



**Chronic Pain**  
AUSTRALIA

National Pain Survey 2020

Faces  
of pain



National Pain Week 2020

#NPW2020



**Chronic Pain**  
AUSTRALIA

## National Pain Survey 2020

### Answers reported by key themes and metrics

Total number of survey respondents - 1217

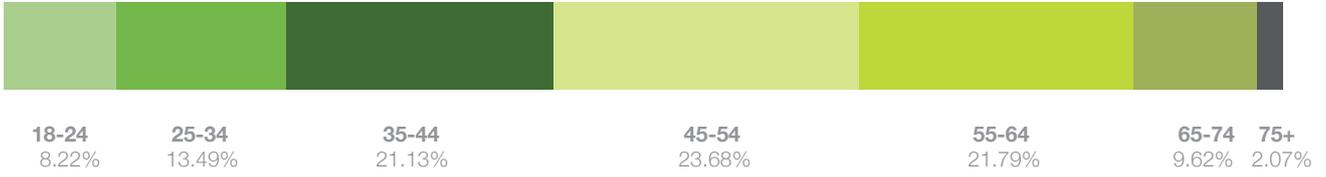
Demographics	1
General Practitioners	2
Pharmacists	4
Other health professionals	6
Federal Government	8
Stigma	10
Medicinal Cannabis	13
COVID-19	16

## DEMOGRAPHICS

Total number of survey respondents - 1217

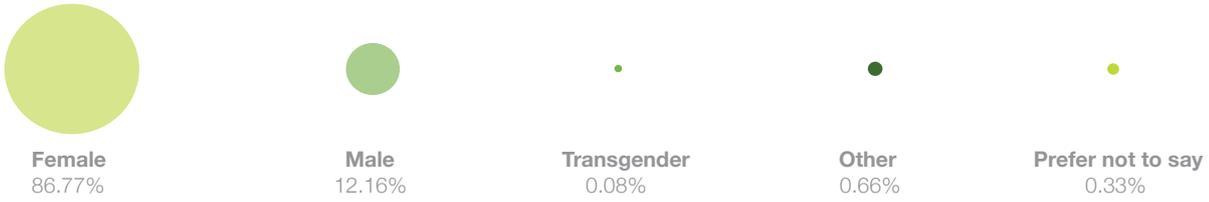
### Question 1

What is your age?



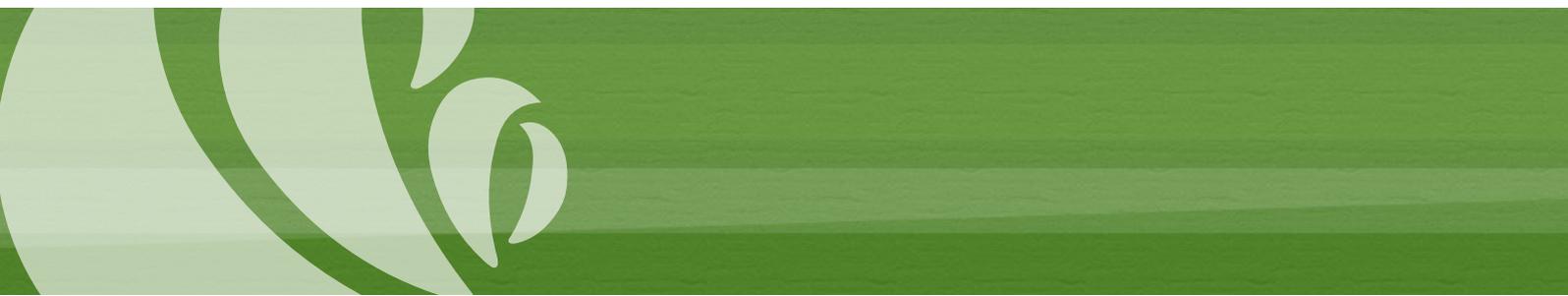
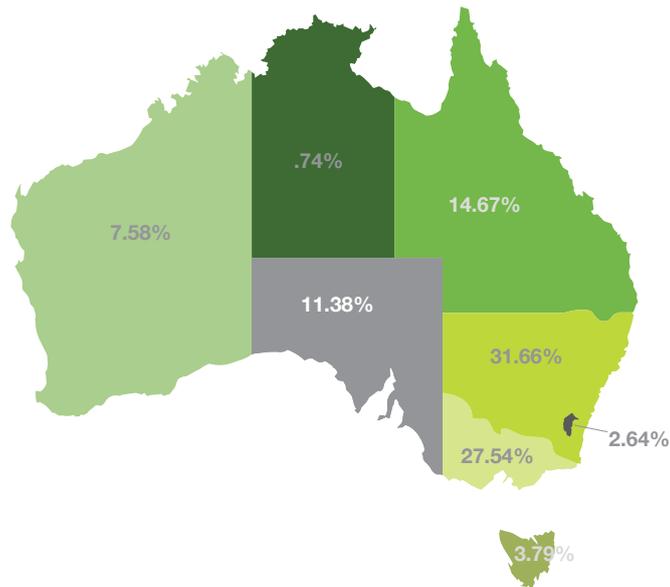
### Question 2

What is your gender?



### Question 3

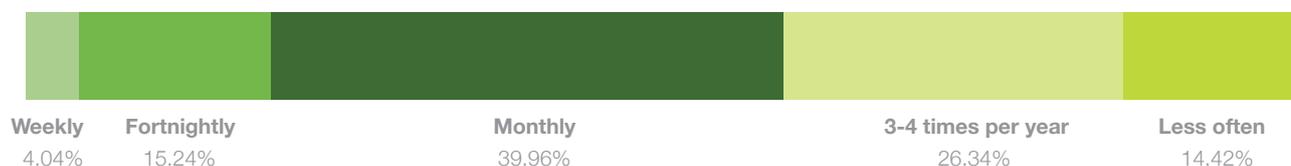
What state do you live in?



## GENERAL PRACTITIONERS

## Question 4

How often do you visit your GP about your chronic pain?



## Question 5

On a scale of 1-10 how well do you think your GP manages your chronic pain?

**5/10**  
Average

## Question 6

What are the most important things for GPs to know, understand and do when treating someone living with chronic pain?

- **We are not one size fits all**

- Further educate themselves about different conditions they might not know much about
- Please just believe us when we say we are in pain
- The experience of ongoing pain is not just due to biological factors but also psychosocial factors and therefore needs a wider treatment plan

- **Pain is real, debilitating and exhausting**

- Put me in touch with other resources and pain management options not just medication
- Listen to me – don't make assumptions about me or my pain
- My pain doesn't stop – just because I am walking today and seem fine doesn't mean that I will be walking well after the appointment or the next day

- **We are not all drug seekers**

- Just because we try to function normally day-to-day doesn't mean we are pain free
- Understand that we don't like using strong pain medication but sometimes it is necessary to assist us live a somewhat productive and worthwhile life
- Know when, how and to who you can refer me to, to better manage my pain

- **Pain affects all areas of our health and lives**

- Have some compassion and treat me like a real person with emotions and feelings
- Sometimes I become so used to my pain that I don't realise I am in pain even though my body is hurting
- Understand that I am in pain – not a hypochondriac

- **Living with chronic pain can be isolating and depressing**

- Ask how I am managing the pain and work with me, not against me
- Have an open mind – the client is the expert in their condition and their body
- Don't judge or stigmatise me

## Question 6 (continued)

- **My pain isn't just all in my head – I am not making this up**
  - Understand and tell me about the side-effects of my pain medication
  - They need to know the limits of their knowledge and admit that – help me find alternative health professionals to help me or work with me to explore what the pain could be
  - It's ok to say you don't know how to treat my pain. Keep helping me manage it with medication and non-medication methods
- **Listen, acknowledge and respond**
  - Understand that the injury has healed and the pain is a separate problem from the injury
  - My pain levels go up and down but the pain is always there
  - After living with pain for so long, many of us know what does and doesn't work for us, take our experience and suggestions onboard.
- **Understand that we have been conditioned to expect no medical professional will believe us**

## Question 7

If there was one thing your GP could do now to help you manage your chronic pain, what would it be?

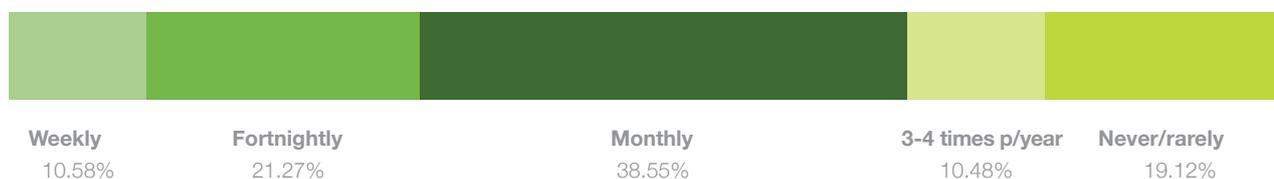
- **Believe me and my pain (50% of respondents)**
  - Keep on championing my rights
  - Understand my condition
  - Provide referrals to other practitioners who can help me manage my pain
  - Let me have pain medication for the times I need it
- **Prescribe medicinal cannabis (25% of respondents)**
  - Be better educated about chronic pain
  - Empathise
  - Take time to consult with me instead of the 6 minutes of your time I am given per visit
- **More investigation into what is causing my pain and continue until the cause is known**
  - I don't know/Nothing
  - My GP does an excellent job managing my pain
  - Consider my whole body don't just focus on my pain when treating me
  - Continue my sessions using telehealth
  - Look at a holistic approach to managing my pain
  - Coordinate my care and link in with the other health professionals I see
  - My GP is managing my pain levels as well as possible. My GP refers me appropriately when necessary and collaborates with my other specialists



## PHARMACIST

## Question 8

How often do you visit your pharmacist about your chronic pain?



## Question 9

On a scale of 1-10, how well do you think your pharmacist manages your chronic pain?

**4/10**  
Average

## Question 10

What are the most important things pharmacists should know, understand and do when treating someone living with chronic pain?

- **I am not a drug seeker**

- Don't treat me with suspicion
- Do not shame me for needing S8 drugs
- Don't judge me
- Believe me and my pain
- Don't interrogate me about my medications

- **Don't discuss my medication needs in front of other customers**

- My pharmacist is great
- Don't assume what I'm saying isn't true or that the medication I have been prescribed is wrong for me
- Understand what it's like for me to live with chronic pain
- Be familiar with my medication history
- Better education about the different types of pain conditions

- **Listen to me and my needs and take me seriously**

- I don't use a pharmacist for my pain management at all
- Know and advise me on the side-effects of my medication
- If we are grumpy, it is because of the pain – not because of them
- Create a friendly working relationship with me
- Have empathy and an open mind
- I see pharmacists as providing medication only – they don't have a role in managing my chronic pain

- **Explain to me in plain English how my medication works**

- Consider what other medication I am taking
- Fully explain the pain relief available whether it be prescription or over the counter
- Just because I have a prescription to a medication which can become addictive doesn't mean I am addicted

**Question 10 (continued)**

- Just because someone looks healthy doesn't mean they're ok
- My GP has prescribed my medication for a reason
- My pharmacist is amazing!

- **When you treat me suspiciously it creates tension between us which exacerbates my pain and does nothing for our pharmacist-patient relationship**

**Question 11**

**If there was one thing your Pharmacist could do now to help with your chronic pain, what would it be?**

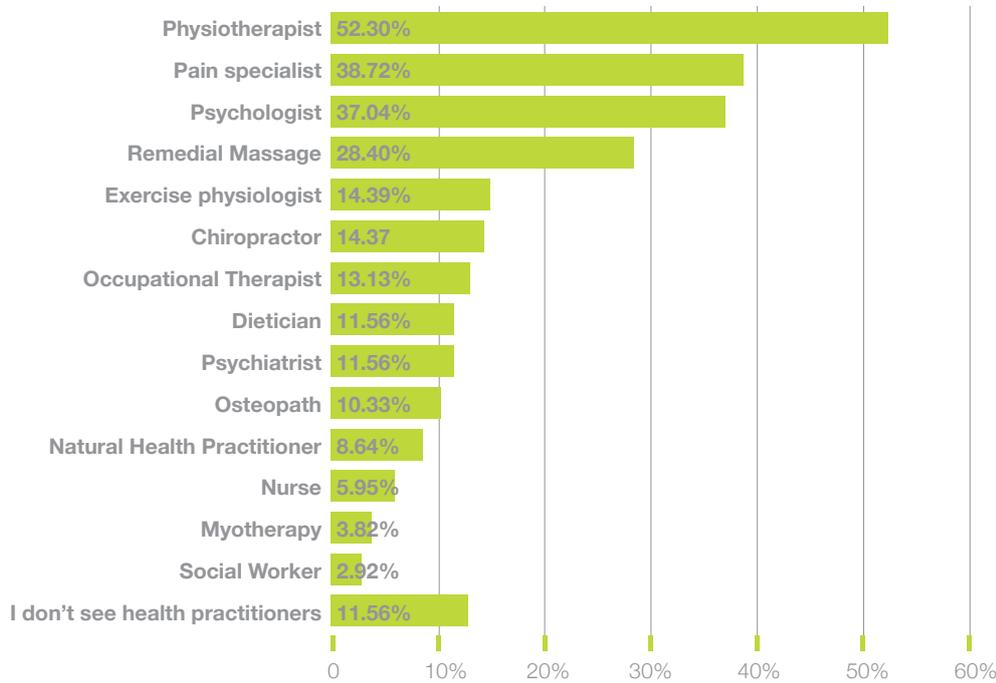
- Be understanding and helpful
- Don't question me about why my GP has changed my medication – I don't always know
- Be more sympathetic than sceptical
- Listen with empathy
- **Don't make me feel guilty when getting my prescription medication – offer me genuine solutions instead**
  - Help me get on medicinal cannabis
  - Understand what it is like for me to live with chronic pain
  - Help me understand what my non-medicine treatment options are
- **Look at the person not just the pain – I am more than my pain**
  - Ensure that I know about the side-effects of my medications
  - My pharmacist is great – they are doing all they can to help me
  - Nothing, because I don't think my pharmacist knows what my condition is
  - Take a non-judgemental approach to me
  - Make sure my medication is in stock
- **Stop being so judgemental and putting everyone into one category. Understand that I can have the same illness as someone, but our symptoms can be completely different**
  - Be more supportive and less judgemental
  - Nothing – the pharmacist's role is to dispense my medication, that's it.
  - Advertise how they can help – I didn't realise they could
  - Be able to deliver my medication to me for the days my pain is so bad I can't leave home



OTHER HEALTH PROFESSIONALS

Question 12

What other health professionals do you see to help you treat chronic pain?



Question 13

Were you referred to them by your GP?

**YES**

61.22%

**NO**

38.78%

Question 14

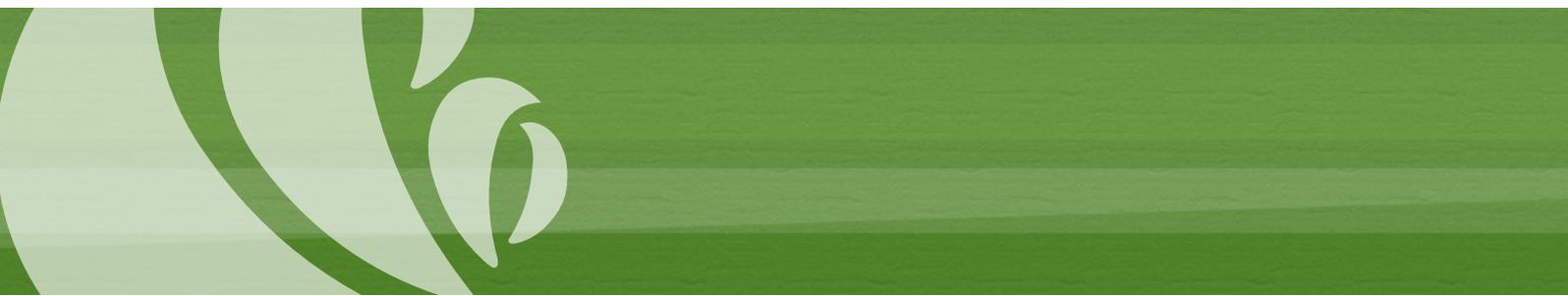
Do you find accessing these health professionals easy?

**YES**

52.04%

**NO**

47.96%



## Question 15

How do they help you manage your chronic pain?

**They help me move.**  
**They help me cope with daily pain.**  
**They allow me to have a life outside of the pain.**  
**They make my life easier.**

- Relocating dislocated joints, healing chronic injuries and helping me gain strength to hold my body together
- They provide me with coping techniques both mental and physical.
- They offer me with practical solutions to obstacles like getting up the stairs on my own.
- I am managing two chronic conditions which are both incurable, they approach treating these from a holistic point of view, looking at the bodies' various systems and breaking it down to a functional level
- By offering a holistic approach to pain management
- They help me moderate my pain and help me gradually increase my resilience and strength
- They help me get my body moving again which reduces my pain
- My Pain Specialist has helped me immensely and I can now have a life again
- Seeing them is like a tune up for my entire body
- They provide a more natural approach to pain management
- They don't really provide me with any real benefit
- They help me understand what exercise I can do
- The massages I receive make me feel better and reduce my pain and give me better movement in my body
- I learn techniques to manage the mental side of pain
- They all work collaboratively together – I have a great team

## Question 16

Do you find utilising these professionals affordable?

**YES**

16.27%

**NO**

83.73%



FEDERAL GOVERNMENT

Question 17

Do you think the government should provide a full or partial rebate for accessing allied health professionals to manage chronic pain?



Question 18

How often do you visit other health professionals?

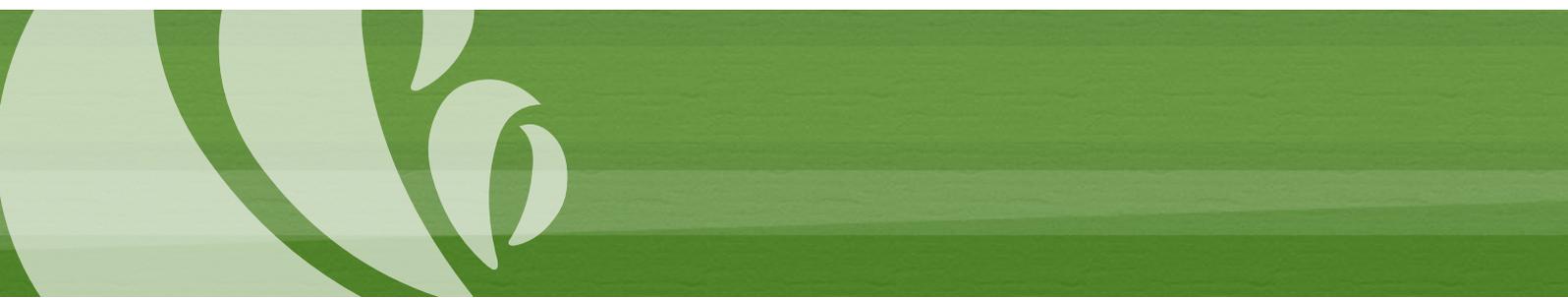


Question 19

What do you think the most important thing is that governments can do to support people living with chronic pain?

*“Don’t put us all in the same box. Stop pulling the rug out from under us when taking drugs off shelves or making them harder to acquire. If we are being monitored by a pain management specialist, then we should not have to jump through bureaucracy hoops or have our GPs scared to prescribe stronger drugs. Government should be protecting us from the medical professionals who promise pain relief they can’t deliver. Such as surgeons implanting devices that are known to fail/not work at all. Or doctors performing other invasive procedures that don’t have a documented rate of success.”*

- Provide more long-term health plans and more affordable ongoing treatments.
- Provide more public pain clinics and subsidise access to specialists
- Provide better Centrelink support to us
- Help with the cost of GPs, specialists and other health practitioner appointments



**Question 19 (continued)**

***“Increase funding visits to allied health professional, the Chronic health care plan available form a GP with 5 visits per calendar year, is not enough - many people with ongoing pain require regular appointments with multiple allied health professionals”***

- Understand that chronic pain can be a disability and not just a symptom and do more to educate the wider community about its impact
- Ensure we have access to the treatments we need at affordable process, so that we can remain functioning members of society
- Help remove the stigma of living with chronic pain
- Make medicinal cannabis more available and affordable

***“Funding through the NDIS and DSP for those with chronic pain conditions. The current criteria is way too restrictive and the hoops we have to jump through are exhausting”***

- Easier access to mental health professionals who I can afford
- Further invest in evidence based pain programs
- Do not restrict needed medication
- Opiates aren't necessarily the enemy and that when used as prescribed can make life bearable
- make the DSP and NDIS accessible
- provide more community based education resources we can use to manage our pain
- Acknowledge that our pain is real and affects our entire life

***“Recognise that affordable allied health services mean I can stay in the workforce longer and contribute to society reducing the overall burden on the health system”***



## STIGMA

## Question 20

**How would you rate your feelings of stigma or negative attitudes because of your chronic pain?**

(One being not at all and 10 being constant)

**7/10**  
Average

## Question 21

**If you do face stigma, can you provide examples of situations when you felt stigmatised?**

“

*People don't understand when you say no to activities or have to leave early*

*I have been treated like a drug seeker by many GPs and specialist, even if I refuse pain relief to prove I just want help with pain management and daily injuries – but I was treated like a hypochondriac instead*

*The belief that because chronic pain can't often be seen, it permits judgement on the degree and debilitation of pain.*

*Being abused every time I park in disability parking with my permit on display. People tell me I shouldn't be parking there because I don't look disabled*

*Countless times being told that you do not look like you are in pain – therefore you are expected to do things that cause extra pain*

*Hospital admissions, where they don't give you your prescribed pain relief because they don't believe you need it or think you are a drug seeker*

*A lady told me I should wear long dresses so people don't have to see my brace that I need to be able to walk*

*Being rejected by medical professionals because they say I'm too young to have chronic pain and I don't look sick*

*Taking time off work for my pain and my employer giving me a written warning for not going to work because of my pain which saw me go to hospital that day*

*Been told that I am a bludger, that I can do things when I so choose, and that I am wasting the taxpayers money. That I don't deserve a disability parking permit.*

”

## Question 21 (continued)



*When I go to buy pain relief medication and questioned on why I need it.*

*My friends believing that my pain should all be over by now*

*Being told pain is a state of mind and if I got some hobbies and friends it would improve*

*Being made to feel like I don't do enough to manage my pain and that somehow I am responsible for the pain that I have*

*People just not understanding what it is like to live with chronic pain all the time – there is no off switch for my pain*

*People can't see my pain – therefore it doesn't exist*

*Friends who do not understand my condition and expect me to have normal behaviour and do the same things they can do*

*Being told/having implied that I am not trying hard enough*

*Was sent to a physician who stated that chronic pain did not cause disability*

*Inability to socialise, people react negatively to invitation refusals*

*My psychiatrist wrote to my GP telling them I was a hypochondriac*

*I told a friend that I had been diagnosed with Fibromyalgia and she told me that I needed to health my mind, body and soul and then I would be fine – ummmm no thanks*

*I don't face any stigma*

*“That's a high dose for someone so young”  
– doctors and pharmacists*

*Holding people up in public due to my slow walking speed and they get mad at me*

*Nearly every time I am out using my walker someone will say “you are too young for a walker”. Many times this is followed by “Have you tried this or that treatment”, the inference being I haven't looked far enough for a treatment of haven't worked hard enough for it to be effective.*



### Question 22

#### What do you think the public should understand about living with chronic pain?

- That my pain is real – I'm not faking it
- The pain is exhausting and debilitating
- A wheel chair is not the only indicator or proof of pain/limitations/disability
- That pain is ongoing it doesn't just get better and it is a serious condition
- We aren't lairs
- You can't always see the pain
- I am not a drug seeker!

***“It's debilitating. I'm not lazy, I just can't do it all and some days I can't do anything. I have no control over it and even when I do everything the best way possible I may still get pain. Being in constant pain is draining, physically and mentally”***

- The pain is constant and wears you down
- Just because you can't see my pain – doesn't mean that I am not in pain
- The pain can take over your life and be very isolating

***“Just understand. Have some compassion. Have some common sense, not everyone has a perfectly aligned spine, not everyone has a high pain threshold.. not everyone can cope without relief, not everyone can just suck it up and be tough. We need kindness from people, not vilification. We are victims of our pain and now we are victims of the system too and we feel like we are being left behind”***

- For some types of pain there is no reason as to why it starts – it could happen to you too!
- Many people hide their pain and even though they look ok from the outside it doesn't mean they aren't struggling
- We are not hypochondriacs
- The pain affects our mental health too
- My pain changes day-to-day some days are good days, some days are bad days
- My pain isn't going away just with one physio appointment
- People of all ages can live with pain
- We get fatigued quickly
- You can't just pop a pill or sleep it off – the pain is always there.

***“That we aren't complaining about a stubbed toe or simple tooth ache, we have pain that has been around for years and in some cases does not go away at all so when we say we are in too much pain today to do something don't compare it because you have no idea how draining it is to be living with constant pain 24/7 and sometimes we do need a break”***

### Question 23

#### How important do you think it is that the public understands what it is like to live with chronic pain?

**8/10**  
Average



## MEDICINAL CANNABIS

## Question 28

What do you think about the use of medicinal cannabis in the management of chronic pain?

“

*I think it can help a lot of people manage their pain*

*I don't know enough to comment*

*Amazing and the way of the future*

*I'd love to be able to try it. Availability is too restrictive and too expensive*

*I'd like to try it but the cost makes it out of reach*

*I don't think the evidence is strong enough to support the widespread use and financial support it*

*I'm all for it, would love to give it a go, anything for some relief*

*If I could access it I certainly would. If I could get off the mind numbing endless pills I need to get through a day I would in a heartbeat.*

*I think it has its place but only for certain people and conditions*

*I think it is a fantastic idea, and would much prefer it to using heavy opioids. However, as is always the case, the moral panic has made accessibility and affordability a key issue.*

*I think it is very helpful for many ailments and if it gets people off higher strength drugs then it's great. The government needs to make it much more accessible for trial. The price of the government sanctioned stuff is a bloody travesty, that's not helping anyone.*

*If it helps a person to keep living their day-to-day life without as much pain then I support it*

*Whole heartedly approve. I use CBD oil which helps*

*Good for some, but not interested in it for myself*

*Absolutely for it! Including medications that contain THC as well. It works like nothing else in my experience.*

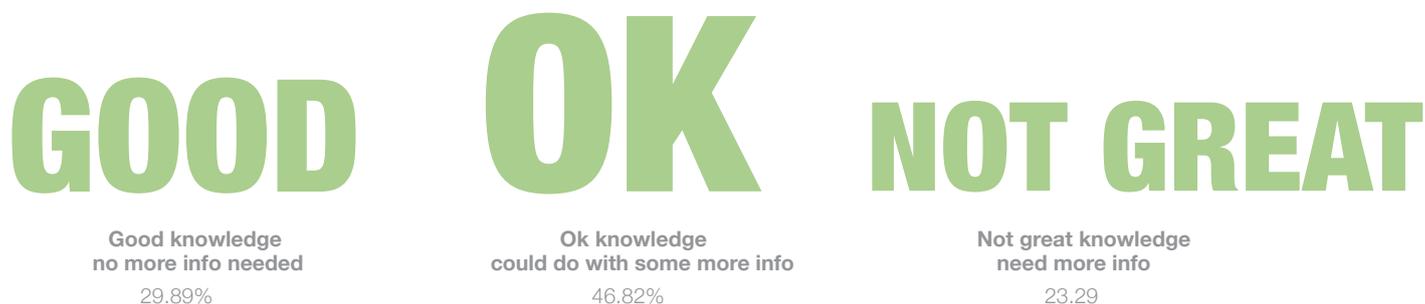
*I think it's the way to go however it's very hard to find a GP who will prescribe it! Especially if you are living in a small country town.*

”



## Question 25

How would you rate your knowledge of the science behind medicinal cannabis?



## Question 26

Have you spoken to your GP about accessing medicinal cannabis?



## Question 27

What was their response?

*“I asked my pain specialist and he just scoffed at me – said that everyone just wants to get high for free”*

- They had no idea about it
- Didn't ask as my GP is not open minded
- Very negative – said there is not enough evidence

*“It is easier to buy it illegally than it is to have it legally approved. Just get some and don't tell anyone”*

- Supports it – my pain specialist has already made the prescription
- Too much trouble to deal with
- Was told it is not available
- Was told my GP couldn't prescribe it
- I was advised not to take it
- Laughed at me
- Very dismissive
- Open to the option



*“They rolled their eyes at me. They looked at me as a junkie. They judged me and deemed my need for an opiate as a sign of my drug dependence. It was disgusting. I was disgusted. They were horrible. I went home in pain.”*

*“He said no, it was illegal, but then suggested I smoke a few cones! My pain specialist however referred me and I am approved for use”*

*“He was laughing his head off. My neurologist was willing to prescribe it, but added that I probably would not be able to afford it.”*

*“Very supportive – I gave him lots of information and he looked through it all”*

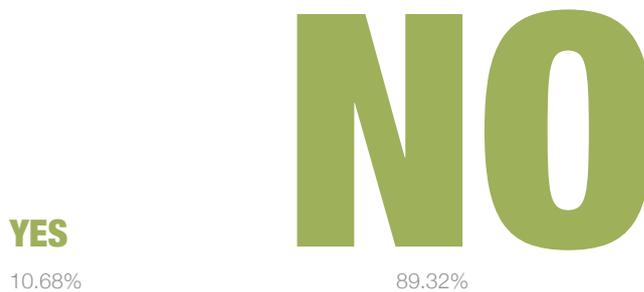
*“He suggested it to me – so did my specialist”*

*“Did not want me to take it and compare it with when doctors prescribed cigarettes stating no clinical studies on side effects”*

- I didn't ask because I was scared
- I know I can't afford it so didn't ask
- My GP told me it was illegal to use cannabis
- On the fence about it

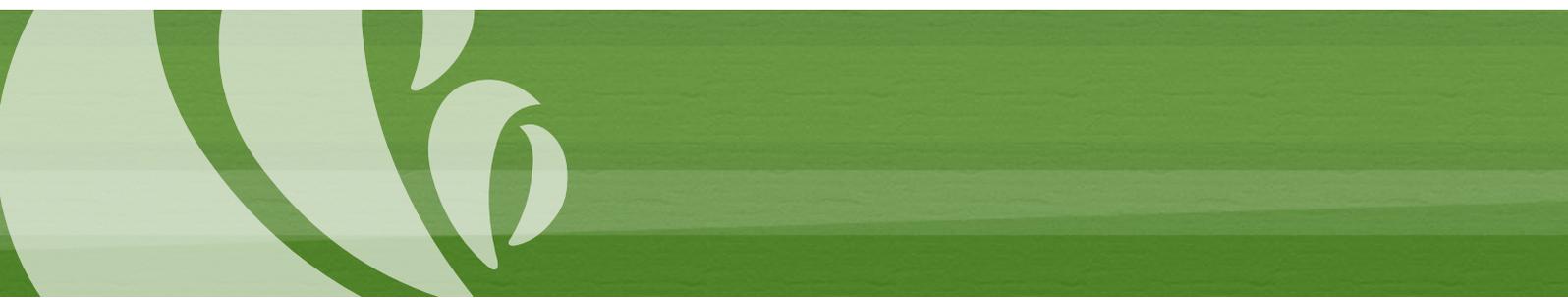
**Question 28**

**If you have been discussing medicinal cannabis with your GP for more than 12 months, have you noticed a change in their willingness to prescribe medicinal cannabis?**



**Question 29**

**Did you know that a pain specialist can provide a prescription for medicinal cannabis?**



## COVID-19

## Question 30

During COVID-19 has the way you manage your pain changed?

**YES**

52.52%

**NO**

47.48%

## Question 31

If yes, how?

- No access to gym/bike/spa/hydrotherapy pool making exercise very difficult
- Less support – harder to access medication and see medical professionals

*“I am immunocompromised so I can’t go to the clinic and need to do everything virtually or over the phone to stay safe”*

*“Strangely it has had a positive effect – life has been a lot less stressful in my family situation”*

*“Working from home has helped give me more energy”*

- I use telehealth a lot for my GP and pain Specialist appointments
- Couldn’t see my usual doctor during pain flares
- Have been using more drugs because I can’t access other therapies at the moment
- I just put up with the pain

*“I feel my pain is exacerbated by the stress of COVID-19”*

- There hasn’t been a change to how I manage my pain
- I’m experiencing more pain, medicating more and not using any allied health services
- My surgery was cancelled
- I have not been able to get my Ketamine Infusion

## Question 32

Have you utilised technology/telehealth to meet with health practitioner during COVID-19?

**YES**

66.91%

**NO**

33.09%



## Question 33

Did you feel a benefit from using telehealth?

**YES**

66.91%

**NO**

33.09%

## Question 34

If yes, why?

- It's a great option when I am too unwell to attend an appointment in person

*"I felt safe and was less stressed trying to find time to get into the doctor when trying to work full time"*

- Saves me so much time than going to in person appointments

*"I am confined to bed mostly. It is so important to have access to my doctor without having to travel to see him. Telehealth is a very important advance for the disabled."*

- It's very easy to access the health professionals I need to

*"Telehealth is awesome. I have to get scripts from my doctor regularly and end up sitting in a waiting room for hours in pain for no reason. Most of my medications are long term and do not require a review every single time I need a new one. I hope they continue to offer these after lockdown."*

- Telehealth helped maintain momentum of my treatment and I have been able to access help during COVID-19

*"Fewer access barriers for people like me with a physical disability"*

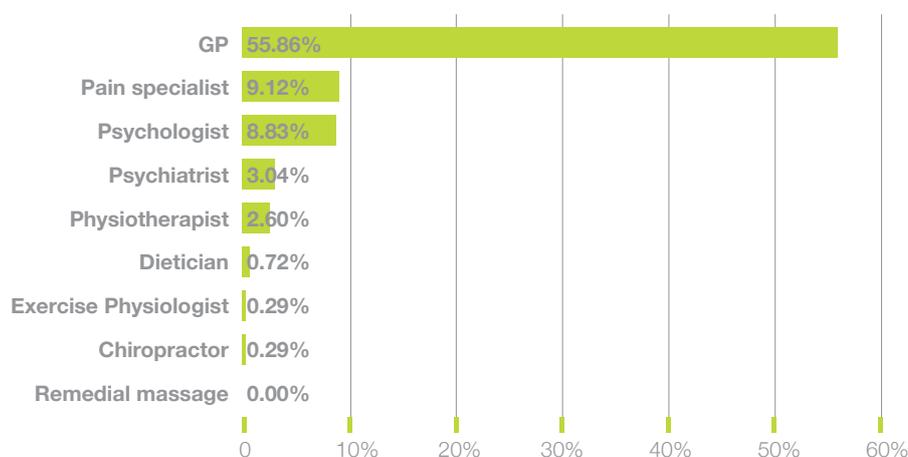
- It keeps us all safe

*"A lot of problem solving can be done over the phone/video chat. It saves a lot of energy and time not having to physically attend the doctors."*



## Question 35

What practitioners are you seeing using telehealth?



## Question 36

If you faced barriers accessing telehealth, please describe what they were?

- My condition needs physical examination
- Hard to know who is available through telehealth and how to access it
- Ability to have privacy during a consultation in a shared home
- I worry about my privacy and confidentiality using telehealth
- It's only available to me over the phone not via video which I would prefer
- The internet is not good enough in my area
- My health professional refuses to see me via telehealth

*“I am not comfortable discussing my mental health issues online”*

*“My doctor phoned me even though I suggested video conferencing. He could not examine my movement at all. Pointless.”*

*“I prefer face to face even if I have to travel. Least at the Pain Clinic particularly with the physio they can ensure any exercises you do are being done correctly. You cannot see which muscle groups are being tensioned over telehealth”*

*“Some health professionals you just need to see face to face. Like physiotherapists, so telehealth is a bit pointless. Tried to arrange a telehealth appointment with an orthopaedic surgeon last month but they said no. Ended up seeing him face to face.”*

**Question 37**

**Do you have good internet connection in your area?**

**YES**

88.17%

**NO**

11.83%

**Question 38**

**Do you feel that you have all the technology you require to engage with your health practitioners through telehealth?**

**YES**

81.63%

**NO**

18.37%

**Question 39**

**Would you consider using telehealth options with your health practitioner once COVID-19 is over?**

**YES**

59.44%

**NO**

19.85%

**UNSURE**

20.71%

**Question 40**

**Over the last 12 months have you experienced a disruption to accessing your medication?**

**YES**

41.17%

**NO**

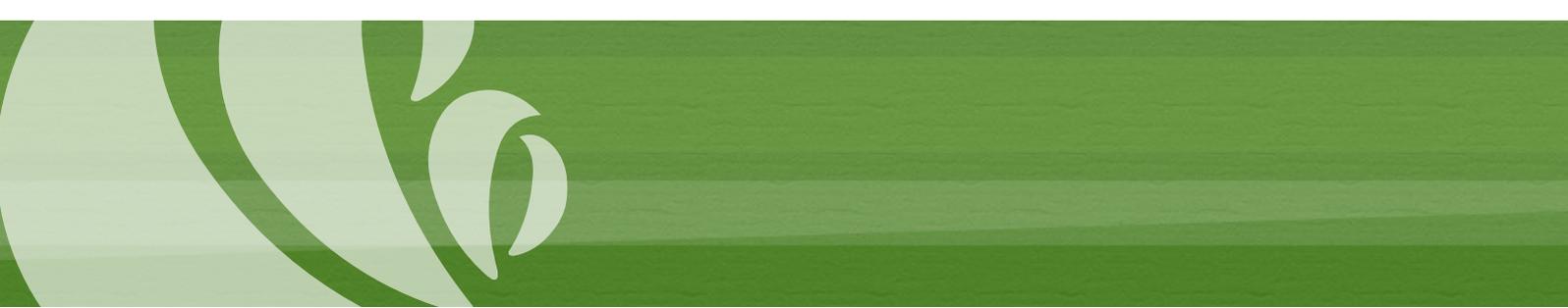
58.83%

**Question 41**

**If yes, can you tell us what happened?**

*“My chemist doesn’t always have one of my medications in supply despite knowing it is a regular requirement”*

*“Hospital based ketamine infusions were cancelled – they have re-opened recently, however I am not willing to be in hospital right now because of COVID-19”*



**Question 41 (continued)**

*“I take hydroxychloroquine and since Trump declared it would cure COVID-19, it has been hard to access”*

*“A previous GP called me an addict and cut my supply off despite taking low dose opiate and having approval from my pain specialist”*

*“A doctor wouldn’t prescribe me pain meds – he actually prayed for me instead”*

*“My doctor was unavailable and I saw another doctor who didn’t believe I was in pain or should be on that tablet therefore he was not willing to give a repeat of the tablet despite needing it until my surgery is back because of COVID-19”*

- Harder to purchase pain relief from the pharmacist due to new restrictions
- The pharmacy was out of my medication
- My regular GP was away and the replacement GP refused me medication
- My pharmacist was out of my medication due to increase demand from people because of COVID-19

