Monitored Medicines Unit
Healthcare Regulation Branch
Queensland Public Health and Scientific Services
Department of Health
Queensland Health
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Re: **Monitored Medicines consultation**

Health Consumers Queensland, Chronic Pain Australia and Australian Pain Management Association are providing a joint submission in response to the Consultation on QScript look-up and Monitored Medicines Standard requirements. Our organisations represent the lived experience of Queenslanders with chronic pain.

QScript is a useful tool in clinical practice, however, more consideration needs to be given to compliance notices, regulatory burden and most importantly service provision. The community of people living with chronic pain continues to feel the burden of medication restrictions since the implementation of Q-Script. This has resulted in unintended negative impacts to this community.

In Chronic Pain Australia's National Pain Survey 2022, 26% or respondents have experienced enforced opioid tapering. Many providers of chronic pain services we speak with have experienced patients being 'dropped' by prescribers as they are uncomfortable prescribing monitored medicines due to regulatory burden and impact. It is estimated that 645,000 Queenslanders are currently living with some form of persistent pain, across every Hospital and Health Service (HHS) and socioeconomic band, costing the Queensland economy $27.83B per annum. (1) Most persistent pain can be managed with medication, education and support in the primary care setting by General Practitioners (GPs), private allied health providers, nurses and complementary/alternative therapists. (2) People living with chronic pain responsibly taking opioid medication under the clinical guidance of their doctor have been subjected to negative consequences due to a lack of consumer engagement and education in the QScript processes and systems.

We are concerned that there is a refusal of health care by health professionals and an undertreatment of pain resulting in significant physical and psychological patient distress due to prescriber's concern of regulatory action.

Perceived scrutiny from the monitoring systems has resulted in some prescribers' and pharmacists' refusing to supply potentially high-risk medications despite appropriate clinical indication. The abrupt discontinuation of medication carries a risk of seizure and overdose death, especially in chronic opioid therapy.

Overall, QScript is a blunt instrument without evidence of improving patient outcomes. Implementation of RTPM systems has shown to increase prescription substitution of prescription medicines and illicit substances. Again, this was reflected in the National Pain Survey showing more people were tapered from opioids but substituted with several sedating medicines and most consumers responded to using alcohol to cope with pain.

More effort should be considered in offering services which adequately support the community with complex chronic conditions. We are also concerned with the recent 'educative letters' sent to what seemed to be almost all prescribers in Queensland regarding non-compliance with QScript look up. These letters are damaging to prescribers' confidence in practice, provide no information on how they can improve their practice or be compliant with regulations and will encourage prescribers to 'drop' patients who are prescribed monitored medicines. Additionally, sending out compliance letters on a Friday is a troublesome time when access to peer-to-peer support, mental health services is limited.

We would encourage the department to review these processes and challenge them to think of less harmful ways to approach compliance and adopt more supportive methods to an already burnout and diminished healthcare workforce. The requirement for 100% compliance with look-up to QScript is unrealistic and the department should, in consultation with stakeholders, decide what is reasonable. The Monitored Medicine Standard is useful regulatory framework for 'best practice' in prescribing or dispensing monitored medicines, however, most clinicians are not aware that the standard exists and more should be done to engage clinicians of these changes.

The issues raised by our community in pain support group meetings and by calls to our Pain Link Helpline include:

- Forced tapering or removal of medication due to additional scrutiny of the prescribing practices of doctors.
- People having their medication tapered or removed without alternatives.
- Incorrect flagging of chronic pain individuals with no recourse or review to rectify the situation.
- Increased financial burden for pain consumers who have frequent GP appointments for scripts. Some consumers tell us that they have to see a doctor every 10 days for scripts.

- Forcing chronic pain sufferers to continue seeing a General Practitioners they do not feel comfortable with (either because their values don't align, they don't seem competent, they are judgemental) because they risk being flagged as doctor shopping.
- Lack of consideration for availability of General Practitioners - wait times, GPs being on leave, public holidays, seeing another practitioner in the same clinic, limited GPs in rural & remote areas, limited number of GPs who bulk bill in that local area, GPs not accepting new patients.
- Pharmacists and GPs not working together to support patient care by disagreeing on a prescription, but not having the capacity to investigate the prescription, and instead cutting the patient off.
- Being immunocompromised, or having Covid, and having limited capacity for doctor and pharmacy visits.
- Different rules and regulations between States and Territories and the confusion experienced by people that live in border communities, or those who travel regularly, or people who live on the road.
- Inconsistencies between online script providers like InstantScript.com.au compared to regular GPs and Pharmacists.

"In the height of pain, experiencing a flare that I had not been through before, I turned to my doctor for support. This is a doctor that I had been seeing for over a decade. Rather than support me with breakthrough opioid medication, I was given a lecture about addiction. So now I have trust issues because my doctor doesn't have my best interests at heart. I already live in a world where most people struggle to understand my invisible illness. Now my doctor doesn't want to understand either." - Siobhan

"I saw a GP close to my work for years. Then I changed jobs and realised I couldn't make it across town to my old GP in their opening hours. I didn't want a doctor that I just saw on telehealth. So, I started searching for a new GP close to home. I went to one, and he just didn't want to deal with a complex patient. I kept searching for another I could collaborate with and feel supported by. It took a few visits to find one I like and because I asked for a refill twice during that time, I'm now flagged for doctor shopping." - Chantel

Chronic Pain Australia conducts the largest nation-wide survey on pain, with 21.79% of respondents based in Queensland. The National Pain Survey 2022 has shown that Australians with chronic pain are unfairly stigmatised, are unable to access high quality health services, and the price of living with chronic pain is unaffordable.

Chronic Pain Australia conducts the largest nation-wide survey on pain, with 21.79% of respondents based in Queensland. The National Pain Survey 2022 has shown that Australians with chronic pain are unfairly stigmatised, are unable to access high quality health services, and the price of living with chronic pain is unaffordable. The consumer lived experience with opioid restrictions has meant that 26% of our survey respondents experienced enforced opioid tapering. 29% of respondents say their GP has put them on antidepressants, 28% on anti-inflammatories, 11% on sedatives, and 10% on medicinal cannabis as a substitute for pain relief. We know that drug induced deaths are caused by the combination of 4 or more substances, and it appears from our national survey that more patients with chronic pain are prescribed combinations of medications that could be more harmful in an effort to reduce opioids. Furthermore, it is well documented that enforced opioid tapering causes consumers to disengage from health care, seek medicines from illicit markets, worsens mental health and causes suicidal ideation. We are very concerned that by restricting access to opioids for some, we are increasing their risk of harm.

In 2018, the Queensland Clinical Senate discussed "Managing the pain of opioids" and one of their seven recommendations was to:,
Advocate for a national prescribing strategy that:

- Informs appropriate restrictions to prescribing in accordance with the evidence;
- Avoids stigmatisation and enables safe prescribing and access for consumers who benefit from such medication; and
- Supports consumers experiencing unintended adverse consequences of analgesic medications.

We are concerned that the good intentions of QScript and Monitored Medicines are not being translated into improved health outcomes and experiences for health consumers in Queensland and importantly, that one of the key aims, to avoid stigmatisation is not being achieved. Our organisations are very concerned that by implementing QScript without improving the access and investment into quality pain management and mental health services, consumer education and self-management, that this program is causing further harm – rather than minimising it.

We recommend that formal mechanisms are created to hear directly from consumers (and their families) who have experience of QScript. (In the meantime, we have provided an insight based on the mechanisms we have available to us). This could be in the form of patient reported experience measures and/or patient reported outcome measures; regular feedback sought from consumers either by way of survey or focus groups to hear their experiences; and that all of this information is fed into a clinical governance review of the system at a state-wide and localised level that involves consumers.

This could then help to identify systems gaps and barriers for consumers accessing appropriate treatment for their pain; if there is variance across the state and is that variance worse for some consumers (e.g. those who live in rural or remote locations, identify as First Nations, where English is their second language, by age etc); and then ensure that the system responds to these consumer concerns in a timely way.

Partnering with consumers in the implementation, oversight and evaluation of this program is essential – consumers could help clinicians and other health staff to co-design appropriate PREMs/PROMS questions, evaluate the data, and make recommendations for future safety and quality improvements.

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