National Pain Survey 2018
Answers reported by key themes and metrics
Total number of survey respondents - 1266

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Pharmacists 3
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 DEMOGRAPHICS

Total number of survey respondents - 1266

Question 1
What is your age?

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>3.41%</td>
</tr>
<tr>
<td>25-34</td>
<td>11.82%</td>
</tr>
<tr>
<td>35-44</td>
<td>24.11%</td>
</tr>
<tr>
<td>45-54</td>
<td>27.11%</td>
</tr>
<tr>
<td>55-64</td>
<td>24.27%</td>
</tr>
<tr>
<td>65-74</td>
<td>8.09%</td>
</tr>
<tr>
<td>75+</td>
<td>1.19%</td>
</tr>
</tbody>
</table>

Question 2
What is your gender?

- Female: 82.83%
- Male: 16.21%
- Transgender: 0.24%
- Other: 0.56%
- Prefer not to say: 0.16%

Question 3
What state do you live in?

[Map showing distribution across different states]

Question 4
Do you live in?

- Own Home: 98%
- Residential aged care: 0.8%
- Other: 1.2%
Question 5
How often do you visit your GP about your chronic pain?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weekly</td>
<td>13.2%</td>
</tr>
<tr>
<td>Fortnightly</td>
<td>16%</td>
</tr>
<tr>
<td>Monthly</td>
<td>34.4%</td>
</tr>
<tr>
<td>3-4 times per year</td>
<td>16.8%</td>
</tr>
<tr>
<td>Other frequency</td>
<td>19.6%</td>
</tr>
</tbody>
</table>

Question 6
On a scale of 1-10 how well do you think your GP manages your chronic pain?

9/10

Question 7
What are the most important things for GPs to know, understand and do when treating someone living with chronic pain?

- Validation - actually hear me, have empathy for me, listen don’t judge
- My pain is not made up
- Further training for GP’s around pain
- Embrace a wholistic approach
- Work with me
- Learn about cannabis as a treatment method
- Mental health issues go hand in hand
- Understand my life and what a day looks like for me
- Don’t rush me if I have been in past my 6 minutes, tell me if I need a longer appointment
- I am not a timewaster
- The pain is real
- Sometimes I need medication to manage my pain – that doesn’t make me a junkie
- My pain varies from day-to-day
- I don’t always want opioids

Question 8
If there was one thing your GP could do now to help you manage your chronic pain, what would it be?

75% of respondents wanted to be prescribed cannabis

- Listen to my whole story and understand my pain
- Help me relieve the pain
- My GP is helping me do as much as I can to manage my pain
- Do more research about pain conditions
- Prescribe me different medication
Question 9
How often do you visit your pharmacist about your chronic pain?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weekly</td>
<td>18%</td>
</tr>
<tr>
<td>Fortnightly</td>
<td>22.4%</td>
</tr>
<tr>
<td>Monthly</td>
<td>32%</td>
</tr>
<tr>
<td>3-4 times p/year</td>
<td>6.1%</td>
</tr>
<tr>
<td>Never/rarely</td>
<td>21.5%</td>
</tr>
</tbody>
</table>

Question 10
What are the most important things pharmacists should know, understand and do when treating someone living with chronic pain?

- Know my medication history, what medication I take and why
- I am not a drug seeker or an addict
- Have empathy
- Listen to me and actually hear me
- Don’t judge me – you don’t know my pain better than me or my doctor
- My pharmacist is great – couldn’t manage my pain without them
- Happy to listen to your advice – but don’t lecture me
- Make sure you have the medication I need in stock
- I don’t want you telling the whole shop what medications I am on – but I do appreciate you checking on how my medication is going
- Understand that my pain changes and often flares up
- Help me understand the side effects of my medication
- Don’t be rude or dismissive of my needs
- “We want to understand what’s happening in our bodies and feel in control”
- “Don’t pry. Respect the privacy of the person and their scripts. They need to understand it is not okay to ask questions in front of other customers”
- The doctor, pain specialist and surgeon have prescribed these medications for a reason. If the pharmacist doesn’t understand why, it’s of no use to question the patient as to why their medical professional has prescribed something for them.

Question 11
If there was one thing your Pharmacist could do now to help with your chronic pain, what would it be?

“Stop the 50 million questions, listen and help”

- Lobby for my right to cannabis / dispense medical cannabis – 1 in 2 respondents
- Nothing – my pharmacist is doing a good job
- Offer me non-pharmacological options
- Listen to me
- Stop judging me
- Be more understanding of me and my pain
- Have stock available
Question 12
Do you know about the Pain MedsCheck trial program?

**NO**

93.39%

**YES**

6.61%

Question 13
Would you do a Pain MedsCheck program in your local pharmacy?

**YES**

28.37%

**NO**

9.62%

**DON’T KNOW WHAT IT IS**

62%

Question 14
Why/why not?

- I don’t know about it
- I would be open to doing it if I knew more about it
- I don’t think this [pharmacy] is the place to do it. I would be much more beneficial to patients to go to a chronic pain specialist.
- I am sceptical that this isn’t a pay-off to pharmacists to recoup the lost income from changes in codeine scheduling
OTHER HEALTH PROFESSIONALS

Question 15
What other health professionals do you see to help you treat chronic pain?

- Physio 18.73%
- Psychologist 7.57%
- Pain Specialist 16.68%
- Nurse 0.82%
- Dietician 0.82%
- I don’t 12.38%
- A combination of health practitioners 42.99%

Question 16
Were you referred to them by your GP?

YES 67.65%
NO 32.35%

Question 17
How do they help you manage your chronic pain?
- It is the foundation to my treatment
- They give me non-pharmacological strategies to manage my pain
- Trying new management techniques with me
- Listening to me
- They don’t really help me
- Helping build core strength
- Providing me with massages and helping with exercise

Question 18
Do you find accessing these professionals easy?

YES 42.74%
NO 57.26%

Question 19
Do you find utilising other health professionals affordable?

YES 12.89%
NO 87.11%
FEDERAL GOVERNMENT

Question 20
What role do you think the federal government has in assisting Australians living with chronic pain?
• To acknowledge that chronic pain is a disability, resulting in access to the Disability Support Pension and Health Care Card
• Making treatments more accessible and affordable
• Improve funding for specialists to reduce waiting times
• Better financial support for people accessing Centrelink payments
• Increase the number of visits allowed under the mental health plan
• Legalise cannabis (1/3 respondents)
• Reconsider the codeine up scheduling – we aren’t all addicts
• Educating the public on what chronic pain is
• Educating themselves on what it is like to live with chronic pain

Question 21
Do you think the federal government is currently doing enough to help support people living with chronic pain?

NO 98.61%
YES 1.39%

Question 22
What do you think is the most important thing the federal government should do to support people living with chronic pain?
• Greater financial support – raising the Newstart allowance
• Acknowledgement that chronic pain is real and life altering, and it can’t simply be fixed
• List chronic pain as an option for the Disability Support Pension
• Make cannabis legal
• Listen to us and understand our needs
• Expand the 5 Enhanced Primary Care Plan
• Provide Medicare rebates on alternative therapies
• Greater funding to make healthcare more accessible and affordable
• Give us hope to keep going

Question 23
Do you agree or disagree with the federal government’s decision to up-schedule codeine from 1 February 2018?

AGREE 29.92%
DISAGREE 70.08%
Question 24

Why do you feel this way?

- Increased need to see GP for something I have been taking for a long time and managing well, plus the extra cost.
- It’s unfair – I wasn’t addicted or abusing my opioid medication
- My pain is unpredictable, I used my medication when I had a flare up which means I don’t always have a script ready, now I must go to the ED when I have a flare up.
- I support the move because the drugs are dangerous and doing people harm (minority view)
- Why should the majority of people who did the right thing suffer because of those who did the wrong thing?
- I don’t take codeine / I’m allergic
STIGMA

Question 25
Do you feel that you face stigma or negative attitudes because of your chronic pain?

YES 86.29%  NO 13.71%

Question 26
If you do face stigma, can you provide examples of situations when you felt stigmatised?

• Every time I see a medical practitioner they treat me as if I am a drug seeker not someone in pain – accused of doctor shopping
• Doctors telling me the pain isn’t as bad as I am telling them it is
• Medical practitioners thinking that just because one part of my body doesn’t work, neither does my brain
• People thinking that I am faking my pain
• Being told by friends/family/boss “but you don’t look sick”
• When I park in a disabled spot I often get bad looks because “I don’t look disabled”.
• Being judged by my pharmacist/pharmacy assistant

I feel stigmatized anytime I say I can’t do something and I get “you’re a fit young 20 year old” back as a response. People don’t recognize the seriousness and extent of my daily pain. They assume I’m making it up, or being a sissy. They tell me to harden up and get through whatever activity I’m doing that I feel I can’t do, simply because they can’t see my illness, until they push me too far and I literally can’t walk or bend, then they take notice. I’m so sick of not having enough money to live a basic life because I’m too disabled to work, but doctors won’t listen to me, and Centrelink won’t let me get disability unless a doctor says I need it, and everyone just looks at me like a lazy dole bludger, and it makes me feel so worthless. I want to do things, and I do when I can, I just can’t work a full-time job, but don’t have the obviousness of a physical disability like being handicapped, so no one takes me seriously when I try to engage in the welfare system we have set up for that exact scenario. I’m stuck in a weird place where I only get youth allowance and can barely afford to live, let alone save and get to do things in life, because I can’t work, but don’t have anyone that takes me seriously enough that I can get disability. I’m discriminated against and stigmatised by everyone from doctors, to Centrelink workers, to my job service providers, to the government itself, who will on one hand give my nan disability for having arthritis in her knee, but because I’m a young male, they just look down on me as a bludger and decide I’m not worthy of help from the system that is there to help me, despite the fact that I have worse pain in more areas than my nan.
Question 27

**What do you wish the public would understand about living with chronic pain?**

- How pain can make you depressed and anxious
- Understand that it is a daily struggle
- Understand that I can’t work because the pain is too bad
- Understand what a day is like for me
- My pain is real – I’m not making it up
- We need medical cannabis to manage our pain
- It affects my whole family, emotionally, physically, financially
- Not all health conditions can be seen
- It can’t just be cured
- I am not a junkie
- Have patience with me/don’t rush me
- We need kindness
- I am not useless
- It’s not like having a bad back/headache every now and then

*You want to get up and do things, go out and live a normal life but your pain cripples you and the medications you are on bomb you out and give you so many other side effects that most days are hard to face. Seeing me in my own home is better than me trying to visit you. I try my best, but it is like living with a ton of bricks tied to you.*

Question 28

**Do you have any ideas as to how the general community could help people with chronic pain?**

- Stop judging people who use cannabis
- Put pressure on the government to help us
- Be aware of what it is like for us to live with chronic pain
- Believe me when I say I am in pain
- Don’t feel sorry for us – but have empathy
- The public need to have a way to get educated about chronic pain
- Understand the difference between living with an addiction and living with chronic pain

Question 29

**Do you think it is important or unimportant that the public understands what it is like to live with chronic pain?**

**IMPORTANT**

- 92.96%
- 7.04%
Question 30
Do you support the need for a public health promotion campaign which explains what it is like for people living with chronic pain and how chronic pain can be managed and prevented?

SUPPORT
92.78%

DON'T SUPPORT
7.22%