for affordable and accessible pain management strategies:

- National information and support telephone line that is resourced by accredited and trained staff and volunteers. (Action Item 2.8)
- Peer to peer support network, facilitated by trained and accredited providers. Peer supporters are identified and trained to support other people living with pain, particularly those who have recently had a chronic pain condition diagnosis (Action Item 2.10).
- Patient-centred interdisciplinary assessment and pain care and support services that takes into the account the health and wellbeing of the whole person is offered in all locations and made available through delivery and funding models at the primary care level wherever possible (Goal 4)

## 4. Impact on mental health

An astounding 96% of respondents report negative sentiments around the reforms.

### Is there anything else you'd like to share around the reforms?



Every day, millions of Australians face a life cut short as they struggle with the physical, mental and emotional toll of chronic pain. Impacting every facet of their lives, nearly 1.45 million also live with depression and anxiety.



*Firstly, I feel maligned - my GP is supportive, and wants to prescribe what I and we feel necessary - but the system is not allowing him to do so. Its also allowing other doctors to be discriminatory without medical reason. I am under prescribed, and often when I go get them filled, I have the pharmacist refuse to fill them because he has a "personal opinion" that I'm using more than I need. I'm tired and upset and then develop severe anxiety at even asking for pain relief.*

Reported comorbidity for chronic pain and depression or anxiety is estimated at 44.6% of patients, which is within the range of estimated values from the international literature. Chronic pain is also a significant risk factor for suicidal behaviour and people living with chronic pain are two to three times more likely to experience suicidal behaviour compared with the general population.



*I cannot keep my pain under control, if my GP is away and I need to see another GP to get a script because it has run out due to the smaller quantities I am falsely accused as being a opioid dependant addict and not given a new script even with explanation of my illnesses and therefore I am left with over the counter meds or having to sit at home in chronic pain and call an ambulance to take me to hospital.*

Major depression is the most common mental health condition associated with chronic pain, with among 30-40% of people with a diagnosed mental health condition also presenting for treatment for chronic pain. High rates of generalised anxiety disorder, post-traumatic stress disorder and substance misuse are often present for people living with chronic pain.



*I could maintain my pain so much better before. I was able to take smaller doses by cutting up tablets, but now I have to take stronger codeine tablets. I feel like a drug addict going to the doctors even though I have tried many other ways to manage my pain.*

There are also lessons that we have learnt from the implementation of opioid reforms overseas, particularly in the United States. [A recent report noted heightened death rates](#), specifically from medication overdoses (including potential self-harm), in those who undergo opioid dose reduction. This reflects reduced tolerance to opioid-related adverse effects (specifically respiratory depressant effects) making people more vulnerable to subsequent overdose, but also to increased agitation and suicidality in those whose opioids are withdrawn.



*For those of us who don't abuse the drug and have acted responsibly which is the vast majority of chronic pain sufferers this has been another kick in the guts. I have numerous conditions due to an auto immune disease and damaged back, the depression caused by being in pain is made 100 times worse when your Dr is too worried about getting in trouble for writing scripts for pain medications that keep me able to get out of bed or not keep me awake all night in pain. Surely the Panadol osteo I'm told to take is far worse for my body than 2 x 15mg slow release Targin a day. It's not like my blood work and scans are lying, even a layman can see I need pain control, yet due to Drs being issued with threatening letters and now even tighter restrictions, Drs will just not prescribe them at all.*

Additionally, the current COVID-19 pandemic is placing significant stress on the chronic pain community. A person living with chronic pain in the current environment is at risk of reduced access to care, script and medication provision issues and potential symptom exacerbation via reduced physical activity and increased psycho-social stress.



*The feelings of persecution because I am in pain is debilitating. My mental health has been unnecessarily put under undue stress by my private pain specialist, GP and by well-meaning yet also scared, misinformed and persecuted fellow pain sufferers. These changes were handled without adequate care, concern or education. I suspect that there were suicides, hospital admissions as well as the mental health admissions that I personally know of due to these changes.*

**Given concerns about understanding the potential impacts of opioid regulatory reforms, and the ongoing impact of the pandemic on the mental health of vulnerable population groups, PainAustralia recommends that targeted mental health support for people living with chronic pain be considered as an important strategy to support the reforms.**

## CONCLUSION

The implementation of the 1 June PBS reforms has once again highlighted the complexity of chronic pain management, and our continued failure to provide holistic and best practice care to this cohort of vulnerable people.

Pain management is at the intersection of emerging and contemporary challenges including ensuring safe and effective use of medications and the impact of the COVID-19 pandemic. Pain is now a rising health issue facing Australia and remains a leading cause of social and economic exclusion.

Urgent action is required that supports consumers, health practitioners and the wider community to improve health outcomes for those living with pain and builds on significant efforts to date to ensure that people living with chronic pain have access to best practice care that is affordable and can be individualised to meet their complex needs.

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