Quick-and-Easy Guide to Commenting on the HHS Draft Report

Q: Why bother commenting?
A: The U.S. Department of Health & Human Services (HHS) oversees the CDC, so that means this department oversees the agency that created the terrible CDC Guideline that has caused all of us chronic pain patients so much grief and agony!

So, by writing its Draft Report, the HHS is telling us it's AWARE that there are serious problems with the CDC Guideline. If HHS receives a lot of additional comments that complain about the CDC Guideline, it's quite possible that it will revise the CDC Guideline in a way that helps chronic pain patients, and that could happen as early as this summer.

Q: How do I make my comments as effective as possible?
A: To make our comments as effective as possible, we should aim to be **as specific as possible** about how the CDC Guideline has harmed us. So instead of just saying that the Guideline has hurt us, we should describe **HOW** it has harmed us.

* Tell **how much** your medication has gone down by, from what dose to what dose.
* Tell **how much** your ability to function has decreased.
* Tell **how much** your ability to work has decreased, if you work.
* Tell **how much** your ability to make money has declined, if you earn money.
* Tell **how much** your ability to exercise has decreased, if you exercise.

* And if your mental state has gotten worse, describe **how much worse** it has become.

Q: Does it matter which words or phrases I use in my comments?
A: According to a researcher at ATIP (the Alliance for the Treatment of Intractable Pain), it matters a great deal. Rhonda Posey, ATIP special projects researcher, has learned that the HHS pays special attention to certain "buzz words and phrases" that appear in comments. Evidently, according to Ms. Posey, if you inject these "buzz words and phrases" in your comments, your comments will be given a higher priority. A complete list of these "buzz words and phrases" is included at the end of this guide.

Q: How do I send in my comments?

A1: Easiest way: Send your comments by email. Just email them to this address: paintaskforce@hhs.gov

A2: Or you can mail written comments to this address:

U.S. Department of Health & Human Services
Office of the Assistant Secretary for Health
200 Independence Ave., S.W., Roo 736E,
Attn: Alicia Richmond Scott, Task Force Designated Federal Officer
Washington, DC 20201

Q: When's the deadline for submitting comments?
A: It's coming up fast. The absolute deadline is 5 pm on Monday, April 1. So let's all get going and comment now!
You can also have anyone who cares for you send in comments separately. But s/he must send comments from his/her own email address for those comments to be considered separate from yours.

Q: How do I write my comments so they relate to the sections of the Draft Report?

A: That's where this "Quick-and-Easy Guide" comes in. The Guide tells you the sections to refer to depending on the kind of comment you want to make.

Q: Do I need to comment on all sections? Or can I just comment on one section? What's the deal with this?

A: You can comment on <u>as few or on as many</u> sections of the Draft Report as you'd like. It's ABSOLUTELY FINE if you choose to comment on just one section of the report. It's also fine if you choose to comment on more than one section of the report. It's entirely up to you.

Q: What might a sample comment look like?

A: Here's an example. Of course, your comment can be shorter or longer.

I'm commenting here about Section 2.4.1. I feel that hospitals are sometimes not responsive to the needs of chronic pain patients after surgery. I myself underwent a radical prostatectomy in 2012. After I had this major surgery, my surgeon forbid me from having any pain medication except ibuprofen, saying his surgery should have cured me of all of my pain (chronic pelvic pain, which I'd had for 10 years prior). He was wrong(!), and I spent a full 36 hours in the hospital with zero access to pain medication. I thus had to endure not only with my standard pain, but also the standard post-operative pain with no relief except that from 400 mg of ibuprofen every 4 hours. This was tantamount to torture. I feel that hospitals should be allowed to overrule surgeons if they see that a patient is suffering, and that hospital officials should be allowed to use their independent judgment in prescribing pain medication to patients following surgical procedures.

Q: Is there a length limit for comments?

A: Yes, the sum total of your comments can be no more than three typewritten pages!

Q: What am I looking at below?

A: Below you will find summaries of each section of the HHS Draft report, with each section identified by its number. At the end of each summary is a statement telling you how to reference that section if you'd like to comment on it.

Q: Where can I find the full Draft Report?

A: Hopefully many DPPR states will post the Draft Report in their Files section. But if it's not there, here's a link where you can read it or download it:

Printable - https://DontPunishPainRally.com/HHSDraft-Print

Online - https://DontPunishPainRally.com/HHSDraft-Web

SECTION 1: INTRODUCTION

Section 1 is just the introduction to the Draft Report. It discusses why the Draft Report was written, who wrote it, etc. You probably won't feel moved to comment on this introduction, as it is quite general in nature. But you may want to read the intro to get some background on the Draft Report's origin and to get a "lay of the land" for the rest of the report's contents.

SECTION 2: CLINICAL BEST PRACTICES

Section 2 is a lengthy section on how various aspects of acute and chronic pain are being treated now, with an emphasis on what the report writers call CBP (Clinical Best Practices), shorthand for what seems to be working the best in pain treatment. Here are the subsections of Section 2.

2.1.1: TREATMENT OF ACUTE PAIN

2.2.: MEDICATION FOR ACUTE PAIN Here the Draft Report emphasizes not using opioids for the treatment of short-term acute pain. It recommends that health care providers use opioids as a last resort. It says that if opioids are to be used, doctors should give patients all kinds of warnings about how addictive opioids are. **If you have opinions about this approach, feel free to comment, referencing Section 2.2.**

2.2.1: RISK ASSESSMENT The main focus here is that doctors should use the Prescription Drug Monitoring Program (you know this! — it's the computer program the doctor checks to see which prescriptions you've filled recently) to keep track of which medications patients are using within their state. Also the report urges that doctors regularly do urine tests on their patients. **If you have opinions about either of these approaches, feel free to comment, referencing Section 2.2.1.**

2.3: RESTORATIVE THERAPIES Main point here is that there is potential benefit for both acute pain patients and chronic pain patients in doing OTHER kinds of therapy than opioid medications (TENS units, physical therapy, aqua therapy, movement therapy, tai chi, etc). More research should be done on these other kinds of therapies, and more emphasis should be placed on using whichever of these therapies works. **If you have an opinion about these approaches, comment, referencing Section 2.3.**

2.4: INTERVENTIONAL PROCEDURES Pretty much what you'd expect. Main point is that "interventional procedures" (e.g., epidurals, trigger point injections, sympathetic nerve blocks, cryoneuroablation, neuromodulation, intrathecal pain pumps, RF ablations, etc.) can all be "valuable options" before starting patients on opioids, and therefore these approaches should be part of a "multi-modular" approach to pain management. **If you've had bad (or good) experiences with these, you may want to weigh in on the discussion, making a comment and referencing Section 2.4.**

2.4.1: PERIOPERATIVE MANAGEMENT OF CHRONIC PAIN PATIENTS Considerations for managing chronic pain patients before and after surgeries. If you ever had a bad experience with your pain management before or after surgery (Editor's note: I did, after a major surgery; they wouldn't let me use any of my pain medications!), you may want to weigh in here. **To comment on this, reference Section 2.4.1.**

2.5: BEHAVIORAL HEALTH APPROACHES This section addresses emotional issues faced by chronic pain patients. It suggests that pain patients can benefit by learning various methodologies to deal with the stress that chronic pain triggers. Suggested methodologies include behavioral therapy, cognitive behavioral therapy, acceptance and commitment therapy, and mindfulness-based stress reduction (the one pioneered by Jon Kabat-Zinn). **To comment on these approaches, reference Section 2.5.**

2.6: COMPLEMENTARY AND INTEGRATIVE HEALTH Similar to some topics discussed in 2.5, this section promotes using alternative treatment approaches. This section focuses on modalities such as osteopathic or chiropractic manipulation, massage therapy, mindfulness, yoga, tai chi, biofeedback, art and music therapy, spirituality, and the use of natural or

nutritional supplements. **So if you've ever tried any of these approaches, feel free to comment on how they either worked or didn't work for you, referencing Section 2.6.**

2.7: TREATING CHRONIC PAIN FOR SPECIAL POPULATIONS Each sub-section deals with the challenges of treating chronic pain with a unique group of people.

2.7.1: TREATING CHILDREN w/ CHRONIC PAIN If you are dealing with this issue, read the section and comment. **Or just comment on your issue and reference Section 2.7.1.**

2.7.2: TREATING OLDER ADULTS w/ CHRONIC PAIN If you are an older adult or you're a caretaker for an older adult, read the section and comment. **Or just comment on your issue and reference Section 2.7.2.**

2.7.3: TREATING WOMEN w/ CHRONIC PAIN If you're a woman or a caretaker for an woman with chronic pain, read the section and comment. **Or just comment on your issue and reference Section 2.7.3.**

2.7.4: TREATING PREGNANT WOMEN w/ CHRONIC PAIN If you're a pregnant woman or a caretaker for a pregnant woman with chronic pain, read the section and comment. **Or just comment on your issue and reference Section 2.7.4.**

2.7.5: TREATING PATIENTS w/ RELAPSING CHRONIC PAIN CONDITIONS If you have a relapsing chronic pain condition or are a caretaker for someone with one, read the section and comment. Examples of such conditions: various degenerative, inflammatory, immune-mediated, rheumatologic, and neurologic conditions such as MS, various cancer syndromes, trigeminal neuralgia, lupus, Parkinson's disease, postherpetic neuralgia, CRPS, porphyria, systemic lupus erythematosus, lumbar radicular pain, migraines, or cluster headaches. **To comment, reference Section 2.7.5.**

2.7.6: TREATING CHRONIC PAIN PATIENTS w/ SICKLE CELL DISEASE If you have sickle cell disease or are a caretaker for someone with sickle cell disease, read the section and comment. **Or just comment on your issue and reference Section 2.7.6.**

2.7.7: TREATING RACIAL AND ETHNIC PATIENTS w/ CHRONIC PAIN The Draft Report defines racial or ethnic groups as including "African-Americans, Latinos, American Indians and Alaskan Natives," so many New Mexicans would fall under this broad category. If you self-identify as such and would like to comment on your experience as a chronic pain patient, **comment on your issue and reference Section 2.7.7.**

2.7.8: TREATING MILITARY PERSONNEL and VETERANS w/ CHRONIC PAIN If you serve or have served in the U.S. military and have chronic pain, read this section and comment. **Or just comment on your issue and reference Section 2.7.8.**

SECTION 3: Clinical and Best Policy Practices

Section 3 deals with what the Task Force who wrote the report considers the best practices for dealing with patients with chronic pain.

3.1: STIGMA Remarkably, the Draft Report does note that patients who use opioid medications face all kinds of stigma as a result of using these medications. The report acknowledges that patients are subjected to both subtle and not-so-subtle messages of shame and stigma from friends, family, acquaintances, health care workers, pharmacists, co-workers, business acquaintances, and it points out that this burden of stigma can, in an accumulated way, trigger mental health problems such as isolation and/or depression. The Draft Report also points out that doctors working in the pain management field also face stigma from their medical colleagues because they treat chronic pain, and that this stigma can be one of the factors driving some doctors out of treating chronic pain. **If you'd like to comment on the issue of stigma and the problems it causes, reference Section 3.1.**

3.2.1: PUBLIC EDUCATION The Draft Report notes that the U.S. general public is poorly educated about the causes of acute and chronic pain. The report suggests that there should be a bigger effort to educate the U.S. public about the causes of chronic pain through a national or through a combination of national and state pubic awareness programs. **If you'd like to comment on this proposal, reference Section 3.2.1.**

3.2.2: PATIENT EDUCATION The Draft Report states that chronic pain patients currently don't have enough access to information on the root causes of their pain conditions or to techniques that could help them deal with their pain. The report says that more information should be made available to help patients understand the root causes of their pain and the fact that pain itself can become a disease. The report suggests that with more information, patients would realize there are techniques they can use (such as relaxation techniques, biofeedback, etc.), to help them cope with their pain. **If you'd like to comment on this issue of patient education, reference Section 3.2.2.**

3.2.3: PROVIDER EDUCATION The Draft Report notes that the health care providers who actually prescribe pain management medications also have a lack of education about the very medications they prescribe. The report states that, other than specially trained pain specialists, fewer than 20% of professionals licensed to prescribe opioids have training on how to prescribe opioids safely. Therefore the Draft Report recommends that health care professionals receive more education on prescribing opioids safely. It says that some of this could be done through distance learning and some could be done in other ways. The Draft Report also notes that many doctors incorrectly view chronic pain as a symptom of a disease, whereas chronic pain is now understood as a disease in and of itself. The report says this new view of chronic pain should be taught to all medical professionals. **If you'd like to comment on this issue of provider education, reference Section 3.2.2.**

3.3: ACCESS TO PAIN CARE This section addresses the disturbing fact that many people in the United States have chronic pain but can't get treatment for it because they lack access to health care professionals and to pain management medication. **If you'd like to comment on this issue of lack of access, reference Section 3.3.**

3.3.1: MEDICATION SHORTAGE The Report notes that over the past several years there have been shortages of many critical opioid medications. It says that the FDA has established an Agency Drug Shortages Task Force to help monitor and manage this problem. [Editor's note: The DEA has been helping create this problem by proposing manufacturing limits for many opioid medications. See: https://www.dea.gov/press-releases/2018/08/16/justice-department-dea-propose-significant-opioid-manufacturing-reduction] **If you'd like to comment on this medication shortage problem, reference Section 3.3.1.**

3.3.2: INSURANCE COVERAGE FOR COMPLEX MANAGEMENT SITUATIONS This section points out a truth that we all know too well: that health insurance companies often make it extremely hard for us to get coverage for our pain management medications. **If you'd like to comment on the insurance-coverage-for-medication problem, reference Section 3.3.2.**

3.3.3: WORKFORCE The Report notes that as of now, there is, on average, only ONE pain management, board-certified doctor for every 28,500 Americans suffering with chronic pain. And of course, the situation grows worse every week with each physician who drops out of treating pain. The report makes a number of recommendations for helping remedy this doctor-shortage situation, which you can read about at this section of the report. **To comment on this sad state of affairs and how it may affect you, please reference Section 3.3.3.**

3.3.4: RESEARCH Here the Report states the obvious here: there needs to be much more research into the whole range of issues related to acute and chronic pain. We need research into how pain syndromes develop, whether or not certain pain syndromes have a genetic component and if so, if there may be genetic-based treatments. We also need research into new, addiction-free medicines for treating acute and chronic pain. And finally, we need more research into substance abuse disorder (SUD), so that we can more effectively help people who develop addiction disorders. **If you'd like to comment on the need for research, reference Section 3.3.3.**

4: REVIEW OF THE CDC GUIDELINE: Ok, so this is perhaps THE MAJOR SECTION of the report for most of us, so don't pass this over. You'll be HAPPY TO KNOW that the Draft Report has a lot of negative things to say about the March 2016 CDC Guideline that has caused all of us with chronic pain so much pain, stress and agony. Below are some of the key NEGATIVE comments from this section. You can also read the full Draft Report's section if you'd like to know the entire contents. **To comment on the CDC Guideline and how it has impacted you or anyone you care for, simply reference SECTION 4.**

Below are five key quotes from the HHS Draft Report about the CDC Guideline. Note how these quotes show that the Task Force writers recognize that the CDC Guideline has caused major problems!

"… at least 28 states have enacted legislation related to opioid prescription limits, and many states and organizations have implemented the guideline without recognizing that the intended audience was PCPs; have used legislation for what should be medical decision making by healthcare professionals; and have applied them to all physicians, dentists, NPs, and PAs, including pain specialists …"

"The CDC guideline was not intended to be model legislation for state legislators to enact."

"An unintended consequence of the guideline is the forced tapering or patient abandonment that many patients with chronic pain on stable long-term doses of opioids have experienced."

The Task Force received public comments indicating that many patients have experienced access issues related to provider fears and concerns with how the guideline would be interpreted and have caused some to consider obtaining opioids from illicit sources or suicide."

"The CDC guideline, along with concern about undue burdens of investigation and prosecution by drug enforcement, has been cited in part by doctors and other key health care providers when deciding to limit or not to provide pain treatment."

List of "Buzz Words" & Phrases that Supposedly Make HHS Prioritize Your Comments

[Editor's Note: I suggest using some of these, but not too many. I worry that a computer algorithm might discard comments that use a large number of these "buzz words."]

psychological issues
osteoarthritis
spinal stenosis
drug hyper mobility
spinal equina adhesions
inflammation
migraine
fatigue
therapy naive
endometriosis
anxiety
arachnoiditis
suicide
accident
overdose
condition aggravated
decreased functionality
complex regional pain syndrome
neuropathic pain
analgesic therapy
rheumatoid arthritis
stenosis
therapy change
behavioral health
anger
multiple sclerosis
fibromyalgia
memory impairment
drug tolerance
limiting abilities

post-operative pain
surgery
acupuncture
fear
fibromyalgia
memory impairment
drug tolerance
limiting abilities
stress
neuralgia
mental health disorders
bedridden
headaches
malaise
high impact injuries
crying
cognitive decline
depression
feeling abnormal
arthritis
Parkinson's disease
physiotherapy
neoplasm malignant
incorrect dose administration
fracture
disability
legal problems
nerve injury
toxic epidermal necrosis
loss of productivity
intervertebral disc
degeneration
hospitalization
chiropractic
injection
sensitivity
physiotherapy
neuropathy peripheral
trigeminal neuralgia
elderly
systemic lupus
erythematosus
asthenia
insomnia

This "Quick-and-Easy" Guide was
created by New Mexico Don'tPunishPainRally™.
Written and edited by Josh Rappaport, state organizer.