



**painaustralia**

**SafeScript NSW**

Consumer Experience  
Evaluation Project  
Final Report

August 2023



# painaustralia

“ Programs like SafeScript NSW are part of the journey, part of the education of the person. It’s not a bad thing, it’s not to say big brother is watching you. It’s there to help you. ”

~Consumer Quote

## Acknowledgements

Painaustralia acknowledges the contribution of the project team: Monika Boogs, Elli Williams, Madeline Thorpe, and Kevin James.

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# About Painaustralia

Painaustralia is Australia's national pain peak advocacy body working to improve the quality of life of the 3.4 million people living with pain. Our aim is to have their voice represented in all health policy and decision making impacting them.





## Pinaustralia's partnership with NSW Health

For the past two-years Pinaustralia has worked with NSW Health as part of its implementation of SafeScript NSW – a real time prescription monitoring system that allows healthcare professionals including GPs, nurse practitioners, dentists, and pharmacists to access a patient's prescription history for certain high-risk medicines, such as opioids and benzodiazepines, commonly prescribed for severe pain relief.

The program is part of a national commitment by states and territories to reduce the harm associated with the use of monitored medicines. The partnership with NSW Health and Pinaustralia has included a video for consumers, a consumer webinar and review and feedback on appropriate messaging for prescribers and pharmacists when interacting with consumers.

With the roll out of SafeScript NSW statewide in May 2022, Pinaustralia has conducted a qualitative evaluation of the program's implementation. Fifteen consumers who live in different regions of NSW were interviewed over a period of nine months at three different times to explore and detail their experience of SafeScript NSW and their resultant interactions with their health professional. Fourteen of the 15 consumers participated in all three interviews and one person participated in the first two interviews and could not participate in the third interview due to unforeseen circumstances.



## Real time prescription monitoring programs

For people living with chronic pain conditions, medication is the most accessible and affordable form of treatment for managing their chronic pain. It is essential that as a community we achieve a balance between ensuring people have access to the medications they need to manage their pain while at the same time ensuring the medications are being used safely and effectively and not being misused.

Real time prescription monitoring systems of high-risk medicines are a clinical tool for prescribers and pharmacists. Increasingly, they have been used as a regulatory option in every state and territory. Their aim is to save lives and reduce harm related to opioid use. In 2019, there were 1644 unintentional deaths due to drug overdoses in Australia with 429 deaths due to pharmaceutical opioids and 582 deaths involving benzodiazepines.<sup>1</sup>

These computer-based programs provide prescribers and pharmacists with an individual's medicine history in relation to their use of monitored drugs such as diazepam and tramadol. In each state and territory, the list of monitored medicines varies and in NSW they include buprenorphine, codeine, morphine, oxycodone, tapentadol, tramadol, lorazepam, temazepam, dexamfetamine and pregabalin.

If implemented well, these real time monitoring programs are a valuable tool to ensure consumers are using medicines safely and limiting medicine

misuse. However, consumers with chronic pain are a vulnerable cohort that already suffer much malignment, misunderstanding and stigma when it comes to their condition. These types of programs, if not implemented well, can add to that stigmatisation as they can lead to consumers being even more misunderstood, labelled as or made to feel like they are drug seekers or visiting multiple doctors for medicines. It is essential therefore to examine the experience of and impact of these programs on consumers with chronic pain, to ensure they are not adding additional burdens on patients.

One way to do this is by listening to and learning from the consumers themselves and Painaustralia would like to thank and applaud the NSW Government's eHealth team for their commitment to ascertain and understand the consumer experience via this project. They have demonstrated their desire to ensure SafeScript NSW is implemented in a way that aids and benefits consumers rather than hamper and add to their hardship.

Painaustralia would also like to acknowledge and thank the members of the project's Clinical Advisory Committee, the members of our Consumer Advisory Group and the 15 participants who gave up their time to provide their valuable insights and detail their experiences of trying to access medication for their chronic pain.



# Recommendations

The themes of stigma; a lack of understanding among health professionals of the unique circumstances of pain patients; and a need for better training, particularly for pharmacists, about how to interact with pain patients were dominant topics throughout all three sets of interviews.

## Our recommendations are:

# 1

### Improved and targeted training and education:

- Including communication involving language and messaging about the particular circumstances of pain patients and the stigma they can be subject to.

# 2

### Painaustralia to work with the NSW Ministry of Health:

- On initiatives that would help to reduce the stigma experienced by pain patients

## Painaustralia's project

The project, which was led by Painaustralia's Deputy CEO, Monika Boogs, consisted of three sets of online interviews with the first series of interviews conducted throughout the month of November and early December 2022. The second series of interviews were conducted in March 2023 and the third set conducted in June and early July 2023.

The aim of the study was to explore the benefits and identify any issues or challenges experienced by consumers as real time prescription monitoring is increasingly taken up and used by prescribers and pharmacists throughout NSW.

It is hoped that documenting qualitative consumer experiences will contribute to an improved and better experience for consumers.

The questions for the three sets of online interviews were developed with the assistance of the project's Clinical Advisory Committee and consumers from Painaustralia's Consumer Advisory Group. The questions formed the basis of the online interviews with consumers and focused on the consumers' experience and knowledge of SafeScript NSW and their own health conditions, the medicines they take and their interactions with their prescribers and pharmacists.





# Participant profile

Participants for the project were recruited through Painaustralia's consumer network which included a call out on social media and through the networks of the members of our Consumer Advisory Group.

Nine women and four men took part in the first and second set of interviews with ages ranging from early 20s to 70s, from all areas of NSW including Sydney, the south coast and regional and rural areas.

All of the participants who took part in the first series of interviews in late 2022 took part in the second series of interviews held in March 2023.

One participant did not take part in the last interview in June due to unforeseen circumstances.

## Health conditions

Some of the symptoms had been experienced for as long as 20 to 30 years with one participant experiencing pain conditions for more than 40 years.

Participants health conditions included:

- Neck pain.
- Migraines.
- Back pain.
- Knee pain.
- Ankle pain.
- Complex Regional Pain Syndrome.
- PTSD.
- Chronic Fatigue.
- Spinal Injury.
- Reoccurring shingles pain.
- Neuropathic pain.
- Arthritis.
- Mast cell activation syndrome.
- Sensitivity to sound.

## Treatments and medications

Most participants undertook a range of treatments to manage their chronic pain. While all participants used medicines at some stage, it was often in combination with a range of other strategies.

Reported medications used included:

- Targin, Palexia, Endone, codeine, Tramadol, Sevredol, Valium, Diazepam, Suboxone, Zolmitriptan, Lorazepam, Endep, Gabapentin, paracetamol, and ibuprofen.

Other ways the participants manage their pain included:

- medicinal cannabis, Lidocaine Patches, exercise, hydrotherapy, ketamine drip, Bowen therapy, attending online courses on pain, visiting psychologist, stretches, tai chi, radiation fibrillation, counselling, physiotherapy, practicing pacing, and surgery.

Throughout the course of the interviews some of the participants reduced or stopped their medication altogether while others increased their medications due to an increase in their pain or surgery.

### Profile Snapshot



9 Women



4 Men



20-70  
years old



Many types  
of pain



Pain for up  
to 40 years

# 1 What we found in the first interviews

- Overall, real time prescription monitoring programs such as SafeScript NSW are accepted by consumers.
- SafeScript NSW is seen as a tool to stop patients seeing more than 4 prescribers for their medicines.
- However, there is a need for more information about SafeScript NSW as the participants had very little knowledge and few conversations with their prescribers or pharmacists.
- Participants also saw SafeScript NSW as a blunt instrument particularly if the health professional they are interacting with lacks an understanding of chronic pain.
- The program is seen by some consumers as too broad, capturing and having a detrimental impact on pain patients who are doing the right thing and trying to manage their conditions.
- Some patients felt stigmatised and had difficulties in obtaining medication for their chronic pain, particularly from pharmacists.
- Some patients were concerned that SafeScript NSW could prevent them from getting access to the medicines they need in the future.







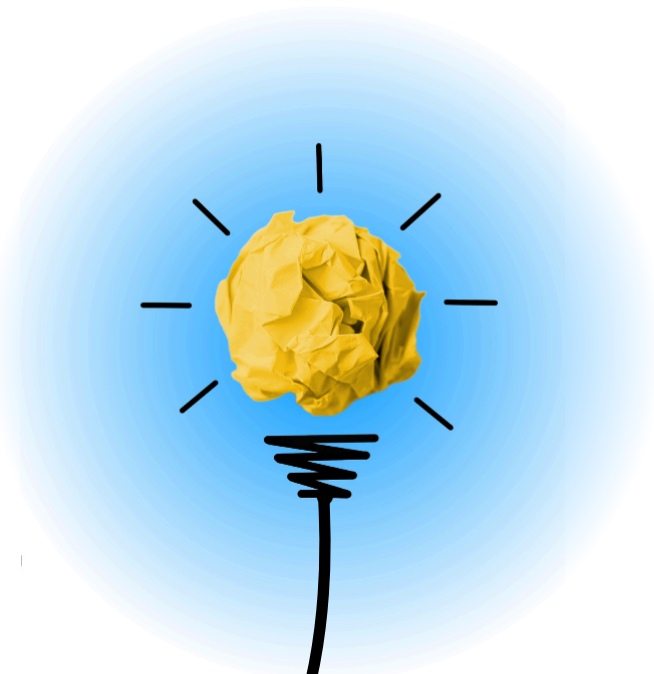
## 2 What we found in the second interviews

- Consumers accept the need for real time prescription programs, however, there are some concerns about implementation and whether the circumstances of pain patients have been considered by government when designing the system and guidelines for health professionals.
- Consumers acknowledged that one of the benefits of the program is that it identifies instances of medication misuse and patients visiting multiple prescribers enabling healthcare providers to intervene and ensure patient's safety.
- The program facilitates safer prescribing practices and increases medicine safety by helping doctors and pharmacists to make informed decisions about the appropriateness of prescribed medicines.
- Patients had engaged more with their health professionals and talked about the real time prescription monitoring program – but in most cases they had brought up the subject themselves.
- Challenges remain in obtaining much needed medicines for consumers who live with chronic pain.
- A level of stigma and misunderstanding of pain patients still exists particularly from pharmacists.
- Greater awareness of the program and its benefits is needed for consumers.
- A greater level of guidance for medical professionals about the program and understanding of the needs of pain patients is needed, this particularly applies for pharmacists.



# 3 What we found in the third interviews

- Increased awareness of SafeScript NSW among both consumers and health professionals.
- Increased awareness of the safety issues involving medication and how they interact with each other and how to avoid harm.
- Increasing number of conversations with health professionals about SafeScript NSW, particularly with GPs who have brought up the topic with consumers who are more aware of their pharmacist and prescriber using the system.
- Fewer concerns about privacy aspects of the program.
- For most participants earlier concerns about being able to access their medications had reduced, however, there were still a few consumers who had been unable to have their medication dispensed or had experienced some awkward scenarios or stigma and remained worried.
- Some patients continue to experience anxiety and apprehension when asking for medication; particularly when getting their already prescribed scripts filled.
- A level of stigma and misunderstanding about pain patients still exists particularly from pharmacists.
- Greater awareness of the program and its benefits is needed for pain consumers.
- An increased level of guidance and training for medical professionals about the program and understanding of the needs and stigma experienced by pain patients is needed.





# The benefits of SafeScript NSW from consumers

Throughout the course of the interviews the program's benefits were largely seen by consumers to be centred around medicine safety and reducing opioid harm and misuse.

Benefits commonly mentioned by consumers were:

- Medicine use for individual patients made safer including greater awareness of how medicines can interact with each other.
- Limited patients visiting more than four prescribers for medicines.
- The system particularly helped consumers' GPs when making clinical decisions for prescribed medication.
- Increased awareness of other pain management options.
- A safer community overall as it helped to limit medicine misuse and reduce opioid harm.

When reflecting what they had learnt about SafeScript NSW over the past year including having several conversations with their GP one consumer said:

*"Every time you go to put a pill in your mouth you think 'do I need it' rather than 'I have been told to take these pills pop, pop, pop'."*



## Positive individual impacts

Feeling safer and knowing all the information is available in the one data system are seen as overall positives of SafeScript NSW.

Participating in this project, having more conversations with their health professionals, and learning about SafeScript NSW has resulted in consumers knowing more about their medications, how to use them and generally being more cognisant about safety.

As one participant who had recently had surgery just weeks before their interview told us:

*"Isn't it funny, I'm constantly asking myself; Now, do I need a pain killer or not? I'm asking myself; do I need this painkiller? Is it just an ache and it's annoying, or should I try some heat on it first? I'm testing myself now where before I would have gone straight for the painkiller."*

When reflecting on how SafeScript NSW benefited them one consumer said:

*"On me it's a good stop-and-think and then carry on, possible in a different manner and possibly not, it's a good review for me."*

One participant said getting into their GP had been difficult, so they had turned to their pharmacist to ask how to take their medicine after surgery and the possible interaction between an opioid and paracetamol.

*"It's my pharmacist who has given me more help...she was saying no its really important to take both as the combination of the two will give you better pain relief."*

One consumer told us:

***"SafeScript NSW has made me more aware, I'm not as nervous or frightened of asking my pharmacist or GP for help or to explain to me...I like the holistic aspect of it all coming together and I know who to go to to get the information I need to know...and I like that if I go to another doctor at the clinic if my doctor is away, they have access to my information, and I feel secure that it's all on the one file."***



One consumer whose pain had increased in the months between the second and third interview said that SafeScript NSW had provided them with greater awareness of the safety issues around medication particularly as they had increased their intake of medicine and were on tramadol, diazepam and also modified release paracetamol.

They and their "outstanding" GP had had detailed conversations about the interaction of their medication, the addictive properties, the pros and cons of taking such medication and policing it with due diligence. They were also fortunate that their GP, pain specialist and pharmacist all worked together.

They said their GP was an advocate of the SafeScript NSW program using it actively when prescribing.

*"These are people that I have an active dialogue with."*

The same consumer had previously had an adverse reaction to a medication and had had concerns with how their medicines interacted with each other.

One of the consumers, who is on a controlled medicine, said the combination of both SafeScript NSW and the implementation of e-scripts had actually helped lessen their anxiety. They had been able to actually go to a different pharmacy where they had been given their medication after being asked for ID and asked if they needed any advice or information.

*"I do appreciate the fact that when I go into a pharmacy, I know they have access to SafeScript NSW, before SafeScript NSW I wouldn't just go to a random pharmacy, because I'm very non-confrontational so I will tend to go to the places I know but I knew that they would have a record of everything I was on, at least the controlled stuff, and they'd be able to see it was all one doctor who had consistently prescribed it for me."*

And another told us that having a recorded history of their medication was of real value and helped provide reassurance.

*"You forget what you have been on and why you stopped taking things, so having that record and having your doctor and pharmacy have access to that is really beneficial. It's seen by more than one doctor, so if something happened to my doctor now, and I had to go to another they could access that information."*

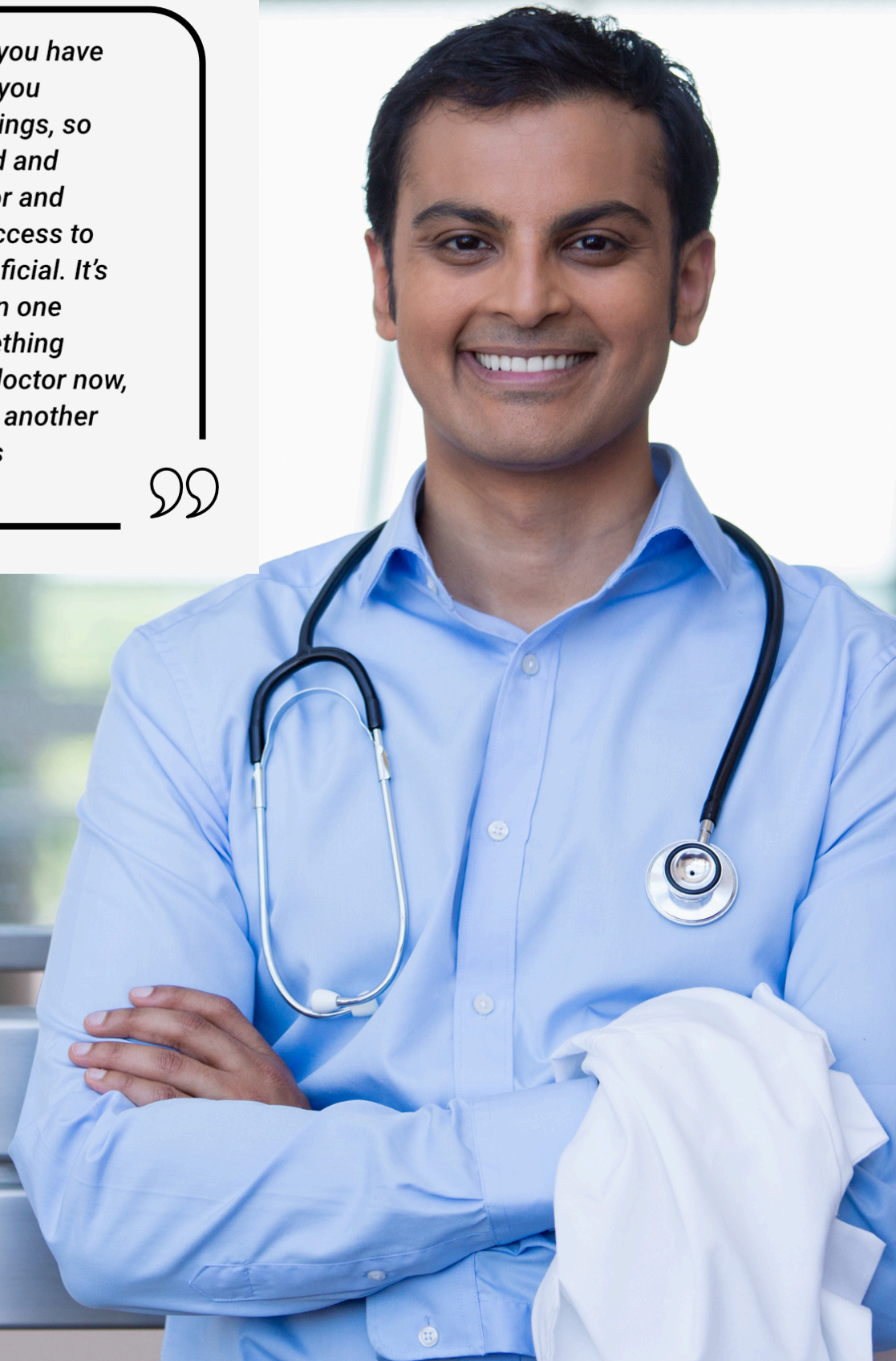
One consumer who is on a schedule 8 drug, has moved locations and is now going to a new primary pharmacist told Painaustralia:

*"I like that it provides universal context so wherever I go they (the pharmacists) can pull up my record instead of refusing a script because I am brand new. I did have one interaction and I completely understand the pharmacist response. I came in on a Sunday morning with a really crumpled script that I had in my wallet for a while for a schedule 8 medication and he did sort of look at me like 'have you had this schedule 8 medicine before and has it been here?' It was when he looked at my record and saw that it was all prescribed by the same doctor and I had been there on multiple times it just wasn't an issue. His initial reaction was one of suspicion which I understand. So, I think in that sense having a track record that anyone can look up that is credible is quite useful especially when you are trying to access a legitimate prescription."*



**“***“You forget what you have been on and why you stopped taking things, so having that record and having your doctor and pharmacy have access to that is really beneficial. It’s seen by more than one doctor, so if something happened to my doctor now, and I had to go to another they could access that information.”*

**”**



## Community benefits

The majority of consumers interviewed saw SafeScript NSW as a community benefit reducing opioid misuse and harm. Even those that said they couldn't see benefits for themselves and were more apprehensive about the program still acknowledged the community benefits. Eliminating patients visiting multiple doctors and providing greater information to consumers about medicine safety emerged as the common themes from the interviews with patients.

Consumers told us:

*"It is tremendous for society...it's about getting information out to people so they can act with an informed choice."*

*"This is a program that's set up to ensure that the health professionals are tracking the way to keep us safe...SafeScript NSW does create a level of safety to ensure that the professionals are tracking our use, so we won't have any adverse reactions."*

*"SafeScript NSW is a good idea and it's a good idea for the simple reason that I have met people who have taken advantage of the situation, but I have also met people who have been on the other side of what I have experienced where they have had a negative experience with the GP and pharmacist. I feel it's a way of just monitoring and finding a GP or pharmacist that will actually listen to you and understand your condition and chronic pain. I think it's a good way for GPs and pharmacists to monitor...I think it's safer for everyone other than the ones that are going to abuse it."*

*"SafeScript NSW should create piece of mind for families, I can't see how in any way, space or form this could be a negative to anybody unless they are trying to do the wrong thing... it's a no-brainer."*

*"I guess it's also kind of one of those things with stigma there are sort of the two aspects of SafeScript NSW. I really like the element it gives pharmacists, and especially pharmacists, because I think they're not involved enough in clinical decision making, so that if there are any doctors errors, or they've gone to two different doctors, and they've prescribed things that just almost never a prescribed together, even with clinical judgment, it enables them to step in. And I think that's of what it's all about keeping people safe."*

One consumer who is a passionate believer in SafeScript NSW and its benefits for not only them, but the entire community told the story of how their mother, who was addicted to Serepax, and oxycodone had been a doctor shopper.

*"My mother was addicted to Serepax when I was a child, and she was a doctor shopper and went around to every doctor she could find to get Serepax and ended up being in and out of hospital to be taken off and to through that rehabilitation. In the lead up to her death she was always in pain and was doctor shopping for oxycodone as well. She died with an addiction to oxycodone. SafeScript NSW is a safety net being established which is long overdue. It's a bloody outstanding thing. This can only do good, no matter which way I wrap my head around this I cannot find a negative aspect...I can't see anything negative about it. I see it as a failsafe."*



“

*“It is tremendous for society...it’s about getting information out to people so they can act with an informed choice.”*

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## Conversations with health professionals

Only some of the consumers interviewed had had conversations with their health professional about SafeScript NSW. Although all patients said that at some stage over the course of the interviews that they had in one form, or another had a conversation about using medicine safely and as prescribed with their GP. Some of the consumers had either mentioned the program to their health professional, or their GP had brought it up, in some instances this had occurred when a patient was flagged by SafeScript NSW.

One participant, who had raised SafeScript NSW and talked about it with their GP, said the doctor had told them “she found it extremely useful” and along with other practitioners at the practice had done a course, updated training on it, and found it had helped them to deal with patients.

*“My doctor was very happy to talk about it for quite a while...but for me personally, it’s corroboration and maintenance of the prior knowledge that I have. SafeScript NSW helps her as it mandates her approach, it gives her a backing that it’s not just her suggesting this, but it is also the system. It’s a great benefit to the doctor which ultimately benefits the patient.”*

*“The GP who is bulk billing GP will see a patient who she has never seen before and will likely never see again. She recounted that it (SafeScript NSW) was helpful for her to keep a track of the patient’s medical history and just get that little bit of context when someone is trying to pressure her into prescribing something for them.”*

Though one consumer who lived in a regional area recounted that their pharmacist had reacted negatively when they asked about the program.

*“She was not impressed as it made her do extra things that she thought had already been done by the doctor...She thought it was unnecessarily busier.”*

“

***“My GP is a big fan and likes the idea of it how it gives him control and helps to minimise risks and he thinks it’s a great thing. My pharmacist is a huge fan and only sees value in it...we spoke about the safety from their professional aspect, and they can keep track of what other GPs have prescribed, what medications a patient has got.”***

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## The challenges faced by consumers

One of the themes that emerged from the interviews is that some pain patients continue to encounter challenges in obtaining medications for their chronic pain. A change in opioid regulations federally, the implementation of real time prescription monitoring programs, continuing stigma and a lack of general understanding about pain from health professionals all contribute to the barriers faced by consumers.

Over the course of the interviews consumers relayed stories of the negative experiences and difficulties they had encountered. This included being unable to obtain their medicines, a lack of alternatives and support offered by either their prescriber or pharmacist, and a lack of understanding and knowledge about pain patients among health professionals.

While there were some concerns about their interactions at their GPs, many of the adverse experiences occurred when the patients' interacted with pharmacists.

Some patients believed the introduction of real time prescription monitoring programs had led to:

- Increased stigma, and;
- Increased anxiety for patients when trying to obtain medication.

As one consumer said:

*"It is not a benefit for me as I don't abuse medicines and in fact it makes me feel more stigmatised and makes everyone with chronic pain more stigmatised. But for people who are abusing medication it is a good thing."*

### Unable to get their medication prescribed or their scripts filled

While consumers generally acknowledged the value of SafeScript NSW, they felt they were unnecessarily and unfairly singled out by either their pharmacist or prescriber. They recounted difficulties in obtaining their medications, particularly when visiting a pharmacy to have their prescribed script filled.

*"The problem is GP opioid prescribing practices are now monitored and they can get into trouble if they are prescribed too much and so they are nervous about prescribing it. So, what's happening is people who are in genuine pain, who are in acute pain, are not getting the medication they need because the GPs are too afraid to prescribe it."*

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*"I'm petrified, I have an appointment on Monday and I'm positive she (the GP) is not going to give it to me. I don't know what I'm going to do for Christmas. I am squirrelling some Diazepam away so I can sleep through the pain over Christmas."*

One patient told us that they tried to get their medications filled but were told it was "too soon" and that they must have had enough medication at home, without explaining any further why this was important and why the prescription couldn't be filled sooner.



Going to different pharmacies, which can be common among chronic pain consumers and for those who travel often, caused a level of anxiety and at times resulted in being denied their medication.

*"I would just get questioned if I went to a different chemist to just fill my script, people can't always go to the same chemist, people's lives are busy and all over the place."*

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*"RTPM has taken up a lot of time, I have had to research the new system, I am nervous every time I go into a chemist, I have had to have many conversations with my GP and my specialist. It does make you fearful of what you are going to encounter in front of people, and it is not easy. It does not make it easy at all, it is not easy anyway, it is a difficult position to be in anyway and it has made it a lot worse."*

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*"My general pharmacy knows me more, I don't know what they see on the screen, but they don't really question me as they know me...but sometimes you can't go to that chemist. We just get put in the same category as somebody who is trying to use multiple doctors and doctor shop and all of that stuff, and I just felt like I had to explain myself to that pharmacist and I don't want to ever be put in that position ever again because it's embarrassing. You feel shameful and that is not cool when a patient has been put on medication for a particular reason and you are being questioned by the pharmacist, who is not my doctor, and they do not know my history."*

One consumer who at one stage went to a different pharmacist than their usual was denied their medication, however, when they went back to the same pharmacist a couple of weeks later and tried again, they did receive it.

*"I asked why he gave it to me this time and he said he gave it to me because he didn't want to make a fuss in front of people and felt bad for me. When it was denied the first time the pharmacists got into a huddle and I knew what they were saying and when they denied the medication, I said that's okay, and I will come back as I still had some of the medication at home. Previously when I was denied, the pharmacist had been quite rude. You feel awful when it happens, it doesn't take much when you have to fill those scripts every week."*

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*"I hadn't seen my specialist for three months and my specialist script had run out about three weeks before that, so my GP was prescribing, and when I went to this new pharmacy, it popped up on the screen and all the lights were flashing and stuff and she starts questioning me 'why do you take this and whose this doctor' and looking at me and I thought wow! I felt awful, and I thought this is horrible. I don't know what to tell you? I have two doctors, a specialist, and a GP. You can see from my records I have taken this stuff for years...it wasn't a very enjoyable experience."*

## Stigma of being a pain patient

The stigma of being a pain patient was a reoccurring theme across all three sets of interviews with consumers. The consumers spoke of numerous occasions where they felt judged and maligned. They did not believe their health professionals had been provided with enough education and training about pain patients, their unique situation, and their conditions.

*"I definitely do feel stigma, I do feel suspicious when I go to get my medications."*

*"I feel judged because I am asking for opioids and every time I go into the pharmacist and they say, 'no repeats on this'...I gave you a script for one box of Endone, it says nil repeat. I can read, I'm not stupid."*

***"I am not an addict; I am actually just a pain patient."***



*"One time after my back surgery, my husband went and got some Endone for me as I was in terrible pain, and the pharmacist wasn't our normal pharmacist and he said 'what's going on with (name)? Why is she taking this?'. And he handed him two boxes of naloxone and he said, 'she needs to take this if she has an overdose'. I take no more than one a day and it's not every day...I was just horrified at the stigmatisation. And even our normal pharmacist, whenever I get Endone made up, I can sort of sense something in him and it's the same with my Triptan, even though it's not an opioid and it's not addictive, it can cause rebound headache if you take too much and take it regularly, and every time I get it made up, the pharmacist says 'what's happening with your migraines?' And it just stigmatises you."*

*"When you are dealing with pain management people, they are already struggling. They are already in a situation where for years they have had to be on something for a diagnosed, difficult illnesses, and for whatever reason they have been put on pain management medicines through their specialists and their GPs and they should be considered in a different category. They shouldn't be lumped into a category of people just abusing drugs. Everyone I know who are on pain management medicine, they all have the same issue and it's gotten worse and worse. So, you are already coming from a fragile patient perspective, someone who has already had to deal with quite significant difficulties in living their daily life and on top of that we have been put in this situation where we are made to feel bad for it. It's a real added hardship that people don't need. People sometimes can't cope with the pain they are in and then get this on top of it."*

One of the consumers who took part in the survey has since started the monthly Buprenorphine injection to address their pain in between their second and third interview. This led to them stopping their medication which included Endone, Targin and the Soma muscle relaxant. They had been considering doing this for some time but had been reluctant to do so as it can only be done in an opioid detox clinic, and they were concerned about being labelled a drug addict.

*“The one thing that bothered me about it, is that you are classed in that category (of drug addict). There is no separate category for pain management patients that just want to get off everything – you are classed in the addiction category.”*

However, the implementation of SafeScript NSW and subsequent negative interactions with various pharmacists over the past few months resulted in them checking into the clinic for a week and having the Suboxone injection at the clinic.

*“Pain patients generally do not like taking everything all the time – it’s generally exhausting. I actually got really tired of that weekly getting medicine and having to find a chemist since they cracked down, looking at you sideways and all of that stuff became like too much. I’m not going to be put through that. I realise they need strong regulations for it, but they also need to look at the treatment of people with chronic pain. They need to put them in their own category, and they need to have policies that will guide chemists on how to treat them (pain patients) because it’s a human right and not put us in a category...patients want to have access to the medication that their doctors prescribe them without any judgement or put into a box that says ‘you’re a drug addict’. It’s so wrong.”*

One consumer said pain patients do not get treated in the same way that patients with other illness are.

*“You are talking to a patient; you are talking to people who are patients, and you wouldn’t talk to a person who has just had surgery or a cancer patient or anyone else in that way.”*

Another consumer asked her GP to write a letter listing her medication as she was going away and was concerned about presenting her medication at airports. The doctor told her that she didn’t want to list all the medications the consumer was on as the ‘list was rather long.’

*“I then felt judged and in fact I judged myself as a result.”*





## What consumers want to see

The improvements that the consumers consistently said they wanted to see implemented were:

- Much greater understanding among health professionals of the circumstances of pain patients.
- More education and training about the situation of pain patients for health professionals.
- The need to offer alternative treatments and options and support for patients from GPs and pharmacists when refusing to prescribe or dispense.
- Better and more empathetic communication from health professionals when interacting with pain patients particularly when refusing to prescribe or dispense.
- Print outs in plain English from the pharmacist about general information on medicine safety and the SafeScript NSW program.
- A register or category with the real time prescription monitoring system or database that identifies pain patients as people who live with chronic pain.

Consumers told us:

*"I think there should be a monitoring system on some level, but they need to reassess it and it needs to incorporate pain management people on a different level to people who just come in who doctor shop because it's so different. It really is. You know we're living our lives, and we are constructive people in the community, and we need to not feel devalued. I know it is a problem but tackling it on this level and like this you are just punishing pain patients."*

*"I don't like the idea of taking pills all the time...I decided a while ago I did not want to live my life every day in pain. It's constant and it's exhausting, and it should have its own category – pain management should be separate, don't put us in that category of abuse."*

*"Has consideration been given to a register of people with chronic pain conditions? Their opioid and other medications, which could have addictive qualities are listed, the types of dosages that are needed for their condition... people with chronic pain could be given the choice of being on the register. "*

*"I don't think it's a very fair system. I don't think it's fair on the chemist either to be honest, as they are going to have to confront all of this stuff. There should be a note system of some kind in the RTPM system that says this patient is a long-term patient, whatever it is to make it easier on people."*

*"More education is definitely needed."*

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*"It is important that the conversation is not awkward, and that any conversation delivers important information but not in a combative way."*

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*"More education and advertisements about real time prescription monitoring is needed as you don't hear about it much in the general media and in newspapers, I see more so I am looking at sites that talk about pain or medications."*

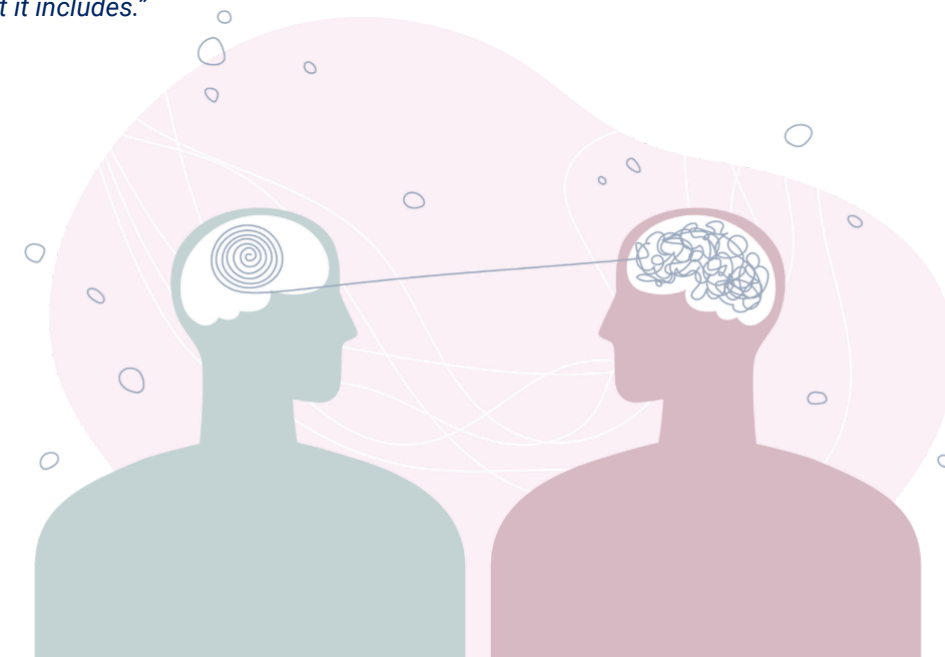
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*"Even though a GP may explain it at the time of the consultation, a lot of people go to a consultation and walk out and hardly remember 20 per cent of it and to then go and see the pharmacist and have someone actually explain it and not just hand them the information sheet and say go home and read it and don't fall off your perch when you starts seeing what it includes."*

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***"Programs such as SafeScript NSW are needed as it compliments a person's journey with chronic pain. There is so much stigma associated with chronic pain and the use of these types of medications to help that person who may have very little knowledge about opioids and any other medications. So, if there are programs like these that can work alongside so they can support patients, they understand why they are prescribed such medications."***

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## Conclusion

Real time prescription monitoring programs like SafeScript NSW are seen as a positive initiative that can protect patients and the community from opioid misuse. Throughout the 12-month project as consumers became more familiar with the program and spoke to their health professional about it, they became more accepting of its benefits, their concerns about privacy diminished and they were less apprehensive about their ability to access medicine in the future.

However, some frustrations remain particularly for those pain patients who are on a number of different medications. They report experiencing stigma and anxiety, and can continue to face significant barriers when trying to obtain their medications. More understanding is urgently needed. Stigma and bias towards pain patients who are treated as if they are visiting multiple doctors for medicines remains a concern for some consumers.

Consumers who live with chronic pain want to see a system that acknowledges their particular circumstances and sees them treated more compassionately and sensitively by their health professionals.



***“Remember that these people are already in very tricky circumstances, they are trying to manage, and they have also been prescribed these medications. They spend a fortune on seeing specialists, I have had seven fibrillations in my neck, you do all you can.”***



## References

1. Penington Institute (2021). Australia's Annual Overdose Report 2021. Melbourne: Penington Institute. ISSN: 2652-7790. Available at: <https://www.penington.org.au/wp-content/uploads/2022/09/Australias-Annual-Overdose-Report-2021.pdf>





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“

*I can't see anything negative about it.*

*I see it [SafeScript NSW] as a failsafe.”*

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*~Consumer Quote*