2024

Representing Concerns of Patients in Oregon

A report from the Oregon Pain Management Commission

Oregon Health Authority

INTRODUCTION

The Oregon Pain Management Commission (OPMC) was created by the Oregon state legislature in 1999. Its mission is to improve pain management in Oregon through education, development of pain management recommendations, and related research and policy analysis. One of the duties of OPMC, per ORS 413.570(1)(c), is to represent the concerns of patients in Oregon on issues of pain management to the Governor and the Legislative Assembly. Since there is no specific reporting requirement in statute, the Commission has not previously provided such reports, but plan to send a similar report each year from now on. The Commission welcomes feedback from the public, Legislature and Governor's office on the format and content of this initial report.

SUMMARY AND COMMISSION RESPONSES

This report contains the findings of a thematic qualitative content analysis of verbal testimony delivered to the OPMC between 1/1/2022 and 5/31/2024 as well as a summary of concerns several Commissioners reported they hear from their patients. Nine commissioners also provided their comments, which are summarized here and included in Appendix A.

Summary of testimony in OPMC meetings

During this time, 15 individuals gave 29 instances of verbal testimony during 7 meetings. Three individuals were responsible for over half of all testimony given. Four major themes were synthesized and are listed below, along with a summary of related Commission actions and perspectives:

(1) Criticism of existing pain management guidelines, including those from the OPMC, OHA, and Centers for Disease Control and Prevention, and descriptions of these policies' negative impacts on patients in chronic pain.

> The Commission does not formally publish guidelines but acknowledges that the 2016 version of the CDC Guidelines on Prescribing Opioids for Pain were misinterpreted by some medical professionals, resulting in negative impacts to some patients. In response, the Commission has adopted a position statement endorsing the updated 2022 CDC Clinical Practice Guideline for Prescribing Opioids for Pain. The Commission's new education module, scheduled for implementation on January 1, 2025, will include a section summarizing key points from this guideline, including the need for individualized consideration of benefits and harms of opioid therapy. In the new version of its pain module, the Commission will also refer to new guidance from the Oregon Medical Board that echoes similar themes.

(2) Concerns about the exclusion of patient voices and differing opinions in a pain management commission which has shifted its focus over the years on addiction instead of pain care.

> Each Commission meeting includes an opportunity for written and verbal public comment. Commissioners frequently discuss public comments and make recommendations to staff based on comments received. The Commission cannot speak to all comments or address all of the concerns presented.

The Commission's focus continues to be on pain management, not addiction. Pain care must consider the risks and potential benefits of each therapy, including medications such as opioids. The Commission has endorsed the 2022 CDC Guidelines (OPMC Endorsement of 2022 CDC Guidelines) regarding opioid prescribing, which emphasize the importance of risk/benefit analysis in clinical decision making related to pain management.

(3) Limited therapeutic options and the healthcare system's non-recognition of patients using long-term opioid therapy leads to lack of treating providers, medical abandonment, and medical trauma.

The Commission recognizes that all modalities for pain management have their limits, and that opioid medication can be a part of therapy when benefits outweigh risks and patient safety is maintained. In addition, the Commission acknowledges that patients being prescribed long-term opioid medications can experience harms from prolonged use and challenges if prescribing is discontinued abruptly or without appropriate taper protocols or shared decision making and support. On the other hand, many patients do experience benefits from reduced reliance on opioid therapy due to the side effects and risks associated with these medications.

People in pain experience barriers to accessing multidisciplinary pain care for a myriad of reasons in Oregon. This can be due to lack of specialized providers in rural areas or insufficient insurance coverage and additional out of pocket costs. Some patients have difficulties with transportation to healthcare settings or must travel long distances to see providers. The commission recognizes these barriers and potential impacts on trauma, has engaged in discussion on these topics and referred to these issues in its previous educational module. Furthermore, barriers to access to care will be included as an area of focus in the updated version of its continuing education module for licensed healthcare professionals which is planned to be released in January of 2025.

(4) Pain is a deeply personal experience which is poorly understood by current biomedical science, making it resistant to one-size-fits-all solutions.

While pain is indeed a highly individualized experience, it is inaccurate to say that it is poorly understood by current biomedical science. The scientific understanding of pain has evolved significantly. Our current understanding is that the experience of pain is influenced by a complex interplay of biological, psychological, and social factors. This way of understanding pain is often referred to as the biopsychosocial model. This is to say that each person's experience of pain can be shaped not only by their physiology, but by past experiences, emotional states, behavioral responses, cultural background, and even their environment.

Given this complexity, we agree that pain doesn't lend itself to one-size-fits-all solutions. While current biomedical science has made great strides in understanding the experience of pain, it still faces challenges in addressing its subjective nature. The individualized nature of pain makes it resistant to standardized treatment approaches, necessitating a more personalized and multidisciplinary approach to pain management.

Moreover, the development of the biopsychosocial model of pain has provided a comprehensive framework for understanding and treating pain. This model acknowledges the complex interplay between biological, psychological, and social factors, guiding healthcare professionals in providing more holistic and effective pain management. By combining this scientific knowledge with an appreciation of the individual nature of pain, healthcare professionals can offer personalized treatment plans that are both evidence-based and tailored to the unique needs of each patient.

The Commission frequently acts in response to comments, including comments summarized in this report. Recent actions supported or requested by people in verbal or written public comments include:

1. Changing the structure of meeting agendas to allow verbal comments on each topic.
2. Developing a position statement endorsing the 2022 CDC Clinical Practice Guideline for Prescribing Opioids for Pain.
3. Referencing the 2022 CDC guideline and a related newsletter by the Oregon Medical Board in its 2025 draft content for the Commission's pain module.
4. Removing language from earlier drafts of the 2025 pain module content which members and commenters agreed could inadvertently exacerbate stigma related to race, gender and history of trauma.
5. Updating the OMPC membership application process, which now includes an online resource to increase accessibility; and includes Race, Ethnicity, Language and Disability (REALD) questions as well as information on sexual and gender identities.

Commissioner Perspectives

What follows is summarized list of key issues related to patient concerns that members of the commission have identified based on their interactions and clinical work with people in pain in Oregon during this reporting cycle. The list is sorted from the most frequently reported concern to the least frequently reported. The individual submissions received from each commissioner are included in Appendix A for further information.

1. Access to pain management care, and especially to multimodal pain management services is limited in Oregon. It is particularly limited in rural areas, for pediatric patients and for gender diverse individuals. The shortage exists for a variety of provider types, including primary care, physical therapy, chiropractic, osteopathic manipulation, acupuncture, massage therapy and behavioral health.

2. Insurance limitations pose a barrier to optimal results and limit access to treatment by providers trained in pain management. Cost sharing and insurance exclusions of certain services including complimentary and integrative services and interventional procedures can prevent patients from accessing optimal care.

3. Patients most commonly benefit from a multimodal approach to pain management, including pain-focused physical therapy, complimentary and integrative care, and pain psychology.

Patients are often not adequately informed by their providers on key concepts related to chronic pain such as neuroplasticity and central sensitization.

4. When patients' current prescriber has moved, retired or is no longer prescribing, patients often can't find another prescriber or primary care physician who will continue to prescribe their preferred regimen. Some providers are transitioning patients to buprenorphine rather than other opioid medications. Others refuse to see patients with chronic pain, especially if they use prescribed opioid medications.
5. People in pain are dismissed and stigmatized by the healthcare system and in society. They say providers and others discriminate against them, and don't believe them about their experience of pain, and many report a sense of isolation. They feel singled out as "drug seekers" or "addicts" if they use medications as prescribed, or even if they do not use medications with risk of dependence.
6. The relationship between opioid medications and chronic pain and substance use is complex. Some members emphasized the importance of opioids as a chronic pain treatment for some patients. Others also emphasized that use of prescribed pain medications can lead to addiction and said loss of access to prescribed medications can lead some patients to seek medications on the street. Some patients with chronic pain have substance use disorders and others do not.

Qualitative Content Analysis of OPMC Public Testimony, 2022-2024

METHODS

Analytic Sample

Between January 1, 2022 and May 31, 2024 there were 9 meetings held by the OPMC. There was public testimony given at 7 of these 9 meetings. These public meetings are listed below, with an asterisk (*) delineating which meetings had no public comment and were subsequently excluded from the analytic sample:

- 2022:
  - April 21
  - September 15*
  - November 17
- 2023:
  - February 16*
  - May 25
  - September 21
  - November 16
- 2024:

- February 22
- May 23

Software Management

For each of these 9 meetings, audio recordings of the full meeting were transcribed using Otter.AI, a speech-to-text transcription application that uses natural language processing to convert audio to text. These transcriptions constitute the source materials for this qualitative content analysis. The transcripts were managed within Marvin, a qualitative analysis software.

Approach

Employing a directed content analysis approach, an inductive approach to analyzing the text was employed during data analysis. Four iterative cycles of coding took place, with the first round dedicated for transcript review before any coding took place; the second for inductive coding of emerging concepts; the third round for reconciling duplication and similarities among codes and consolidating concepts; and the fourth for grouping of codes into categories and, ultimately, themes. For the final two rounds, the use of parent-child codes was utilized to initially create specific codes which were then collapsed into broader (parent) categories. A single coder approach was used. This coder is an OHA employee who does not work or interact with OPMC members.

Acronyms used in this report

The following table provides a list of the acronyms and abbreviations used in this report.

Acronym	Term
ACE	Adverse Childhood Experience
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare and Medicaid Services
FDA	Food and Drug Administration
HERC	Health Evidence Review Commission
LTOT	Long-term opioid therapy
MME	Morphine milligram equivalents
NIH	National Institutes of Health
OHA	Oregon Health Authority
OIH	Opioid-included hyperalgesia
OPG	Oregon Pain Group
OPMC	Oregon Pain Management Commission
ORS	Oregon Revised Statute

FINDINGS

Baseline characteristics of individuals giving public testimony

Between 1/1/2022-5/31/2024, a total of 15 unique individuals gave 29 instances of verbal testimony at a OPMC meeting. Three individuals were responsible for over half of all verbal testimony delivered (16 instances out of the 29). These 3 individuals would often give multiple rounds of testimony in a single meeting. Two of these 3 self-identified as pain patients and the third was a pain caregiver. See Table 1 for an overview of OPMC testifier demographics.

Table 1: Characteristics of testifiers at OPMC Meetings 2022-2024

	2022 (2 meetings)	2023 (3 meetings)	2024 (2 meetings)
Discrete count of individuals	6	8	7
Declared conflicts of interest	0	1	0
Self attestations			
Person living with chronic pain	6	3	6
Pain caregiver	0	1	1
Pain provider	0	4	0

The majority of the 29 instances of public testimony given during the study period was provided by people who self-identified as living with chronic pain.

Among providers who delivered public testimony, one was an acupuncturist who spoke on behalf of the Oregon Acupuncture Association. The other 3 providers who testified were physicians: an addiction medicine and primary care physician from Birmingham, Alabama; a physical medicine, rehabilitation and pain medicine physician from Salem, Oregon; and an addiction medicine and primary care physician from Portland, Oregon.

There was one conflict of interest disclosed by a physician in 2023, who disclosed a brief period in 2020 when he owned pharmaceutical stock.

Descriptive analysis of public testimony

Before synthesis of public testimony for themes and patterns took place, a public comment summary was developed to give an overview of topics discussed by each testifier at OPMC. See Table 2 below.

Each meeting was assigned a number, and each unique participant was assigned a letter. Therefore, repeat testifiers can be observed delivering testimony throughout this two-year period.

Table 2: Public comment summary

Meeting Date	*Testifier ID*	*Summary of Testimony Given*
2022-4-21	1A	OHA precludes legacy patients from being able to obtain opioids to be functional, even when doctors are willing to prescribe past 90 morphine milligram equivalent (mme[1]). Despite making some headway in chronic pain management, progress often stalls and ends up with the same anti-opiate bias, and the evidence provided by the community is not being heard. Questioned whether the public's concerns have been communicated to the governor as mandated.
2022-4-21	1B	Doctors are not knowledgeable about how to treat chronic pain in children. They discussed their and their child's chronic disorder, emphasizing the lack of effective pain management options for children. They described daughter's challenges in school and limited medical options, leading to severe mental health struggles including suicidal ideation.
2022-4-21	1C	They said it is extremely difficult to find primary care due to their history with pain medication, which has made them an unlikely candidate for doctors despite significant self-weaning from opioids. They highlighted the broader issue where patients are denied post-operative pain management, leading to dangerous and prolonged suffering.
2022-4-21	1D	They are concerned over the lack of value placed on patient input in OPMC meetings, saying that testimony opportunities do not overlap with commission discussion. They expressed concern over OPMC membership overlap with Oregon Pain Guidance (OPG) members and asked if OPMC contracts with OPG.
2022-11-17	2E	They said there has been a shift in OPMC's focus over the last several years from pain advocacy to an addiction focus. They said that people in pain no longer have any representation, and reaching out to the Legislature or the Governor has not been helpful.
2022-11-17	2F	They said there is a need for better representation for pain patients, especially as there are no available pain management clinics in rural areas. They said

[1] Morphine Milligram Equivalents (this measure compares the strength of doses of different kinds of opioid medication)

		they asked the commission to address the lack of pain care providers for pain patients.
2022-11-17	2D	They said people with pain do not have value for OPMC; the OPMC was once very patient-focused before membership changes shifted the commission into a group that does not embrace a spectrum of views on chronic pain prescribing.
2023-5-25	3E	They said the updated 2022 CDC guideline is more flexible than the 2016 guideline's focus on a 90 mme limit. There is a need for patient-centered care. They voiced criticism for FDA's black-box warning on OIH. Called for balanced discussion and quality evidence.
2023-5-25	3D	They shared a published study that they said describes the rarity of OIH for opioid users, and that eliminating opioid therapy for central pain syndrome is not appropriate. They said quality evidence is important to prevent further harm.
2023-5-25	3G	They expressed concerns that patient concerns have not been heard by OPMC since around 2018-19. They highlighted the importance of valuing pain patients as integral parts of the pain management team and being accountable to the public. They said data indicates the high number of chronic pain patients in the US and the low percentage of them getting addicted to opioids when prescribed correctly. They said there is a need for transparency and public input in the Commission's deliberations and proposed publishing information on their website.
2023-5-25	3H	They said acupuncture is an important non-pharmacological intervention for acute and chronic pain, is cost-effective, clinically effective, and supported by multiple large organizations such as the NIH, CMS, and CDC. They said that acupuncture has evidenced mechanisms affecting pain perception through multiple biological pathways and discussed the potential of acupuncture in pain management, modulation of brain activity, and other physiological effects.
2023-5-25	3E	They stressed the ongoing need for representation of patients who benefit from long-term opioid therapy (LTOT). They raised concerns about the lack of such representation in the pain module and advocated for including prescribing in continuing education on pain care. They highlighted the difficulties pain patients face in finding primary and prescribing providers, leading to medical abandonment and health decline.
2023-5-25	3D	They described the role of pain management in helping to raise their children. Said there was an observed reduction of public interest in commission

		meetings, attributing it to stakeholders not feeling their input is valued. They stressed the dire situation in Oregon regarding access to acute, post-operative, and palliative pain care due to a focus on reducing opioid prescriptions, calling it a state of emergency.
2023-9-21	4G	They highlighted concerns regarding inaccuracies of the commission's draft endorsement #7 of the CDC guidelines, specifying that it is not an accurate portrayal.
2023-9-21	4I	They emphasized the need for individualized care despite the commission's assertion of no evidence supporting long-term opioid therapy. They discussed studies showing limited but existent evidence of opioids' effectiveness in managing chronic pain and compared it to other conditions where opioids are used. They discussed the association between chronic pain and suicide, pointing out several studies suggesting that opioid dose reductions are statistically linked with suicides. They said that chronic pain is linked to suicide, irrespective of opioid involvement, and signaled that tapering prescriptions might statistically be associated with suicides. They concluded that better pain care could reduce suicide risk but was not the sole solution.
2023-9-21	4J	They expressed concerns about OPMC's draft endorsement of recommendation #7 of the CDC guidelines. They emphasized that while evidence supporting long-term opioid therapy is limited, it does not imply no evidence exists. They also discussed the negative impacts on pain management clinics and fears among young clinicians about prescribing opioids. They also discussed existing racial and ethnic disparities in opioid prescribing and stressed the importance of individualized care.
2023-9-21	4K	They discussed the uncertainties in current pain research, noting that there is little evidence supporting or contradicting the efficacy of long-term opioid use due to limited studies. They emphasized the importance of honest communication between providers and patients about these uncertainties.
2023-9-21	4G	They provided the Oregon statute definition of 'intractable pain' and explained its relevance in medical and legislative contexts. They noted appreciation for [4I]'s comments and stressed the need for balanced modules that reflect the reality of patient care, insurance coverage, and accessibility to specialized treatments.
2023-9-21	4E	They read a comment on behalf of the National Council of Independent Living, emphasizing that the statement 'no evidence supporting the use of long-term opioid therapy' does not align with the CDC guideline's acknowledgment of limited evidence. They expressed concerns over the negative impact of such

		rigid statements on patients with disabilities and advocated for individualized treatment without a one-size-fits-all approach.
2023-11-16	5L	They shared 7 years of data from Salem Health Pain Clinic's 2,600+ patients regarding suicide attempts among taper and non-taper patients, revealing no connection between opioid tapering and suicide attempts. Emphasized the importance of considering psychiatric comorbidities, particularly bipolar disorder, which significantly increases the risk of suicide attempts. While the general population prevalence of bipolar disorder is approximately 4%, Salem pain clinic's bipolar prevalence was 14%. Endorsed a careful, gradual approach to opioid tapering.
2024-2-22	6D	They voiced concerns about the OPMC's adoption of the term 'pain science' and cautioned against a singular model of thinking. They expressed concern about OPMC's draft suggestion to use adverse childhood events (ACEs) for screening, stating that the ACEs questionnaire was intended for research rather than screening. They emphasized the importance of including opioid prescribing practices in the addendum draft, arguing that the current version excessively emphasizes the controversy around opioid medication.
2024-2-22	6G	They spoke on the importance of patient experience and education, suggesting that the model should be realistic about current limitations in access to multimodal pain management. They argued against labeling opioid use as controversial and pointed out that non-opioid medications also have side effects. They stated a concern that the commission appears to prefer certain study findings over others, leading to a lack of objectivity.
2024-2-22	6M	They described their traumatic experience with pain management providers, detailing the negative impacts of being forced to taper off opioid medication and take suboxone, which resulted in severe dental issues and increased disability. They highlighted the broader issue of discrimination and lack of proper care for pain patients, calling for more attention to patient experiences rather than statistics.
2024-2-22	6C	They emphasized the need for discussions on implicit bias in patient care, especially against Medicaid and Medicare patients, as well as racial biases in affecting quality of care and called for the inclusion of opioid treatment discussion in the module and highlighted the poor insurance coverage for alternative pain treatments.
2024-2-22	6E	They discussed the undertreatment of pain in Oregon. They also emphasized the need for long-term opioid pain medications to be an option and the risk of medical abandonment, where patients are dismissed by doctors and

		experience health crises. They called for the inclusion of these issues in the updated pain management module and urged OPMC to reassess the influence of opioid deprescribing programs.
2024-5-23	7D	They described the restructuring witnessed in OPMC membership over time and warned of patient harms. They called for reports to the legislature and highlighted recent medical board updates acknowledging harms from oversteps in pain management guidelines, and suggested OPMC follow suit and stressed the importance of unbiased and high-quality individualized care, even if high-dose opioid prescriptions are required.
2024-5-23	7G	They emphasized the educational module on pain management should be unbiased and present various pain management options. They expressed concerns about the unbalanced presentation of modalities, saying that some are more detailed than others and identified a need for a holistic approach considering patients' accessibility. They said there is a lack of recent research supporting the effectiveness of certain medications over opioids for chronic pain and expressed concerns about the influence on decision-making.
2024-5-23	7N	They explained how opioids enable them to function after numerous surgeries. They also highlighted the challenges of accessing pain medication post-operation due to changes in prescribing practices and pharmacy stock issues. In addition, they emphasized the importance of addressing stigma related to chronic pain, the need to educate about implicit and explicit bias in pain management, and the need for pediatric pain education.
2024-5-23	7O	They shared their experience of being cut off from pain medications, leading to severe impacts on their life, including having to quit graduate school and experiencing torturous pain. They criticized the conflict of interest in pain management and overdose response on the OPG website, rising stigma, and ineffective multidisciplinary approaches in actual practice.

Thematic analysis of public testimony

Upon primary analysis, 37 child codes were identified, and 4 parent themes were generated. Quote attributions include meeting identifier followed by testifier identifier (e.g., 8C). See Table 2 for meeting and testifier IDs. Themes are presented in descending order (e.g., the most frequent observations which were collated into a theme are discussed first).

Theme 1: Criticism of OPMC application of 2016 and 2022 CDC guidelines

Criticism of existing pain management guidelines and policies, including those from the CDC, OPMC, and OHA, and descriptions of these policies' negative impacts on patients in chronic pain.

Participants expressed significant frustration and disappointment concerning the 2016 CDC guideline's impact on chronic pain management in Oregon. The 2016 CDC guideline, which gave recommendations on opioid prescribing practices, was heavily criticized as was OPMC for misapplying the guideline, causing significant harm to chronic pain patients:

"Basically, these rules that the CDC claims were never meant to affect people like me...we're the unintended consequences of these policies." (1A)

Initially aimed at reducing opioid misuse, CDC's 2016 guideline was later updated in 2022, with an acknowledgment that policies ought to be more patient-centered, flexible and individualized, and that their 2016 guideline had inadvertently caused harm to patients who require opioids for pain management. Participants asked the OPMC to affirm this sentiment.

"We were excited about the new [2022 CDC Opioid] guidelines because it gives more flexibility than the 2016. And I think that was the purpose, we are in contact with some of the people who were on the task force for the new guidelines. I think that that was really their focus was to give more flexibility and make the guidelines more of a just a basic guideline instead of a hard limit and whatnot. So providers could have the freedom to, you know, practice individual medical care." (3E)

"We asked the Oregon Pain Management Commission to join the CDC and reject one size fits all dosage limits and mandatory tapering as these have done so much harm to people with disabilities in our state." (4E)

Further, participants expressed concerns over OPMC's decision-making process around the 2022 CDC guidelines on opioid prescribing, in which the OPMC's draft endorsement of the 2022 guidelines stated that there is no evidence of benefit for opioid therapy (recommendation #7). Testifiers asked the OPMC to revise their position.

"I believe that a statement that there is no evidence of benefit would accelerate the forced stoppages that have drawn the concern of CDC and others, and leave doctors without a leg to stand on. And staying in alignment with what the CDC has said is a good thing. So I suggest affirming limited evidence, and endorsing the CDC statement that while opioids are non-preferred, care must be individualized." (4I)

“I did read CDC guidelines. And thank you for the commissioners pointing out their concerns. Point seven[2] is not accurate portrayal of the CDC guidelines. I'm sorry to say that I don't know who wrote it.” (4G)

Testifiers stated that OPMC’s initial interpretation of the CDC guideline was incorrect and that it has led to the complete removal of patients from pain management services, and that the CDC has acknowledged this through an updated release of their 2022 guideline.

“[...] since the CDC came back and said our guidelines weren't meant to be interpreted the way they were. It wasn't supposed to remove patients from pain management completely” (7C).

“In January of this year, we saw the medical board updated its statement of philosophy on pain management. Not only that 2022 CDC guidelines, which simply gave a link to and urge providers to educate themselves, but the board also boldly and accurately acknowledged how the oversteps and missteps in recent years have led to serious patient harms. The board added this information to its permanent website and also to the board's recent seasonal newsletter announcement. We have not seen similar action by the pain commission.” (7D)

Testifiers also noted that current OHA and OPMC policy further undermines physician autonomy, impacting decision-making at an individualized level. This neglect of non-addicted pain patients, though stemmed from the 2016 CDC guidelines, was exacerbated by membership changes that continue to reinforce a non-opioid pain management approach:

“Nowadays, we have a lot of doctors that will not treat with opioids because they're simply afraid of the medical board or DEA." (7G)

“Doctors are scared. Patients are scared, and because of the way the 2016 guidelines were interpreted in Oregon, we have become the number one state for the least managed pain.” (1C)

“The commission could…ensure that doctors know they are safe from prosecution taking on complex cases that in some cases may require higher than average opioid prescribing.” (7D)

The diverse perspectives on the CDC guidelines reveal significant concerns about their impact on chronic pain management. While aimed at mitigating opioid misuse, the guidelines have, based on testimony received, led to unintended consequences such as medical abandonment, nonconsensual tapering, and a lack of individualized care. The testimony underscores the need for revised, evidence-based, and flexible policies that cater to the unique needs of chronic pain patients.

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[2] CDC recommendation 7 refers to the evaluation of benefits and risks. A staff summary included in meeting materials stated that there is “no evidence supporting the use of long-term opioid therapy. After this public comment, the OPMC endorsement was revised (based more closely on the 2022 CDC guideline) to state “Evidence on long-term effectiveness of opioids remains very limited. Evidence exists of increased risk for serious harms (including opioid use disorder and overdose) with long-term opioid therapy that appears to rise with increase in opioid dosage, without a clear threshold below which there is no risk.”

Theme 2: Not feeling heard or represented at the OPMC

Concerns about the exclusion of patient voices and differing opinions in a pain management commission which has shifted its focus over the years to addiction instead of pain care.

The experiences of chronic pain patients as they navigate the OPMC involve frustration, systemic exclusion, and calls for more inclusive policies. Testifiers frequently stated that they felt ignored, especially when voicing a counterpoint to OPMC's stance on the evidence related to opioid prescribing for chronic pain.

"We just simply don't get heard…We have been telling you how it's affecting us, but we're not getting heard." (1A)

"The third main duty of the commission to represent the concern of the patient in Oregon has been ignored. I don't see much improvement in that I don't see that [the] commission is being completely objective and patient friendly." (6G)

"It is my understanding that your group was created to help people in pain like me, at a time when pain is untreated as it is now. I ask you to start responding to the lack of care crisis that has overwhelmed our medical care. Please listen to the patients and include their real-life experiences in the conversation so the real opioid crisis can be remedied." (6M)

"At this point, patients and advocates wonder why we even attend, if it's even a valuable use of our time. Public comment wasn't even on the agenda until we mentioned it. If our comments and perspectives aren't important and aren't represented, then I'm not sure we will attend." (2D)

Testifiers also stated that the focus of the OPMC has shifted over the years, having started as a pain advocacy group and later evolving to mainly be concerned about addiction.

"I learned of the group's work in 2007 from Senate Bill 880, which was an amazing bill for pain patients and their providers. But now the commission seems to focus on addiction and alternative treatment that ignores non-addicted and intractable pain patients who cannot be rehabilitated and who are successful on opioid therapy. With the focus on addiction, it would be better to remake this group into an addiction commission and establish another commission that focuses on helping people in pain." (2E)

"The direction has changed from protecting the patient to more regulatory pain module work." (6G)

Some testifiers mentioned that patients feel compelled to become advocates due to systemic neglect.

"The pain commission was the first entity I reached out to in 2015. I witnessed the commission dramatically restructure over the years, specifically from 2017 onward. My colleague and I have been reiterating the same urgent warnings of patient harms over the years. This can be validated by our past testimony." (7D)

"After becoming an advocate, I learned that many Oregonians in pain are ignored. So, I searched for help." (2E)

“And I'm speaking from personal experience, and from hundreds of other people that I speak to regularly, because I do my best to advocate for the community because there are so many people that are just simply too ill to deal with it. And we all are in the same boat.” (1A)

Finally, participants expressed concerns over the recurring involvement of anti-opiate bias and conflicted members in OPMC’s decision-making process.

“For years, Oregon has propelled deprescribing programs without assessing the harms to patients…Change Management Consulting was contracted to work with OPMC and OPG from October 2019 to September 2023, with an emphasis on promoting deprescribing non-opioid and non-pharma pain treatments, and they had responsibility to work on the pain education module. We cannot ignore how these contracts influenced prescribing in Oregon.” (6E)

“It feels like an exclusive club where doctors or any potential members with any other views than the widely accepted one of the group is excluded from membership consideration. Some highly respected providers we have known have applied and been told that their values don't align because they prescribe opioids for chronic pain or intractable pain. They won't reapply because their values haven't changed.” (2D)

Theme 3: Lack of access to appropriate pain care in Oregon

The Oregon health system's limited therapeutic options and non-recognition of patients with a history of opioid use results in a lack of treating providers, medical abandonment, and medical trauma.

Testifiers said that getting access to appropriate pain care was extremely difficult if not impossible in Oregon.

"Right now, it is challenging for a pain patient to find a primary provider even if they aren't asking them to prescribe. And it is almost impossible to find a provider who will prescribe pain medicine." (3E)

"Because of my history alone, I was informed by OHP that the likelihood of me finding a doctor was slim. So, this isn't just about getting access to opioids. This is actually about getting access to care and having doctors not even wanting to see us or get us into the door." (1C)

"Oregon's hyper focus on reducing prescribing pain medication has had a chilling effect on a certain patient population, as well as an increased fear by clinicians to treat them, and as mentioned earlier, poses a risk for those that decide to go to the street and can't access proper care." (3D)

"First doctor next to me is about 40 minutes and practitioners that would help with, let's say, fibromyalgia, myofascial release, first one is in Portland an hour and a half away." (4G)

"It took several hours, but there was no education to the physicians on how to treat post-op acute pediatric pain. Nobody knew how to dose my son properly. And I was informed that there's no education for the new doctors on this. They just assume the kids just need Tylenol and ibuprofen. There's nothing, there's no wiggle room. So that was a very traumatic as you can imagine, for my four-year-old and me and the nurses and the doctor, everyone was crying." (7N)

Testifiers also voiced the need for a patient-centered pain care approach across Oregon and especially in rural areas. The lack of patient centeredness has led to widespread medical trauma among people with chronic pain, leading to forced tapering of opioids, medical abandonment, and lack of access to opioid alternatives.

"The provider was extremely condescending, judgmental, and accusatory towards me. I felt violated, leaving every appointment in tears feeling guilty for having painful medical conditions. Later, I learned that this was a consistent treatment towards all patients. I attended the clinic for about a year, then COVID hit, the clinic suddenly shut down, and I was forced to taper off completely over the course of two weeks, the only option given to me was Suboxone. The amount of medical trauma this provider put me through is staggering." (6M)

"…Trauma and psychological correlations can play out in ways that involve some combination of lecturing patients, creating bright line rules on opioid therapy, not responding to the patient at times, and retraumatizing because, well, because many clinicians—including and perhaps especially doctors—turned out to be extremely poor in demonstrating most of the skills necessary to developing respectful and non-traumatizing relationships with adult patients." (7D)

“When a patient loses a provider for a myriad of reasons in Oregon, this should not equate to the loss of continuity of care, increased disability, loss of independent living, or should a person ever be contemplating illicit drugs as the only option for pain relief.” (7D)

“I have been cut off from my pain medications by a pain management clinic and that has caused me great difficulty in my life. I equate that to torture.” (7O)

Testifiers also underscored the lack of appropriate alternatives to pain management and the profound psychological trauma that can result from not getting appropriate pain management.

“She called the suicide hotline last week, because mentally she can’t handle the pain that she is in.” (1B)

“There was a discussion on how difficult access to multimodal pain management is, and it is true, it's almost like a fairy tale nowadays. So maybe besides talking about the ideal pain management approach that is almost impossible today, make the [OPMC] module more realistic and update as access to multimodal pain management approach improves, if ever.” (6G)

“Insurance does not cover a lot of these alternative treatments. Patients do want them. They are helpful, but insurance coverage is not there. The Medicare coverage like for ketamine, acupuncture, massage, it's just not there. So where is the bridge? While we're waiting for these services to be taken care of?” (6C)

“I personally will never use a pain management clinic again. I find them punitive. They use epidural steroid injections inappropriately. And when you use a treatment modality that doesn't work, you have to wait two to three months for your next appointment to explain how it didn't work. So that leaves people in torturous pain.” (7O)

“I was coerced into taking suboxone because no providers were willing to prescribe me my previously stable opioid medication or an equally effective pain medication. They gave me the excuse of an epidemic.” (6M)

Theme 4: Science of pain is evolving, individual, and complex

Pain is a deeply personal experience which is poorly understood by current biomedical science, making it resistant to one-size-fits-all solutions.

A less pronounced but consistent sentiment expressed throughout years of testimony was that the speakers' experiences with pain had been distinctly complex and that the science of pain has not yet been developed to the extent that it can explain why intractable pain has no treatment.

"There is a significant slice of the pain community with intractable conditions who benefit from long term opioid therapy, LTOT. Yet I don't see anything in the pain module for patients like me." (3E)

"The term pain science looks to have been adopted by the Pain Management Commission in recent years. It also appears to be a term utilized a lot in physical therapy space that I have seen. Pain science has been described, to me, as pain does not always equal injury. I think we must be careful when one model of thinking is being repeated and pushed to adopt…Conversations about pain, like science, is never settled and should always be evolving and changing." (6D)

Testimony also mentioned that a variety of factors should be considered when creating an individualized, clinically appropriate pain regimen:

"The patient's history within the context of his or her life, shared decision-making, negotiation of care plans over time, based in part on medical information, and that shared narrative is also critical for the context, social supports and disability status." (7D)

"In fact, you know, my doctor, he has just straight out told me—and I feel very fortunate enough today that I even have a doctor that treats me halfway decent—but he is willing to increase my dose up past 90 MME. But he says that there's no way that he could possibly do so, because there's simply no teeth. And anything that gets put down for people like me, for people that have serious multiple injuries that I have tried every single one of these projects that you tell us all is this multidisciplinary way to somehow get through our pain.. Well, there's some of us, me included, that have gone and jumped through every hoop...and it just simply doesn't work." (1A)

"Please listen to the patients and include their real-life experiences in the conversation so that the real opioid crisis can be remedied." (6M)

"One thing we can learn from this is that we need an individual and patient-centered approach to all medical care, including pain care." (3E)

"But I really wanted to emphasize to this group that care needs to be individualized between prescriber and patient with discretion and risk and benefits." (4J)

"You spend years and years of education, studying people. You don't need tools, look at the patient. Hear what the patient is telling you. Believe the patient." (3G)

Visual representation of testimony

In addition to a narrative synthesis of testimony and generation of themes, a visual representation was also developed as a word cloud. Word clouds are a visual representation of text which is often used in order to convey keywords. A word cloud generator, WordClouds.com, was used to create a cluster of words whose size correspond to the frequency with which it was mentioned throughout OPMC testimony. The bigger and bolder a certain word appears, the more often it was stated. Once the word cloud was generated, the reviewer removed definite articles (for example, words like “the”, “an”, etc.), conjunctions (for example, words like “because”, “for”, etc.) and clauses (“but”, “however”, etc.), as well as mention of any individual names, and set a minimum threshold criterion of 5 mentions in order for the word to be included in this visualization.

APPENDIX A

Zachary Corbett, LAc, OPMC chair:

Re: my own patients with pain:

I find most patients have no understanding of the pathophysiology of chronic pain, despite being in care for many years. I am often the first provider to introduce the idea of central sensitization and neuroplasticity to them, and how chronic pain can be attenuated or even eliminated. However, their other diagnoses like diabetes were fully explained to them.

Also, many patients tell me that effective pain management care is 1./ limited by insufficient numbers of providers trained in relevant specialties 2./ insufficient insurance coverage available for the available providers to achieve maximized, stable results.

Russell Wimmer, PA-C, OPMC Vice-Chair

The largest concerns with my patient panel and community of providers as they hear from their patients are the following:

- Access to services that would otherwise improve their function and quality of life; specifically services along the lines of physical therapy, chiropracty, OMT, acupuncture massage therapy and mental health/behavioral health services.
- Challenges include both access to providers and practices within their region, as they are few far between, with practices being largely overburdened. Additionally, public pay options, often either do not cover, or have high prohibitive co-pays for the services despite the standard of care and primary care strongly advocating their benefit.
- Finally, as is present throughout the US, there is a significant shortage of access to primary care providers.

Carolyn Concia, RN

I am writing to express my concern regarding the discrimination and challenges faced by chronic pain patients in accessing appropriate opioid therapy. My patients have experienced firsthand the stigma and barriers that many Oregonians suffering from chronic pain encounter simply by requiring a medicine that allows them to remain in the workforce and spend time with their families, boosting their overall quality of life.

Despite the availability of various treatment modalities, opioids remain a crucial component of pain management for certain patients. However, increasingly stringent regulations and misconceptions surrounding opioid use have led to discrimination against those who legitimately rely on these medications to function and maintain a reasonable quality of life. According to the Oregon Overdose Prevention Dashboard, about 250,000 Oregonians have filled prescriptions for opioid medications in recent quarters.

Chronic pain patients face skepticism, judgment, and even denial of care from healthcare providers due to fear of regulatory scrutiny or negative public perception. Such attitudes not only undermine Oregonians' rights to adequate pain relief but also perpetuate misunderstanding about the complexities of chronic pain management.

The following passages are answers chronic pain patients (whose provider could no longer prescribe) received when searching for a new provider to manage their pain. (A spreadsheet with names, dates, and times is available upon request.) No one could secure a new provider.

One large hospital community in the Portland/Metro area adopted a zero-opioid prescribing policy. For the patients for whom opioids are proven safe and effective, this one-size-fits-all policy is destroying the livelihood of chronic pain patients.

- When patients contacted their insurers, they were given a few names of providers that the insurers thought would continue medication management for chronic pain. One insurer refused to give any names.

- When patients reached out to said providers, they received the following responses:

"We have a zero opioid prescribing policy."

"We will see you, but switch you to Buprenorphine."

"We only do procedures. No medication management."

"We are no longer accepting new patients."

One chronic pain patient reached out to a primary care practice in Hillsboro and asked if she could be seen for primary care needs only, emphasizing she did not need a provider to prescribe opioids, and the response was,

“We took a vote, and we decided not to take any chronic pain patients.”

Another office responded,

> "We don’t see patients like you.”

As an advocate for compassionate healthcare and evidence-based medicine, it is imperative to address corporate policies and medical systems that deny access to pain care. Ensuring that all chronic pain patients receive the respect, support, and treatment they deserve is essential for upholding the principles of ethical and effective medical practice. Thank you.

Britta Gurgel, PT

As part of one of the few comprehensive pediatric chronic pain centers in the state, my physical therapy colleagues and I have noted the following challenges especially in youth with chronic pain:

- Not feeling heard or believed by medical professionals, teachers and staff at school, employers, and peers.
- Experiencing discrimination, bullying, and/or isolation due to invisibility of the disability.
- Access to care can be limited for patients who identify as genderqueer, gender fluid, non-binary or transgender which we know these populations experiences chronic pain and chronic conditions at a higher rate.
- Difficulty accessing providers who understand and feel comfortable working in pediatric chronic pain, especially in more rural areas.
- Limited external resources for mental health supports for patients in rural areas in conjunction with PT treatment.
- Occasionally limitations in the amount of appointments approved for physical therapy, with insurers not understanding the potentially slow rate of progress in chronic pain.
- Some insurers not covering complementary and integrative interventions for people under 18 (ex: massage therapy).
- The financial burden of differential diagnosis and costs (financial or otherwise) of pain treatment.
- Sole emphasis placed on weight on a cause or weight loss as a treatment of pain.

Making pain better understood across settings (medical, educational, societal) and the fact that it also affects many children and teens, especially those who experience the intersectionality of race, ethnicity, gender, and socioeconomic status that also have been shown to affect health care and health outcomes, may make a world of difference in quality of life.

Eve Klein, MD

Many of the people who come to us for treatment of opioid use disorder report that they also experience chronic pain. In years past, we formally surveyed our patient population and found that about half were experiencing chronic pain in addition to opioid use disorder. Most of our patients tell us that their opioid use first started with a prescription for pain.

From my past work in pain management, I know that most people who have chronic pain do not have opioid use disorder, but some do. Sometimes people with chronic pain develop opioid use disorders over time. And sometimes that can be deadly. I also saw patients with chronic pain who accidentally overdosed on prescription opioids even without having opioid use disorder.

We need to make sure that people with chronic pain have access to effective treatment. We also need to acknowledge that opioids come with very real risk, both for the person with chronic pain and also for the community. There is an important role for opioids in chronic pain management, and opioids need to be approached cautiously and judiciously with both patient and medical practitioner understanding and appreciating the risks.

Terance Manning, ND

I practice interventional pain management, where our goal is to provide relief of pain and improved function, without prescribing opioid medication. Unfortunately, there are many patients where either their insurance does not cover these procedures and/or the procedures fail to achieve satisfactory pain relief or improvement in function. I have been practicing in this field, in Oregon, for 8 years.

Over the last couple of years, I have had patients reporting some very concerning things.

1. Their pain medicine prescriber has moved or is no longer prescribing pain medicines out of fear of the OMB.

2. I have personally seen at least 8 patients who had been on long term pain medication, their provider stopped prescribing, the patient was unable to find another provider to take over prescribing, so the patient resorted to buying pain medicines off the streets.
3. I used to work with a board certified Pain physician who left our practice. When this provider left, we had dozens of patients who needed to find another provider to take over prescribing. I witnessed the administrative effort it took to find all of these patients a provider. Most patients had had at least 3 refused referrals from "pain management" clinics. We had hoped that the patient's PCP would take over the medications, but many refused or at the very least showed great reluctance due to fear of the OMB, even though the patients being referred had had a long record of following their pain contract and not diverting or abusing opioids. Eventually we found all of them the appropriate care, yet it took over 6 months to accomplish this.
4. In general, my patients with persistent pain report being under-treated, dismissed, and are disgruntled with the system as they want to be able to work, yet cannot function well enough to do so. Furthermore, they report emotional trauma from the judgements of the media, CDC, and clinicians who write them off. They report that the state and federal regulations have swung so far one way, that it is these authorities, not the individual clinicians, that are abandoning them.

Christine Martin, MD (Associate Professor, OHSU Pediatric Anesthesia)

As a pediatric pain management physician working in the OHSU Pediatric Comprehensive Pain Management Center, I care for a diverse group of pediatric patients experiencing chronic pain. These patients most commonly benefit from a multimodal approach to pain management, including pain focused physical therapy and pain psychology. Access to these services is limited in Oregon, especially in rural areas. It can be excessively difficult for patients and their families to travel long distances to access these services. Furthermore, we do not have enough providers offering these services to meet the needs of our current pediatric pain patients.

Another coming theme that negatively impacts the experience of pediatric pain patients is the lack of mental health services throughout the state for pediatric patients. Many of these patients also suffer from mental health conditions, such as depression, anxiety and post-traumatic stress disorder (PTSD). Lack of treatment of these conditions makes it very difficult to address and manage chronic pain when they coexist in a pediatric patient.

Finally, one of our main objectives in management of pediatric chronic pain is improving daily functioning. Improving functional status typically includes a focus on returning to school or improved school attendance. Returning to school can be incredibly important to improve pain

management. However, there is a lack of school support to help facilitate returning to school with modification that makes it possible for children with pain to be in school. Facilitators between the school system and health care providers would be incredibly beneficial for this patient population. The OHSU Novel Interventions in Children's Healthcare (NICH) is a wonderful program that provides a trained interventionalist to assist pediatric patients navigate their health conditions within and apart from the health care system. NICH has been very beneficial for some of our pediatric pain patients. However, access to this program is limited by insurance coverage and geographical locations. Improving access to this program and/or developing other similar programs would be incredibly beneficial for our pediatric pain patients. These programs can also be cost effective by decreasing the utilization of emergency care while improving patients' health and outcomes.

Scott Pengelly, PhD

Many (not all) procedures needed for mitigating pain not available to pain patients who are covered by OHP (Medicaid).

Several physical therapists and some acupuncturists will not treat pain patients with OHP due to extraordinary difficulty getting paid.

Cannot find PCP.

PCP will not treat me due to opioids.

Complex pain patients: "We don't treat that here."

Delays for diagnostic testing, specifically

Results from blood draws take weeks.

Authorization for MRI CT scan long, long delays.

Pain patients must endure painful physical therapy that is painful and beyond their capacity before being permitted to consult for next step in procedure, i.e., MRI exam.

Stuart Rosenblum, MD

As requested, I am providing you with a summary of my patients' concerns. As you know, I am a board-certified specialist in pain management, and I have been providing care for over 40 years. My clinic is following over 1000 patients for long term care of chronic pain. The following issues are prevalent:

1. Anti-opioid bias: Patient's complain that they are singled out by pharmacists and health care providers as "drug seekers" or "addicts." Patients are often questioned by pharmacists as to why they need opioid medications. Primary care physicians may refuse to see patients because they are on opioid medications. It is often assumed that patients being prescribed methadone or buprenorphine are "addicts," however, these medications are commonly used for legitimate pain management.
2. Lack of access to healthcare providers willing to treat chronic pain: There are fewer physicians and health care providers willing to treat patients with chronic pain now then 5 years ago. There are large areas of Oregon without any providers willing to treat chronic pain. As a pain specialist, I have patients travel 6 hours to my clinic for care, few physicians are willing to prescribe even low dose opioid therapy. Fewer clinics are willing to allow the routine prescribing of low dose opioid therapy, prescribers fear the risk of sanctions from the Oregon Medical Board.
3. Mishandling and misunderstanding of the opioid epidemic: My patients are aware of the ravages of illicit fentanyl use. They are aware of the vast number of patients impacted by illicit drug use. However, they feel that the focus on legitimate opioid use as medically supervised, has been an inappropriate target for those attempting to solve the opioid epidemic.
4. My patients and I worry about finding a replacement doctor for me. I am 75 years old, and I will retire this year. We worry about the patients being unable to find adequate replacement care. I work with Shea DeKlotz, PA and we manage almost 400 patients with implanted spinal infusion pumps. To date, I have been unable to find a replacement for our services and this may create a hardship for these patients.