



mito
ACTION

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The background features abstract, overlapping green geometric shapes in various shades, creating a modern and dynamic look. The shapes are primarily triangles and polygons, some semi-transparent, layered against a white background.

CDC's New Opioid Guideline: What this Means for the Mito Community

**April 1, 2022
9AM PST/ 12PM EST**

Welcome/Introductions

The background features abstract, overlapping geometric shapes in various shades of green, ranging from light lime to dark forest green. These shapes are primarily located on the right side of the slide, creating a modern, layered effect. The rest of the slide is a plain white background.

Today's Presenters



George Lippman, Social Justice Advocate, Chair of the City of Berkeley Peace and Justice Commission



Charles Mitter, Ph.D., Emeritus Professor, College of Computer, Mathematical and Natural Sciences, University of Maryland; Former Chair, Department of Entomology



Cary Sanders, MPP, Senior Policy Director, California Pan-Ethnic Health Network

Agenda

- ▶ Welcome/Introductions (5 min)
- ▶ Our Story (5 min)
- ▶ What do the Guidelines Do? (7-10 min)
- ▶ Take Action! (7-10 min)
- ▶ Questions and Answers (10-15 min)
- ▶ Conclude (5 min)

Discussion

Have you or a family member...

- ▶ Ever been denied access to opioid pain medications even after trying other therapies that were not successful?
- ▶ Ever had a doctor abandon you?
- ▶ Been forced to taper your pain medications against your will?
- ▶ Had insurance or your pharmacy refuse to cover your opioid prescription?

Our Story...



Our Story...



What do the proposed CDC Guidelines Do?

- ▶ Background: *Prevalence of Chronic Pain & Opioid Use*
- ▶ 2016 CDC Guidelines
- ▶ 2022 Draft Revision
- ▶ Concerns and Challenges

Background: Prevalence of chronic pain

Chronic pain is the leading cause of disability

- Overall, ~ 20% of U.S. adults (53 million people) report chronic pain
- 7% (19 million) have high-impact chronic pain, limiting work or life activities

Chronic pain among mito patients

- Historically, chronic pain has not been included among the core symptoms of mito.
- Nearly all adult mito patients experience pain from their disease, per recent numbers
- Two-thirds suffer chronic pain, with average impact comparable to chronic back pain
- It's likely that more than 35,000 U.S. adult mito patients, and 10,000 mito kids, live with chronic pain.

Effect of chronic pain on lives

- Under-treated chronic pain known to harm mental health, cognitive function, ability to work, suicide risk, life expectancy, etc.
- Health-related quality of life for mito and other patients with chronic non-cancer pain has recently been judged to be comparable to that of advanced cancer patients

Background: Opioids and chronic pain

Most chronic pain patients do not choose opioids...

- ▶ They may use other drugs, or other options such as physical therapy, interventional therapy (e.g. surgery), behavioral therapy, or holistic therapy (acupuncture, chiropractic, etc.).

For some, however, only opioids relieve pain enough to allow acceptable levels of function and quality of life.

- ▶ 5-8 million U.S. adults use opioids for chronic pain.
- ▶ These probably include thousands of mito pain patients.

Therefore, opioid policy matters to the mito community.

2016 Guideline: Origins

In 2016, the CDC published “[CDC guideline for prescribing opioids for chronic pain.](#)”

- Prompted by epidemic of overdose deaths from prescription opioids, which went from 3,000 in 1999 to 15,000 in 2015
- Guideline aimed at primary care doctors prescribing opioids to adults with non-cancer chronic pain.
- Emphasis was on reducing prescription of opioids, to reduce overdose deaths
- Stressed risks of long-term opioids, skepticism that they are even effective.
- Proposed strict, one-size-fits-all numerical limits on size and duration of opioid doses

2016 Guideline: Consequences

Opioid prescribing went down by almost half

- The Guideline strongly reinforced an existing trend toward restriction of opioid prescribing.
- The total U.S. prescription rate peaked in 2012, then declined every year since, to record lows now..

But total opioid overdose deaths are still increasing!

- Deaths from prescription opioids have leveled off
- Total number of overdose deaths involving opioids **doubled** between 2015 and 2021, to over 100,000.
- Great majority of overdose deaths now involve fentanyl and/or other street drugs, not those prescribed to the patient.

Misapplication of Guideline created a new pain epidemic

Recommendations intended as voluntary, but instead...

- Codified into restrictive policies by pharmacies, payers, providers, laws
- Countless lives have been damaged
- Many patients have had their opioid doses arbitrarily cut or eliminated
- Harmful effects of such tapering now well documented
- Some patients commit suicide, others seek dangerous street drugs, risking overdose.
- Climate of opioid hysteria, doctors are afraid to prescribe opioids, some abandoning patients.
- Pain patients have a hard time finding healthcare at all.
 - 80% of primary care providers now reluctant or unwilling to accept a new patient needing opioids

2022 Draft revision of Guideline

Draft revision was released for public comment, Feb. 2022, after years of controversy

Major improvements over 2016 version:

- Recognizes pain as a major public health issue.
- Acknowledges harm from 2016 Guideline.
- Removes strict day/supply and dose limits from recommendations.
- Cautions against rapid reductions or discontinuation of medications.
- Emphasis on individualized, patient-centered pain treatment.
- Focuses on disparities in pain care.
- Warns against using Guideline as basis for inflexible standards across patients or systems.

Concerns and challenges

Proposed revision could greatly improve the lives of millions of chronic pain patients, BUT a lot still has to happen first

- Draft revision must be formally adopted by the CDC.
- Very strong voices inside and out of the CDC still favor the 2016 version.
- Overwhelming support in public comments needed to ensure adoption of the new policy; failure would be disastrous.

Adopting the revised version does not guarantee that it will be put into practice

- Huge effort needed to undo the harmful policies spawned by the 2016 version, including educating our individual providers.
- Revision itself retains shortcomings to be addressed (e.g. too focused on exceptions rather than individualized care); more info [here](#) and at www.mitoaction.org/advocacy/pain
- MitoAction can make ongoing contributions to advocacy on chronic pain

Take Action!



Take Action

Submit Comments to the CDC TODAY!

- ▶ Comments are due **Monday, April 11th at 12:59 ET**
- ▶ Numbers count – each submission is considered a unique entry
- ▶ The CDC must read and consider every comment before finalizing their guidance
- ▶ Each comment is submitted in the public record, therefore you may choose whether or not to include personally identifiable information

How to Submit Comments

ONLINE:

- ▶ Go to www.Regulations.gov or www.Federal Register.gov
- ▶ Search for [Docket ID number CDC-2022-0024](#)
- ▶ Click on “Comment Now” and you can type your comments into the comment box or upload a document

BY MAIL:

National Center for Injury Prevention and Control
Centers for Disease Control and Prevention
4770 Buford Highway NE, Mailstop S106-9
Atlanta, Georgia 30341
Attn: Docket No. CDC-2022-0024

Tips for Writing Comments

- Introduce yourself: Name//Where you Live
- What do you like about the proposed Guideline? Why are the changes important?
- What don't you like about the proposed Guideline? What would you like to see instead?
- Tell your story, including any harms that have occurred as a result of the 2016 Guideline, and whether you feel this update will address them

Example: “Even though the guidelines exempt palliative care doctors, mine still refuses to acknowledge my pain and has labeled me an addict and convinced all my doctors to ignore my pain. Without additional education, I’m worried I’ll never be able to get relief.”

- Be brief but specific. If you feel comfortable, mention your diagnoses, how your medication helped you to engage in life activity, and what activities were prevented when you lost access, if you did:

Example: “I have Mito. With medication, I was able to garden, cook for my family, and even travel. After my medication was denied, I am bedridden at home.”

- Talk about the process of commenting, how easy or hard was it?
- For additional talking points, see [NPAC’s summary here](#).

Source: National Pain Advocacy Center: <https://nationalpain.org/advocacy-alert>

Take Action

Call your Senator/Representative TODAY

- ▶ Speak with your Senators and Representatives in Congress about the damaging impact that the 2016 Guideline had on people with pain.
 - ▶ You can contact your House of Representative or Senators by phone by calling the **U.S. Capitol Switchboard: (202) 224-3121**
 - ▶ Call the number, give the operator your zip code, and he/she will connect you with your elected officials' office.
 - ▶ You can also access this information online at: www.House.gov or www.Senate.gov

Question & Answer

Thanks for Joining Us!

To learn more visit
www.mitoaction.org/advocacy/pain

