Public Comments for ICR 202412-0920-006

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Comments Received:

I applaud the CDC for its objectives here. However, as a chronic pain patient with Ehlers Danlos Syndrome, several autoimmune conditions, and spinal/pain issues from a surgery gone wrong, I believe that:

- 1) Three years of a study is a very long time when people with chronic pain have already been suffering for years if not longer at this point. I was on a dosage under the 90 MME, but in 2014 I was forced to go to half of the dosage that had allowed me to live a normal life. The idea that there will be data collection & study for three years, and then likely a couple more years to change things...I believe there will be a lot of people who will become worse off or even die due to the overwhelming stress that pain puts on the body. I've lost so much of my life due to previous CDC policies and reactions from the medical community, so while I'm grateful you're trying to access the success and/or damage, the idea of wasting 3+ more years of my life while waiting around for the CDC to have answers is incredibly frustrating. Can there be a sub-survey that focuses on the chronic pain patients that has conclusions within a year? Because changes need to be made now, not half a decade from now.
- 2) Chronic pain patients need to be separate from the acute pain patients. Their needs are completely different. When surveying patients, I believe it's important to get a wide range based on the various illnesses they have, as each condition has its own challenges. Conditions where pain is the main symptom need to be given priority.
- 3) Alternate therapies such as spinal cord stimulators & injections need to be looked at not only for how effective they have been, but also to determine if physicians are being rewarded financially for pushing these therapies.
- 4) Success rates for all therapies should not be determined based on patient records. I've seen too many doctors claim a procedure a success in my medical record when I've indicated that I'm actually worse off. A doctor's idea of success is often different from a patient.
- 5) There needs to be an assessment of how the media news, documentaries, TV shows like "Dopesick" has influenced the medical community.
- 6) People who are are in hospice also need to be looked at & studied, as too many people are being refused opioids at their end of life because they are told they might become addicted. The idea that someone might become addicted when they are weeks or days away from dying is a jaw-dropping, ridiculous, and cruel reason to deny this medication.