Testimony of Cindy Steinberg
Senate HELP Committee Hearing on "Managing Pain During the Opioid Crisis"
February 12, 2019

Introduction

My name is Cindy Steinberg and I have lived with chronic pain for more than 18 years. I am also a chronic pain support group leader of 18 years, the Policy Council Chair for the Massachusetts Pain Initiative, and the National Director of Policy and Advocacy for the U.S. Pain Foundation.

Thank you for holding this critical and timely hearing on the state of pain management in the United States, and how the opioid epidemic impacts people living with chronic pain. Our country is facing two public health challenges that are often conflated as one: chronic pain and opioid use disorder.

This is the first of what I hope will be many hearings focused on improving pain management for the tens of millions of Americans who are suffering. It's a conversation that is long overdue. The opioid crisis has only underscored our failure to provide adequate, safe, accessible treatment options for pain relief.

Chronic pain is an enormous and costly public health problem

The number of Americans impacted by pain, the human suffering involved, and the cost to the health care system and society is staggering:

- 50 million Americans suffer from chronic pain, or pain that lasts most days or every day for six months or more.[1]
- 20 million Americans suffer from high-impact chronic pain, or pain that interferes with basic functioning, including work, sleep and activities of daily living, like personal hygiene and household chores. [2]
- Pain is the number one reason that Americans access the health care system.[3]
- Pain is the leading cause of long-term disability in the United States.[4]
- In 2010, pain cost the United States $560-635 billion a year in direct medical costs and lost productivity.[5]
- People with moderate pain spend an extra $5,000 a year on health care expenditures than people without pain; those with severe pain spend an extra $8,000 a year.[6]

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[1] https://www.cdc.gov/mmwr/volumes/67/wr/mm6736a2.htm
[2] https://www.cdc.gov/mmwr/volumes/67/wr/mm6736a2.htm
[3] https://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=57
[4] https://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=57
[5] https://www.jpain.org/article/S1526-5900(12)00559-7/fulltext
[6] https://www.jpain.org/article/S1526-5900(12)00559-7/fulltext

- People with chronic pain are four times more likely to experience anxiety or depression,[7] and 10% of all suicide cases involve chronic pain.[8]
- 80% of veterans returning from Operation Enduring Freedom and Iraqi Freedom live with chronic pain.[9]

Despite the impact of pain, we have failed as a country to effectively address it.

- At present, less than 2% of the NIH's budget goes to pain research.[10]
- Veterinary students spend 3-4 times as many hours studying pain management than students in medical school.[11]
- For every 8,700 people with high-impact chronic pain, there is only one board-certified pain specialist.[12]
- Patients can only expect to achieve, through their various treatments, an average reduction in pain of only 30%.[13, 14]

Chronic pain is a disease of the nervous system distinct from acute pain

I would like to make an important clarification about chronic pain before continuing any further. Acute pain serves as a normal and vital signal, alerting us that something is wrong and protecting us from further injury, such as the pain of a broken bone or abdominal pain before a ruptured appendix. But when pain continues past six months—regardless of the cause—it transitions into chronic pain. Neuroscience research now shows that chronic pain becomes a disease in and of itself, with measurable changes in the brain, spinal cord, and peripheral nervous system.

Chronic pain devastates lives

Think about the last time you experienced pain. Maybe it was because you whacked your elbow against a cabinet or burned your finger on a hot pan. Do you remember how it took your breath away and commanded your attention? You could not do anything else until the pain subsided.

All of us have experienced physical pain at some point. What is difficult to imagine is pain that never goes away. But I'd like you to envision it. Try to imagine how the pain would impact your daily life, your career, or your relationships.

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[7] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3000181/
[8] https://annals.org/aim/fullarticle/2702061/chronic-pain-among-suicide-decedents-2003-2014-findings-from-national
[9] https://www.ncbi.nlm.nih.gov/pubmed/20104399
[10] https://www.hhs.gov/about/budget/budget-in-brief/nih/index.html
[11] https://www.ncbi.nlm.nih.gov/pubmed/21945594
[12] http://www.abpm.org/faq
[13] https://www.ncbi.nlm.nih.gov/pubmed?term=21704872
[14] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3841375/

Chronic pain is relentless agony. It’s often described as being imprisoned in one’s body and tortured 24/7 with no means of escape. Unlike a serious illness such as cancer, where patients can often receive treatment and resume daily life, victims of chronic pain are often forced to cease life activities in perpetuity. They cannot work, care for their families, or engage in social activities.

This loss of function, productivity, and independence is heart-wrenching. People with chronic pain lose their sense of self. They feel worthless, helpless, and very, very alone.

We can, *and must*, improve pain care

The need to improve pain care has never been more urgent. We can and must do a better job in improving pain management by:

- Promoting individualized, integrative, multi-modal care plans.
- Breaking down coverage barriers to a full range of non-pharmacological as well as pharmacological treatments.
- Investing in vital collection and reporting of epidemiological data on pain.
- Improving public, patient, and provider education about pain management.
- Breaking down stigma that creates barriers to proper care.
- Investing in ongoing patient support and teaching of self-management skills for living with a chronic illness and pain.
- Increasing research into understanding the basic mechanisms of chronic pain in the human body and the development of novel safe and effective treatments.

My story: Learning firsthand about pain care in America

More than 18 years ago, on an otherwise typical day at my job as a manager at a technology company, a stack of unsecured filing cabinets—and the cubicle walls leaning up behind them—fell on top of me, crushing me beneath them. The accident left me with severe, unrelenting back pain that continues to this day.

No matter what therapy or medication I tried, I simply couldn’t be upright for more than a couple of hours at a time without an enormous increase in pain and muscle spasms. Even aside from my job, it was a struggle to do basic things I had previously taken for granted: bathe my young daughter, and cook dinner for her and my husband. Everything that required being upright was and is still is a challenge. After a discouraging, difficult, and, at times, demeaning five-year journey of searching for help for my pain while trying to hold on to the career I loved, I finally found a doctor who helped me.

Even with a treatment plan, the pain eventually forced me to give up my career. Out of my own sense of loss and isolation, I decided to start a support group for others living with chronic pain. I was shocked at how many people started showing up for my monthly pain group meetings—all ages, men and women, and diverse racial, ethnic and socioeconomic backgrounds.

A remarkably common experience is that everyone has had to see at least 4 or 5 health care practitioners before they could find help for their relentless pain, if they ever do, and many did not. There was no one-size-fits-all treatment; what worked well for one person might cause a bad reaction in another. The quest for help was exhausting and frustrating—each person had dealt with having their pain dismissed or downplayed by healthcare providers. It was also expensive: affording treatment could easily drain a family's resources. Living with severe pain most likely means you struggle to work—combine that with high health care costs, and you have a potentially ruinous problem.

It has been 18 years and I am still running this group today. More than 400 people with chronic pain have come to this local group. I knew I was helping these individual lives, but I had to do more. Despite my daily pain and physical limitations, I decided to dedicate all the energy I could to improving pain care in this country.

In 2009, I became Policy Council Chair for the Massachusetts Pain Initiative—an all-volunteer organization that is comprised primarily of healthcare providers who treat individuals with pain and donate their time to the organization and its mission to improve pain care in the Commonwealth. Working together with Massachusetts lawmakers and regulators, I have led our successful efforts to establish pain education and opioid prescribing continuing education requirements for physicians, create pain policies with professional licensing boards, establish a pain specialist consultation service for general practitioners, and require Massachusetts public and private insurers to cover a full range of pain management therapies.

In 2013, the U.S. Pain Foundation asked me to work on federal pain policy for the organization. U.S. Pain Foundation is a patient organization with thousands of ambassador advocates and tens of thousands of supporters nationwide that educate, support, and advocate for Americans living with chronic pain. The organization advocates for common diseases like cancer and arthritis, as well as rare or complex conditions like Ehlers-Danlos syndrome, migraine disease, and complex regional pain syndrome; or pain from trauma, like a motor vehicle accident or my own accident.

In my role with U.S. Pain, I advocate for improvements in pain care at the national level.

I am honored to have been appointed to a number of key pain policy committees at the federal and state level: the Interagency Pain Research Coordinating Committee, the highest ranking federal pain policy oversight committee chaired by the NIH; the HHS Pain Management Best Practices Interagency Task Force, established by the CARA legislation; a National Pain Strategy Expert Working Group; Massachusetts Governor Charlie Baker's Opioid Working Group; and the Massachusetts Drug Formulary Commission.

Managing pain during the opioid crisis

There has never been a more important time for policymakers to improve pain management in the United States. The focus on the opioid crisis, while absolutely necessary, has resulted in unintended consequences for chronic pain patients, who are being stigmatized for their disease and in many cases, denied medically necessary treatment. Too often, well-intentioned reforms have harmed or unfairly penalized people with legitimate pain.

Conflation of two populations

A critical misunderstanding that pervades media coverage of opioids and pain is the conflation of two largely distinct populations—those with the disease of chronic pain and those with the disease of opioid use disorder.

Demographic research on these populations has shown that chronic pain sufferers tend to be largely female and over the age of 40 and those with opioid use disorder tend to be largely male and under the age of 30. These are two largely separate groups with very little overlap.

Repeated research *within the chronic pain population* has found the risk of addiction to be small, on average less than 8%[15] and in patients with no history of abuse or addiction, studies have shown the rate of addiction to be between .19% to 3.27%.[16,17]

Speaking from personal experience and from 18 years of helping hundreds of chronic pain sufferers manage their conditions, opioid prescription medications are not the enemy, nor the savior, when it comes to chronic pain.

Opioids are one treatment modality among many pharmacological and non-pharmacological treatments for pain. They should not be a first line treatment for chronic pain and ideally should be used in conjunction other therapies. They should primarily be considered in the case of severe chronic pain, and in the case of moderate pain when other options have failed. When they are prescribed, patients should be carefully screened for risk factors for abuse, like a prior alcohol or other drug misuse or a personal or family history of substance use disorder, and counseled in safe use and storage.

Opioids do not help all pain sufferers and when they do help, they do not completely take the pain away. Nevertheless, they are an important option. For many pain sufferers who take them responsibly and legitimately, they are a lifeline that allows them to have some quality of life and lessen their relentless pain.

Treatments like physical therapy, massage, behavioral therapy, and injections may be helpful, but few insurance plans cover these options fully, if at all. For a person with severe pain who is struggling to work part-time, costs for complementary therapies that are not covered by insurance may cost hundreds of dollars a week, and this is not

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[15] https://www.nejm.org/doi/full/10.1056/NEJMra1507771

[16] https://www.ncbi.nlm.nih.gov/pubmed/18489635

[17] https://www.ncbi.nlm.nih.gov/pubmed/20091598

affordable. Furthermore, people with pain who live in rural areas or have physical limitations that impede travel may have difficulty even physically getting to appointments for non-pharmacological options, like physical therapy or injections.

For patients without risk factors for abuse and where opioids are clinically indicated, it is cruel to take away a treatment option without offering any realistic alternatives.

It is essential that treating clinicians be permitted to evaluate individual benefits and risks for each patient and that all appropriate pharmacological, interventional and complementary therapies remain available.

As a result of well-intentioned measures to contain the opioid crisis, such as restricting the supply of prescription opioids, intense regulatory scrutiny of physicians, the establishment of ceiling doses and day limits on the number of opioids that can be prescribed, legitimate chronic pain patients are being made to feel like criminals simply for seeking relief—many of whom have been on long-term stable doses of their medication for years.

We, and other pain patient groups, have heard from thousands of chronic pain patients who have been forcibly tapered off their medications or dropped from care by their doctor. It's easy to understand why, for many providers, restrictions on opioids have made it simply too burdensome to prescribe them, even when they may be beneficial. Some providers are outright leaving the specialty of pain medicine out of fear, a devastating development given there is already a dire shortage in the field: less than 1% of physicians are specialized in pain management. Even if a clinician does continue to prescribe opioids, patients feel like criminals for taking them and are constantly terrified that the slightest misstep might be misconstrued as a sign of misuse or addiction.

This has caused tremendous unnecessary suffering and anxiety, and has led many to contemplate or attempt suicide. As I mentioned earlier, recent research found that at least 10% of suicide cases in America involve chronic pain. This number may be surprising to the average person, but not to pain patients, who know the fear and helplessness all too well.

In the near term, we can and must restore balance to opioid prescribing with de-politicized, rational and clear-eyed recognition of the risks and benefits of these medications. In the long term, we must invest in the discovery of new, effective, and safer options for people living with pain.

Federal efforts to improve pain management

Fortunately, the federal government has launched several important policy planning initiatives to improve pain management. HHS has included improved pain management as one of its Five Pillars to address the opioid crisis and the FDA has released its Opioid Blueprint and Innovation Challenge to promote the development and use of approved medical technology and non-opioid medication, and the development of new medical devices and non-addictive medications.

In 2016, HHS, under the auspices of the NIH and the Interagency Pain Research Coordinating Committee, released the comprehensive National Pain Strategy. The National Pain Strategy emphasizes the need for patient-centered, integrative pain management practices based on a biopsychosocial model of care that enables providers and patients to access a full spectrum of pain treatment options including pharmacological and non-pharmacological treatments and complementary therapies.

In 2017, the Interagency Pain Research Coordinating Committee and the Office of Pain Policy at the NIH released the Federal Pain Research Strategy, a long-term strategic plan for basic biomedical research to advance our understanding of the neurobiological basis of pain.

Recent promising initiatives

I applaud Congress for initiating two of the most promising developments in advancing the science and clinical treatment of chronic pain in 2018. These are the Helping to End Addiction Long-term (HEAL) Initiative at the NIH and the establishment of the HHS Pain Management Best Practice Interagency Task Force.

The HEAL initiative will invest in research on addiction and pain. The goals of the pain research are to understand the process by which acute pain turns chronic, discover novel targets for pain treatments, advance previously discarded pharmaceutical assets for reasons other than safety, develop a pain clinical trials network, and discover biomarkers for chronic pain.

Congress established the HHS Pain Management Best Practices Interagency Task Force in the Comprehensive Addiction and Recovery Act (CARA) with the charter to identify gaps and inconsistencies in best practices for acute and chronic pain management adopted by federal agencies and propose recommendations to address those gaps and inconsistencies.

Secretary Azar appointed an exceptional group of pain management and substance use disorder experts, including my fellow witness today, Dr. Halena Gazelka, whom I am proud to serve alongside on the Task Force. The Task Force has been ably led by Dr. Vanila Singh, the Chief Medical Officer of HHS who is a well-qualified board certified pain management physician. We have worked hard over a seven-month period to review the literature, discuss and deliberate on each section of the report, consider all the input we received including that of thousands of patients and offer the best possible advice we could provide on the most current consensus on best practices in pain management.

A draft report is currently out for public comment with the final recommendations report due out at the end of May 2019. I strongly encourage Congress to formulate an action plan to implement the best practices recommendations in the report.

Pain management policy recommendations

1. Surveil the national burden of chronic pain through NIH data collection, analysis, and dissemination

Despite the enormous human and economic impact imposed by chronic pain on our nation, there is no concerted effort within the government to ascertain and make publicly available high-quality data on chronic pain. National surveillance efforts are needed to evaluate population-level interventions, evaluate the impact of changing public policies, and identify emerging trends and needs. For example, we would expect that our aging population with age-associated pain-producing conditions such as cancer, diabetes and arthritis is leading to substantial increases in the incidence and cost of pain to the nation. But without data to understand this trend, how can we effectively plan for and manage this burden, as well as contain its cost?

It is critical that Congress create and fund a National Chronic Pain Surveillance System (NCPSS) at NIH to collect epidemiological data to clarify the incidence and prevalence of various chronic pain conditions. The NCPSS would enable NIH to collect data that will: identify trends, subpopulations at risk, and the health consequences of pain in terms of morbidity, mortality, and disability; clarify the incidence and prevalence of pain syndromes differentiated by age, comorbidities, socio-economic status, race, and gender; and assess direct cost of pain treatment in terms of utilization of medical and social services and indirect costs such as missed work, public and private disability and reduced productivity. Simply put, better data equals better pain policy and better health outcomes.

2. Transform pain treatment through implementation of pain management best practices

Pain care across the United States is highly ineffective, inadequate and inefficient. Integrative, multimodal pain care based on a comprehensive assessment and an individualized care plan including a combination of non-pharmacological and pharmacological treatments developed and guided by a knowledgeable healthcare provider with input from the patient is best practice, but many barriers prevent access to such care. These barriers include inadequate insurance coverage for pain management services, lack of education and training of physicians and other healthcare providers on core competencies in pain management, time constraints that deter physicians from managing chronic illness, shortages of pain management specialists and lack of research and evidence base on treatment modalities that currently exist, especially which modalities are best for which type of pain and in what combination.

Fortunately, as I noted earlier, Congress, HHS, and the NIH have already authorized and developed two excellent public policy blueprints for improving pain care in the United States: through the National Pain Strategy and the HHS Pain Management Best Practices Interagency Task Force (PMTF). The National Pain Strategy is the nation's first interagency strategic plan to implement a system of safe, effective, evidenced-based care. HHS released the strategy in 2016, after a nearly two-year period of thoughtful development among six federal agencies, along with 80 nominated experts from the medical, scientific, patient, and advocacy communities.

Through CARA, the PMTF was charged with identifying gaps and inconsistencies in best practices for acute and chronic pain management, as well as proposing recommendations to address those gaps and inconsistencies. The subsequent report was drafted by a panel of 29 pain management and federal government health agency experts selected from an extensive and thorough search throughout the country. The PMTF report, including its recommendations, is currently out for public comment, with the final report due at the end of May, at which time Congress must develop an action plan to implement the recommendations.

3. Invest in pain research at the NIH

The federal investment in pain research has been chronically and grossly incommensurate with its human and societal burdens. Very little is known about the prevention, causes, and mechanisms of chronic pain. Substantial initiatives are urgently needed to develop pain treatments without abuse potential. Further, generating high-quality evidence that can guide clinicians and patients in making informed decisions about safe and effective pain management is imperative.

An essential response to the opioid crisis must include an increase in the federal pain research investment. The cost savings of discovering improved chronic pain therapies will far surpass the increased costs of research. Beyond relieving suffering from both chronic pain and substance use disorder, development of improved pain therapies will spur introduction of innovative products with global markets, increase workplace productivity, and reduce expenditures for federal entitlement programs such as Medicaid, Medicare, and Social Security Disability Insurance. A meager 1% reduction of the United States costs of pain would translate into approximately $6 billion in annual societal savings.

The recently begun HEAL Initiative is a start, but it is limited in scope to a few specific areas. The federal pain research budget including the HEAL Initiative pain work still only represents 2% of the NIH's annual budget for a disease that affects 50 million Americans and is the leading cause of disability. The Federal Pain Research Strategy, released in 2017 under the auspices of the IPRCC and the NIH Office of Pain Policy, is a comprehensive strategic plan developed using the same thoughtful, inclusive process of work teams comprised of the nation's brightest medical and scientific experts in the field of pain research. Congress should use this strategy as blueprint to expand and expedite our investment in pain research.

Other important policy recommendations

Although the National Pain Strategy and the HHS Pain Management Best Practices Interagency Task Force Report discuss the recommendations below, among many others, I have chosen to highlight these as priorities from a patient perspective:

- Ensure access to any medically necessary treatment so long as benefits outweigh risks for that individual patient.
- Improve public and private payer coverage for integrative care based on individualized treatment plans, so that patients and their healthcare providers can select from a full range of pain management therapies, including non-pharmacological complementary treatments, novel medical devices and innovative non-addictive pharmacological treatments.
- Provide grants for patient support group networks that educate and empower patients to self-manage chronic pain using a skill-based chronic disease model.
- Invest in large-scale efforts to improve public, patient, physician, and other healthcare provider education in pain management. This is essential to restoring empathy and compassion, eliminating damaging stigma and reducing the tremendous burden of pain and suffering among millions of Americans living with chronic pain.

Summary and Conclusion

I would like to sincerely thank the HELP Committee for holding this hearing focused on pain in America. Chronic pain is the most prevalent, costly and disabling health condition in the United States, yet it remains largely unknown, poorly treated, and misunderstood relative to other prevalent diseases such as cancer, diabetes, and heart disease. It has been called the “hidden epidemic,” and rightly so.

The opioid crisis has revealed decades of underinvestment in research aimed at understanding the mechanisms and treatment of pain, such that we have no completely effective therapies that will eliminate chronic pain and only a handful of good ones that substantially help carefully selected patients. It should come as no surprise that we have had to rely on imperfect treatments for pain relief. While these treatments may help those who use them appropriately, they have led to huge costs for others and society-at-large.

We have also turned a blind eye to the tremendous physical pain of millions of our fellow Americans. These people are your constituents, your families, your friends, and your neighbors. We can and must do better.

As you plan future legislative action, I hope Congress will consider these key points:

- Chronic pain affects 50 million Americans, including 20 million Americans who live with high-impact pain.

- The financial and societal burden of chronic pain is enormous: it costs the United States an estimated $635 billion annually in terms of lost productivity and health care costs. It is the leading cause of long-term disability.

- Chronic pain is a disease of the nervous system and brain that can and does last a lifetime. It is distinct from acute pain, which is time-limited.

- There is no one-size-fits-all approach to treatment for pain. Individualized care is essential. Patients must work closely with their healthcare providers to weigh the benefits and risks of each option.

- Chronic pain and opioid use disorder are distinct and separate diseases. Many patients use opioids legitimately and safely.

- We must restore access to care and medically necessary treatment for tens of thousands of pain patients who have been dropped from care by fearful and frustrated providers or who have been forcibly tapered off stable doses of opioids that have helped them for years and left to suffer with relentless pain. This is inhumane and morally reprehensible.

- A multimodal, multidisciplinary approach to treatment—that includes both pharmacological and nonpharmacological options—is essential to effective, long-term pain relief. Inadequate insurance coverage, high out-of-pocket costs, and limited availability are significant barriers to effective care.

- Prescribing reform was necessary to address the opioid crisis. However, we must be cautious to ensure that these reforms are thoughtful, balanced, and consider the needs people with opioid use disorder as well as the needs of people with pain.

- Investing in public, provider, patient and policymaker education about acute and especially chronic pain is fundamental to progress in the care, well-being and productivity of millions of Americans.

- Expanding research at the NIH into our fundamental understanding of the mechanisms of pain in the human body is essential to discovering safer, more effective treatments—and someday a cure—for chronic pain, and for reducing reliance on opioids.

- The National Pain Strategy and the HHS Pain Management Best Practices Task Force Report are excellent public policy blueprints for jumpstarting a national commitment to pain care improvements. These initiatives must be funded and implemented.

The American crisis of inadequate treatment of chronic pain demands Congressional attention. We have done the work to determine effective next steps; it is now the work of Congress to fund these necessary recommendations. I call on you to commit to an investment commensurate with the scale of this crisis to once and for all solve the enormous problem of pain in America.