

PAINS | project



LOST IN CHAOS:

The State of
Chronic Pain in 2016

LOST IN CHAOS: The State of Chronic Pain in 2016

Presented by the Pain Action Alliance to Implement a National Strategy (PAINS)

Introduction

German philosopher Frederick Nietzsche said, “Out of chaos comes order.” Many accept the profundity of Nietzsche’s famous comment, among them some chronic pain advocates. In June 2011, the Institute of Medicine published *Relieving Pain in America (RPA or Relieving Pain)* and established as its highest priority development of a national population health plan to be completed by the end of 2012. Pain advocates believed that such a plan would bring much needed attention to chronic pain and, in addition, bring order, direction, and resources needed to address this critical public health issue. In March 2016, the Department of Health and Human Services (HHS) published the *National Pain Strategy (NPS)*. The *NPS* advanced all the recommendations made by the IOM committee and the notion that underpinned *Relieving Pain*, i.e., a “cultural transformation in the way pain is perceived, judged and treated” is needed.¹ Furthermore, the *National Pain Strategy* provided a plan to transition from a *biomedical* pain care model, i.e., one based on prescription medications, interventional procedures and surgeries, to a comprehensive *bio-psychosocial* chronic disease management model.² Unfortunately, the report arrived amidst a firestorm around the new guideline for opioid prescribing published by the Centers for Disease Control (CDC) just days before. Throughout 2016, the attention of the media, the public, healthcare providers, and policy makers was on the opioid epidemic—NOT chronic pain—and to the extent that chronic pain received attention, it was conflated with the opioid epidemic. Consequently, to date, the *National Pain Strategy* has received little attention.

The tension between these two public health issues—chronic pain and addiction—characterizes the state of pain in 2016.

In 2016, the estimated 33,000 unintended deaths in 2015 associated with opioids reported by the CDC eclipsed concerns about under treated chronic pain and publication of the *National Pain Strategy*.³ Unfortunately,

many have pitted these two important public health issues against one another as problems competing for attention and resources, or, worse yet, they have been conflated into one concern with what the IOM committee labeled “the opioid conundrum” at the center. Beyond the opioid connection, there are multiple overlapping public health issues, including:

- Both chronic pain and opioid use disorders are diseases
- Both patient populations have been stereotyped, stigmatized and poorly served by the healthcare delivery system
- Both require more research, data collection and analysis
- Both call for a public health response
- Both advocacy groups are far more likely to achieve their articulated goals by collaborating on common concerns.

Furthermore, there are individuals who have a dual diagnosis of chronic pain and addiction, and although the size of this population overlap is not currently known, it does exist and needs to be defined and understood.

“a cultural transformation in the way pain is perceived, judged and treated” is needed.

The National Pain Strategy Report: A Different Focus

Relieving Pain in America reported that there were “at least 100 million Americans” who live with chronic pain—“more than all those who live with diabetes, heart disease and cancer combined.”⁴ From the very beginning, this number was met with broad disbelief.⁵ Although well-substantiated, the eighty-plus expert volunteers who drafted the *NPS* chose not to focus on the 100 million, but rather to acknowledge that there is a broad spectrum among those who live with chronic pain and to narrow their focus on those most affected by it. To call attention to this patient population, a new term was coined—“high-impact chronic pain”—defined as pain “associated with substantial restriction of participation in work, social, and self-care activities for six months or more.” The report explained this by saying, “This term is introduced in the *NPS* for development of research tools that will allow population level data collection on the degree to which pain interferes with people’s lives.”⁶ The *NPS* report also expanded its focus beyond that of the IOM committee to include concerns about the opioid epidemic.

“high-impact chronic pain” — defined as pain “associated with substantial restriction of participation in work, social, and self-care activities for six months or more.

Opioids Take Center Stage

In the five years following publication of *Relieving Pain in America*, the abuse of opioids came to be considered by policymakers and the public as the most pressing public health concern in America—an issue far more urgent than addressing chronic pain. The rising number of opioid related deaths, especially among white teenagers and young adults,⁷ spurred massive media attention and pressured policymakers to act. Therefore, a comprehensive, well-coordinated federal response to address the opioid epidemic, partially initiated earlier, was fully launched in 2016.

Some argue that the national initiative to address the opioid epidemic is unlike anything since the public health response to the HIV/AIDS epidemic in the late 1980s. In response to a question about the opioid epidemic during a nationally-televised debate, John Kasich, Governor of Ohio and candidate for the Republican presidential nomination, said, “And sometimes I wonder how African-Americans must have felt when drugs were awash in their community and nobody watched. Now it’s in our communities, and now all of a sudden we’ve got forums, and God bless us, but think about the struggles that other people had.”⁸

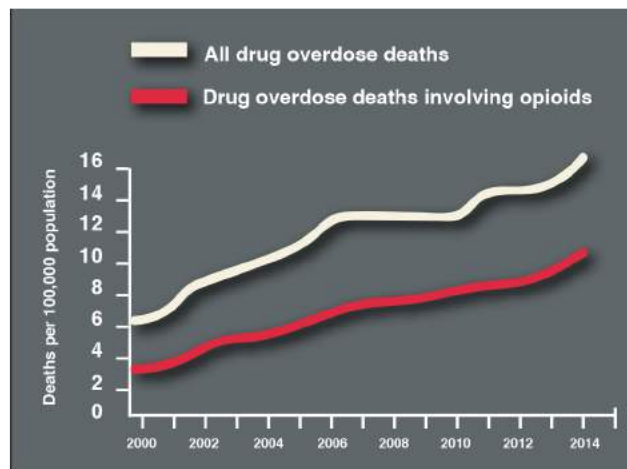


Figure 1. The CDC’s age-adjusted rate of drug overdose deaths and drug overdose deaths involving opioids – United States, 2000-2014⁹

The CDC's Actions Spark a Firestorm

In September 2015, the CDC published the *Guideline for Prescribing Opioids for Chronic Pain*. They were quickly met with widespread criticism and concern about the *Guideline* preempting publication of the *National Pain Strategy* which had been expected for months. In response to criticisms waged in December, the CDC announced that they would open a second comment period in early 2016. Unfortunately, events at the end of 2015 were a harbinger of the chaos that was to come in 2016.

Although significant criticism was expressed by professional organizations and patient advocacy groups during the second comment period, the *Guideline* was published in March virtually unchanged from the original version. Pain experts expressed a host of concerns about the CDC *Guideline* and its potential harmful impact on those living with chronic pain.

When asked about his view, Jim Cleary, Associate Professor of Medicine, University of Wisconsin School of Medicine and Public Health; Physician, Palliative Care Program, UW Health; Director, Pain and Policy Studies Group, WHO Collaborating Center for Pain Policy in Palliative Care; and Program Leader, Non-Communicable Diseases, UW Global Health Institute said, "...the appropriate management of pain, both acute and chronic, is a major issue in our society for which we need integration of multiple modalities. The *National Pain Strategy* recognizes that opioids may be an effective modality for some people for some pain conditions. Rather than addressing the multimodal management of pain, however, the CDC *Guideline* focuses on the restriction of opioid use, diminishing the importance of appropriate pain management for tens of millions of Americans."

Nursing leader Judith Paice, PhD, RN, and Director of the Cancer Pain Program at Northwestern University, Feinberg School of Medicine, expressed concerns about the makeup of the committee that drafted the CDC *Guideline*; she said, "Pain management is best conducted by an interdisciplinary team. Therefore, comprehensive and meaningful clinical practice guidelines must be developed by experts representing

the richness of multiple disciplines and specialties." Others were concerned about the sequencing of the release of the *NPS* and the CDC *Guideline*. Bob Twillman, PhD, Executive Director of the Academy of Integrative Pain Management, reported "Several federal employees involved in the *National Pain Strategy* effort have suggested that since HHS released both the CDC *Guideline* and the *NPS* in the same week, there was an unintended effect causing the *NPS* release to be overshadowed and not to be reported on extensively."

"the appropriate management of pain, both acute and chronic, is a major issue in our society for which we need integration of multiple modalities."

And still others expressed concerns that by specifically focusing on primary care providers (PCPs), the perception would be that the CDC was blaming PCPs for the opioid problem. There were also questions raised about the CDC's process, and ultimately substantive issues were raised about the lack of evidence for their recommendations. In his "President's Message" published in *Pain Medicine*, the journal of the American Academy of Pain Medicine, Daniel Carr, MD, DABPM, FFPANZCA (HON), expressed his thoughts about the process the CDC undertook and the lack of representation by chronic pain patients. He said, "In urgently confronting this (the opioid) epidemic, CDC did not use Federal advisory committee selection standards for transparency and allowed minimal opportunity for comment upon the first draft by prescribers or patients. The identities of the guideline's authors and advisors were not disclosed until public and Congressional pressure demanded doing so; the initial group included no patients or their representatives."¹⁰ Carr went on to say, "Worse, several CDC recommendations are not supported by evidence. Their implementation will lead to denial of care or substandard care for patients"¹¹

Although the majority of the twelve recommendations made by the CDC were widely supported, 2016 began with a firestorm of activity by advocates for those living with chronic pain who expressed concerns that:

- Those convened by the CDC to develop the guideline were predominantly addiction specialists
- Primary care providers and chronic pain patients were not involved in the CDC's process
- “Strong” recommendations were based on “weak evidence”
- Dosage and duration limits for opioids were prescribed
- Although labeled “voluntary,” state medical boards, third-party payers, and others would codify them

In sum, the biggest fear of advocates for those living with chronic pain was that the guideline would have an unintended impact on the ability of chronic pain patients, especially high-impact chronic pain patients, to access care they need.

No one argued that the opioid epidemic is not a serious problem, that the CDC did not have a role in addressing this problem, nor that broadly-accepted clinical guidelines for opioid prescribing were not important to improving chronic pain care. The concern of those advocating for chronic pain patients was that the CDC's efforts

conflated these two important public health issues into one problem. Furthermore, there was concern among those advocating for the publication and implementation of the *National Pain Strategy* that the CDC's efforts were primarily focused on containing the prescribing of opioids as a tactic to address the opioid abuse problem and were not part of the broader, integrated/comprehensive approach to chronic pain management advocated for in the *NPS*.

The opioid epidemic sucked all the oxygen out of the room in 2016.

Other Federal and State Responses to the Opioid Epidemic

After much debate and with little response to concerns raised by the pain advocacy community, the *CDC Guideline for Prescribing Opioids for Chronic Pain* was published on March 15, 2016. Although it drew enormous attention, the *Guideline* was not the sole response of the federal government to the opioid epidemic. In 2015 and 2016, the federal government initiated the following strategies to address opioid abuse and unintended deaths associated with it:

March 2015—Secretary Burwell's Opioid Initiative.¹² U.S. Department of Health and Human Services Secretary Sylvia M. Burwell announced this initiative to reduce prescription opioid and heroin-related overdose, dependence, and death. Three priority areas in the initiative include providing training and educational resources to assist providers in making informed prescription-writing decisions, increasing the use of naloxone, and expanding the use of Medication-Assisted Treatment (MAT).

October 2015—White House Drug Policy.¹³ The Obama Administration issued a memorandum to federal departments and agencies that defined prescriber training and improving access to treatment as two important steps in combatting the prescription drug abuse and heroin epidemic. There were also several state, local and private sector actions announced as part of this policy that included having more than 540,000 healthcare providers complete opioid prescriber training in the next two years, and reaching more than 4 million healthcare providers with awareness messaging on prescription opioid abuse, among others. Other parts of the policy include community prevention and overdose response, treatment, and enforcement and supply reduction.

December 2015—IPRCC Response to CDC.¹⁴

When presented with the proposed *CDC Guideline on Opioid Prescribing for Chronic Pain*, although members of the Interagency Pain Research Coordinating Committee (IPRCC) agreed with the CDC's goal to stem the tide of overdose deaths related to prescription opioids, several concerns were expressed. There were concerns with the lack of inclusion of people who suffer from pain, or their advocates, on the expert panel, limited opportunities for public comment on the draft of the guideline during its development, the transparency of the deliberations of the experts and the role of the federal agencies in developing the guideline, concern that prescribers and payers are likely to enforce guidelines inflexibly even if they are not mandatory, and concerns about whether the weak evidence made the determination of the strength of the recommendation overly dependent on the makeup of the panel.

March 2016—CDC Guideline for Prescribing Opioids for Chronic Pain.¹⁵

This guideline was published for primary care physicians who are prescribing opioids outside of active cancer treatment, palliative care, and end-of-life care. Three issues the guideline touches are 1) when to start or continue opioids for chronic pain, 2) opioid selection, dosage, duration, follow-up, and discontinuation, and 3) assessing risk and addressing harms of opioid use.

March 2016—FDA Drug Approval Policy.¹⁶ New policies of the FDA called for new safety labeling changes to opioid medications, both immediate release and extended release, including warnings of the potential for misuse, abuse, addiction, overdose, and death, and stated that they are committed to combatting the public health crisis of the opioid epidemic.

May 2016—FDA Advisory Committee on Extended-Release/Long-Acting (ER/LA) Opioid Analgesics Risk Evaluation and Mitigation Strategy (REMS).¹⁷

The results from the assessments of the ER/LA Opioid REMS were discussed, and the FDA sought both committee and public comments on its efforts. Comments

were made on whether the REMS with Elements to Assure Safe Use (ETASU) actually assures safe use, properly maintains a patient's ability to access their needed drugs, and whether it minimizes the burden to the healthcare delivery system.

July 2016—Comprehensive Addiction Recovery Act (CARA).¹⁸

Some of the provisions provided in this legislation are to expand the availability of naloxone, expand resources to advance treatment of incarcerated individuals with addiction disorders, increase the amount of disposal sites for unwanted and unused prescription medications, strengthen prescription drug monitoring programs, expand educational and prevention efforts, and to begin an evidence-based opioid and heroin treatment and intervention program. It is the first large federal legislation on addiction in 40 years, and its programs (including those previously mentioned and more) are rooted in all the areas needed to create an effective response to the epidemic—prevention, treatment, recovery, law enforcement, criminal justice reform, and overdose reversal.

August 2016—“Turn the Tide Rx.” In his campaign, Surgeon General Vivek Murthy is calling on his colleagues to sign the pledge to counter the opioid crisis in the United States.¹⁹ The national movement is calling for physicians to educate themselves on how to treat pain safely and effectively, screen patients for opioid use disorder and provide/lead them to evidence-based treatments, and to treat the issue as a chronic illness rather than a moral failing.

October 2016—DEA's announcement to reduce opioid allocation.²⁰

In an effort to decrease the implications of the opioid epidemic, the DEA has reduced the total amount of nearly all Schedule II opiate and opioid medication that can be produced in 2017 by 25 percent or more. Manufacturing of hydrocodone will specifically be reduced by 66 percent. The DEA says that reductions are based upon a decreased total demand on the medications as indicated by prescriptions written by DEA-registered practitioners.

December 14, 2016—21st Century Cures Act.²¹ The 21st Century Cures Act is bipartisan legislation which states that its purpose is “To accelerate the discovery, development, and delivery of 21st century cures, and for other purposes.” Among many other purposes that were funded by this act, \$1 billion over a period of two years was provided for opioid treatment and prevention programs and will potentially expand treatment options. In total, \$4.8 billion was awarded to the National Institutes of Health.

Many advocates for comprehensive chronic pain care feared that the imbalance in the federal government’s attention to chronic pain and to opioid addiction would minimize the significance of the chronic pain issue and its impact on our society. They also feared that efforts to contain the opioid epidemic would unintentionally make the lives of those who live with chronic pain even harder than they had been described in the IOM report, *Relieving Pain in America*, five years earlier.

In addition to all the activity at the federal level, there was a flurry of parallel activity among the states. Amy Goldstein, Executive Director of the State Pain Policy Advocacy Network (SPPAN), a program of the Academy of Integrative Pain Management (AIPM), said, “In the past few years, there has been an unprecedented growth in the number of proposed policies at the state level that affect pain management. This is in large part due to policymakers who have been scrambling to address challenges related to opioid misuse, abuse, and diversion as well as chronic pain.” Bob Twillman, Executive Director of AIPM, said, “We expect to see many more state policies proposed in 2017, as we look at what happened in 2016 on the federal level—the passage of CARA and the release of the *NPS* and *CDC Guideline for Prescribing Opioids for Chronic Pain*.” In 2016, SPPAN tracked more than 1,600 proposed bills and 1,000 regulations.

Reactions from the Medical Community

Reactions from the medical community to this policy frenzy were mixed. The American Medical Association (AMA) which had established a Task Force to Reduce Opioid Abuse in 2014, weighed in early on the CDC Guideline and expressed concerns about it. Specifically, they expressed concerns about recommendations for specific dosage and duration limits based on low- to very low-quality evidence. In the summer of 2016, under pressure from their state chapters concerned about the opioid epidemic, their board issued a lengthy statement making several recommendations intended to address the growing opioid problem. However, it concluded by affirming the AMA’s commitment to improving chronic pain care. It said:

1. Our AMA will advocate for an increased focus on comprehensive, multidisciplinary pain management approaches that include the ability to assess co-occurring mental health or substance use conditions, are physician led, and recognize the interdependency of treatment methods in addressing chronic pain.

2. Our AMA supports health insurance coverage that gives patients access to the full range of evidence-based chronic pain management modalities, and that coverage for these services be equivalent to coverage provided for medical or surgical benefits.

3. Our AMA supports efforts to expand the capacity of practitioners and programs capable of providing physician-led interdisciplinary pain management services, which have the ability to address the physical, psychological, and medical aspects of the patient’s condition and presentation and involve patients and their caregivers in the decision-making process.²²

“Most people don’t understand how chronic pain impacts your life. People think you’re just whining, that you’re not in that much pain. It’s hard to understand unless you’ve experienced it ... Chronic pain never goes away. It’s a constant companion in your life, so you have no choice but to persevere.”

— Mike Hockley, living with pain

100 million Americans live with chronic pain, and many live meaningful lives built on strength, hope, and courage. Visit painsproject.org to learn more.



In North Carolina, the State Medical Board (NCMB) published a letter written by Dr. Pascal O. Udekwu to all those licensed by the board reminding them that the *CDC Guideline* is voluntary and that “[the] NCMB has no desire to see chronic and acute pain go untreated or undertreated for fear of regulatory intervention. The Board wants pain to be effectively treated, including treatment with opioids, in a responsible manner. That is NCMB’s ultimate goal.” In concluding his letter, Dr. Udekwu stated that “The best advice I can give licensees is to keep the focus on providing safe and appropriate care. This will serve you and your patients, well.” Good advice, but there is increasing concern about the stress being placed on the therapeutic relationship between physicians, in particular primary care providers, and chronic pain patients.²³ In 2016, the American Academy of Family Physicians (AAFP) Foundation funded PAINS and Dr. Joseph LeMaster, Assistant Professor and Clinical Physician Researcher in the Department of Family Medicine at Kansas University, to explore these relationships in ten primary care practices across the U.S. Although full data

collection is not yet complete, Dr. LeMaster offered his impressions of the primary care doctors they have interviewed. He said, “Despite their struggle to meet the wide variety of needs for their patients and a clear message that they have mostly had to ‘figure out’ how to manage these needs after formal medical school/residency training, most docs have worked out an approach to managing chronic pain with which they are most of the time comfortable. There are patients for which their approach doesn’t work well, and for those patients they do their best, sometimes uncertainly with variable results.... Docs (we have interviewed) are highly committed to caring for these patients, no matter at what cost to themselves, or how difficult they may find it at times.”

Challenging Stereotypes

The *CDC Guideline* and a multitude of scholarly articles and pieces in trade and popular publications fueled the perception that primary care providers and chronic pain patients have been major agents in creating the opioid epidemic. This public health issue also began to be highlighted in television dramas, radio talk shows, and even late-night comedians/satirists regularly conflated the opioid epidemic with chronic pain. In late October 2016, John Oliver, host of an HBO late-night program, did a 20-minute monologue on the opioid crisis. His primary target was pharmaceutical manufacturers, but he also implied that doctors were complicit as well by “how freely they prescribe them...” *Last Week Tonight with John Oliver* was a rare opportunity when CDC data and a film clip of the Surgeon General were included in a late-night monologue.

In 2016, adults and children who live with high-impact chronic pain caused by injuries, cancer treatment, sickle cell disease and other genetic diseases, car accidents, failed back surgeries and a myriad of other problems continued to be portrayed as drug seekers, whiners, and weak of body and mind. U.S. military veterans returning from recent conflicts are inordinately represented in the chronic pain population. As Dr. Lynn Webster, vice president of Scientific Affairs of PRA Health Sciences and past president of the American Academy of Pain Medicine, cites on his website, “...a June 2014 report in *JAMA Internal Medicine* showed an alarmingly high rate of chronic pain—44 percent—among members of the U.S. military after combat deployment, compared to 26 percent in the general public.” In fact, nearly half of patients within VA healthcare centers have chronic pain, pain is one of the most prevalent symptoms of returning military members, and previous research has found that past military service could contribute to pain “hypersensitivity”.²⁴

Long-recognized stereotypes were reinforced in 2016, the challenges of people living with chronic pain increased, and relationships between chronic pain patients and their primary care providers (PCP) were increasingly stressed. Many PCPs made the decision simply NOT to prescribe opioids under any circumstances.²⁵ Chronic pain patients who had

been well-managed with medication therapy found themselves looking for physicians and/or pharmacists willing to prescribe medications they had sometimes relied on for years to function maximally. The quality of pain care that the IOM report and the *National Pain Strategy Report* were intended to improve declined precipitously.²⁶ The anxiety and desperation of chronic pain sufferers also continued to be a devastating issue.²⁷

At the end of 2016, the National Fibromyalgia & Chronic Pain Association (NFMCPA) circulated a survey to their constituents. Within 24 hours, they received nearly 4,500 responses. Ultimately, more than 5,000 people responded, and NFMCPA received more than 6,000 comments revealing a patient population filled with anxiety about their current situation. The following responses to the NFMCPA survey are particularly illuminating; when asked:

Would you say that people understand that chronic pain diminishes your quality of life?

85.7% responded NO

Would you say that you have fear of not being able to find healthcare to help you control your pain?

77.7% said YES

Do you feel that people believe you about your pain?

71% said NO²⁸

“The courage and conviction of those who live with chronic pain places on our society a duty to care for them. As the IOM report stated, there is a ‘moral imperative’ to do so.”

**— Dr. Rosemary Flanigan, CSJ,
philosopher and healthcare ethicist**

A Moral Imperative to Address Chronic Pain

First among the IOM committee’s “Underlying Principles” was the statement that “effective pain management is a moral imperative, a professional responsibility and the duty of people in the healing professions.” This notion was carried forward and was foundational to development of the *National Pain Strategy*, but the reality is that the current situation makes it very difficult for caring physicians to provide the comprehensive care their chronic pain patients need and deserve. Behavioral health and complementary services often essential to chronic pain management are too frequently unavailable, and when they are, they are seldom covered by most healthcare insurance plans. Martha Brown Menard, PhD, LMT, Executive Director of the Crocker Institute, a not-for-profit dedicated to promoting evidence-informed healthcare, said, “It is astonishing that despite a significant body of evidence documenting the effectiveness of complementary therapies by licensed practitioners, it continues to be very difficult for people living with chronic pain to access these relatively low-cost and low-risk interventions. Organizations including the Joint Commission and the American Cancer Society have recommended therapies such as acupuncture and massage for many years now. Yet when patients find and use these therapies successfully on their own, health insurance rarely reimburses them.

Considering the potential cost savings, improved functional outcomes, and reduction of the risks associated with opioid use, it’s difficult to understand why so many healthcare organizations and third-party payers have failed to integrate these therapies more widely.”

Furthermore, healthcare professionals who are committed to the Hippocratic axiom, “Primum non nocere” or “First, do no harm” but have little pain care education in their professional training are increasingly uncertain about what the “right thing” to do for their chronic pain patients is and concerned about their personal risks associated with prescribing opioids.²⁹

So, the question for the coming year is, how does the current situation change? Perhaps, more importantly, is it possible for the *National Pain Strategy Report* to fulfill its promise and potential? Both inside and outside the federal government, prominent individuals and groups continue to believe that the *National Pain Strategy* can and will transform chronic pain care in the U.S., and in spite of the challenges of 2016, continue to work hard for those who struggle to live with chronic pain. Thomas Novotny, MD, MPH, Deputy Assistant Secretary for Health (Science and Medicine), enthusiastically accepted responsibility for implementation of the

NPS Report, and although no funding has yet been appropriated for this work, Dr. Novotny has assembled a dedicated team committed to moving forward strategies outlined in the report. Others in federal agencies are also involved and dedicated to this effort. Kathy Greenlee, JD, former Assistant Secretary for Aging at HHS, committed staff to Dr. Novotny’s team. She said, “Our office committed staff and resources to the *NPS* Implementation Strategy Committee because of the critical nature of this public health issue, especially to seniors and people living with a disability.”

Although, in no way do they equal efforts to address the opioid epidemic, efforts at the federal level were not limited to publishing the *National Pain Strategy Report* in 2016. The NIH Interagency Pain Research Coordinating Committee established a Federal Pain Research Strategy (FPRS) Planning Committee, which includes the NIH/NINDS Office of Pain Policy, members of the NIH pain consortium and members of the IPRCC, and has assembled a diverse and balanced group of scientific experts, patient advocates, and federal representatives who are working to identify and prioritize research recommendations as a basis for a long-term strategic plan to coordinate and advance the federal research agenda. The key areas listed below will provide a framework for development of the strategy upon which important cross-cutting elements will be addressed.

- prevention of acute and chronic pain
- acute pain and acute pain management
- the transition from acute to chronic pain
- chronic pain and chronic pain management
- disparities in pain and pain care

In addition, professional societies, patient advocacy groups and policy organizations continue to use their influence to support these efforts and to promote implementation of the *National Pain Strategy Report*. The efforts of the Consumer Pain Advocacy Task Force (CPATF), a coalition of 16 consumer organizations working to improve the health, well-being, and treatment of those living with life-altering chronic pain. The CPATF organizations have been working collectively since 2014 and in 2016 united around one goal, i.e., to work collaboratively to promote, support and monitor the implementation of the *National Pain Strategy*.

Christin Veasley, Founder of the Chronic Pain Research Alliance and one of CPATF’s co-facilitators, said when asked why the task force had decided to focus entirely on implementation of the *NPS Report*, “A sustained advocacy effort over many years will be needed to ensure that the objectives and deliverables of the *National Pain Strategy* are widely implemented. This task cannot be accomplished by one or even a handful of organizations. There is power in numbers. A collaborative effort among organizations representing patients and consumers, healthcare providers and scientists will have the greatest chance of success, which is why the CPATF decided to focus its advocacy efforts on the *NPS*.”

In early 2016, PAINS (Pain Action Alliance to Implement a National Strategy), producer of this report, made a decision to focus its attention on one aspect of the *NPS*, i.e., to change the public narrative about chronic pain and those who live with it. The key audience of PAINS’ No Longer Silent initiative is the media. The goals of this initiative are to:

- 1) build and mobilize a public narrative regarding chronic pain
- 2) showcase chronic pain patients and the life-altering effects this disease has on their lives
- 3) highlight the strength, courage, and success of those who manage to live a meaningful life despite debilitating pain by delivering a message of hopefulness
- 4) advocate for comprehensive pain management, including the appropriate use and management of opioids to treat chronic pain.

PAINS is confident that, if these goals are accomplished, comprehensive chronic pain treatment will improve the lives of millions of Americans, save billions of dollars, and reduce opioid use disorders.

“With chronic pain, the intensity can change so much from day to day, sometimes you just have to put one foot in front of the other.... Ultimately, we’re just normal people living with a disease. We struggle, we laugh, we hope for a better tomorrow.”

— Angel Perry, living with pain

100 million Americans live with chronic pain, and many live meaningful lives built on strength, hope, and courage. Visit painsproject.org to learn more.

Imagining 2017 – 2022

In the next five years, the federal government must provide leadership to transform the vision first articulated in the IOM report and then reiterated in the *National Pain Strategy Report*, i.e., “people experiencing pain would have timely access to patient-centered care that meets their biopsychosocial needs and takes into account individual preferences, risks, and social contexts, including dependence and addiction” into reality.³⁰ To transition from vision to reality will require significant effort by many organizations and leaders across the U.S. It will require a paradigm shift in the way chronic pain, those who struggle to live with it, and those who care for them are thought about by the American public. Essential to this transformation is clarifying the relationship between chronic pain and opioid addiction and addressing both issues with a public health approach. Balance between these two issues is essential, and appropriately funding comprehensive chronic pain management must be understood as part of the campaign to curtail the opioid epidemic.

Some of those things essential to restoring balance between chronic pain and opioid addiction include:

- establishing relationships between leaders in both advocacy communities, identifying common ground, and working together collaboratively
- educating media and the public about both chronic pain and opioid addiction as diseases
- clarifying the relationship between these two public health issues and the role opioids plays in both
- increasing philanthropy and public investment for prevention, education, care, and research in both chronic pain and addiction
- engaging third-party payers (both public and private) in developing sustainable comprehensive chronic pain care programs
- expanding consumer involvement in policy development
- educating healthcare professionals about both issues and how best to address them
- providing access to evidence-based self-management programs

Some of the things that need to be done can only be accomplished by federal agencies, but many can be accomplished outside the federal government—at the state level and by non-governmental organizations. Public/private partnerships and community-based efforts as called for in the IOM report are essential to change of this magnitude.

It is time for all stakeholders to walk away from the challenges of 2016 and recommit to the notion that as a society, we have a moral imperative to address both these issues and the capacity to do so.

Authors of this report wish to make a strategic recommendation for all those involved to call on the new administration to hold a White House Summit in 2018 to address the need to fully implement the *National Pain Strategy*. Preliminary objectives of such a meeting could potentially be to:

- restore balance between efforts to address chronic pain and opioid addiction
- advocate for access to comprehensive care for all those who live with chronic pain and/or opioid addiction
- make naloxone available to all those at risk of opioid overdose
- support development of pilot programs that are sustainable
- encourage reimbursement for comprehensive models
- fund research for safer medications and to clearly define the relationship between chronic pain management and opioid addiction
- promote collaboration among advocates working on behalf of both patient populations

Evidence emerged in 2016 that there is willingness to begin working together among some prominent pain and addiction advocates. One of those is Yngvild Olsen, MD, MPH, FASAM, Medical Director of the Institutes for Behavior Resources Inc/REACH Health Services in Baltimore City, who has written and lectured extensively on opioid use disorders and treatment. Dr. Olsen stated, “There is a great deal in common with the policy agenda for preventing and improving treatment for opioid

addiction and those advocating for comprehensive care for people living with chronic pain. In addition, although we don’t know the size of the overlap between these two populations, we know one exists. It is time for us to work together.”

This report began with a quote by Frederick Nietzsche and concludes with another, “That which does not kill you makes you stronger.” Those who live with chronic pain and those who have had the privilege of interacting with this patient population on a regular basis know the truth of both of Nietzsche’s statements, as do surely those who struggle with substance use disorders, in particular opioid addiction, and those who advocate on their behalf. Both patient populations are underserved by our current healthcare delivery system, and often, affordable treatment and access to integrative therapies are simply not an option.

The focus of this report, however, is on those who live with chronic pain, many of whom feel they have been scapegoated by the opioid epidemic and believe that their lives have been made even more difficult by the conflation of these two important public health issues. Reality suggests that chronic pain patients deserve attention and respect. Against amazing odds, they prevail through strength of character, tenacity, and courage.

Maybe Nietzsche was right.



Living with Pain: Jonathan Bell

Jonathan is one among many in his family who was born with HbS beta thalassemia, a rare form of sickle cell disease (SCD). He is in his mid-to-late forties and is very close to his family which owns and operates a home remodeling business. Currently, there are four generations in the Bell family living with SCD, and Jonathan appears to be the patriarch of his clan. He is a tall, thin, handsome young man who is readily memorable for his boyish smile, the mischief in his big brown eyes—and for his commitment to helping others. He limps; most often he wears an orthopedic boot on his right foot, and sometimes he needs to walk with a cane. The cold weather exacerbates his pain, and his limp is worse in the winter months. He describes the pain in his joints like a “giant toothache” in whichever joint or joints are affected by platelets taking their revenge.

He drives one of those BIG trucks like guys in construction often drive. He likes his work. When asked why he does work that is physically taxing, he replied, “That’s what my family does, and it’s really rewarding to help someone repair their home or to help someone turn a house into a home.”

Jonathan has natural leadership skills and is an integral member of PAINS’ Citizen/Leader Group that has provided advice and counsel to PAINS for the past three and a half years. He attended the charter meeting and attends every monthly meeting if he can get there. When the mission for PAINS was announced, i.e., to “transform the way pain is perceived, judged and treated” the night the Citizen/Leader Group met for the first time, he said, “I’ll do whatever I can do. If you need officers, sign me up.” Ever since then, the group facilitators have called him “Pres.” Although no officers have ever been established, Jonathan is clearly recognized as a leader within this group.

He has used his leadership skills to organize and sustain sickle cell associations in both Kansas and Missouri because his hometown, Kansas City, is divided by a state line. He is charming and persistent and uses his abilities skillfully, e.g., he convinced former Kansas City Royals third-baseman and Hall of Famer, Frank White, to help raise money for sickle cell research by associating himself with a community walk. He also convinced John Bluford, then President and CEO of Truman Medical Center, a public hospital that sometimes struggles to fund basic programs, to give special attention to sickle cell patients. Jonathan has spoken at national meetings, served as guest faculty in medical schools and at professional conferences, and is currently involved with a Patient Centered Outcomes Research Institute (PCORI) grant.

“Most people with chronic pain want to live normal lives, to be productive citizens. But you have good days and bad days, and the stigma of opioid abuse causes many of us to withdraw ... We need to let people know that chronic pain is real; it's a disease. And by being open and talking about, we can make things better for millions of people living with it.”

In late October, Jonathan attended a conference focused on patient engagement for PCORI awardees that was held in Chicago with staff from PAINS. Anyone who has flown into the Chicago O'Hare Airport knows what a challenge it is to manage—even for the most able-bodied. Although the fall had been mild, it was bitterly cold that weekend; the Cubs were in the World Series, and the entire city was packed. Transportation was difficult to access, and the hotel where the meeting was being held was huge and not in any way convenient for a person for whom it is difficult to walk. To get from guest rooms to a restaurant or the ballroom where the conference was being held required a walk of at least a quarter mile; those who planned the conference scheduled a standing reception and built in several “interactive” exercises which required attendees to be on their feet and to move about a very crowded room the first day of the conference.

The second morning Jonathan was late; Myra Christopher, Director of PAINS who was with him, said she was worried and decided to wait outside the ballroom until he came. As she could hear the meeting beginning, she saw Jonathan enter the hallway to the ballroom. It was at least two football fields long. She said that as she watched him slowly walk toward her, it was obvious that he was in a lot of pain and that watching him, she physically ached for him. When he reached her, all he said was, “Sorry I'm late.”

At a Citizen/Leaders' meeting a few weeks later, she asked Jonathan if she could share with other members of the group how proud she was to be with him and how challenging she knew it had been for him and often is for all of them to be involved in various PAINS' events. After she told their shared story, Jonathan said, “I didn't want to tell you this then because I knew you would feel bad, but when I woke up that morning I couldn't walk. I had to crawl to the bathroom where my pain pills were and then lie on the floor until the pain eased up and I could get dressed. That's why I was late.” It's hard to imagine how Jonathan does all that he does and yet maintains the positive spirit that energizes all those who encounter him.

References

- 1) The Interagency Pain Research Coordinating Committee. "National Pain Strategy: A Comprehensive Population Health-Level Strategy for Pain." (2016). p. 8
- 2) Ibid., 3.
- 3) "Injury Prevention & Control: Opioid Overdose." Centers for Disease Control and Prevention. CDC.
- 4) Institute of Medicine of the National Academies. *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. Washington, D.C.: The National Academies Press, 2011: 19. Print.
- 5) Pizzo, Philip A., M.D., and Noreen M. Clark, Ph.D. "Alleviating Suffering 101—Pain Relief in the United States." *The New England Journal of Medicine* 366.3 (2012): 197–199.
- 6) "National Pain Strategy." (2016): p. 9.
- 7) Wilkerson, Richard Gentry, MD, et al. "The Opioid Epidemic in the United States." *Emergency Medicine Clinics of North America* 34.2 (2016): 1–23.
- 8) Keith, Tamara. GOP Candidates Address Forum On Addiction in New Hampshire. National Public Radio. 6 Jan. 2016. Radio. Transcript.
- 9) CDC (2016). "Increases in Drug and Opioid Overdose Deaths—United States, 2000–2014." *Morbidity and Mortality Weekly Report (MMWR)*. Centers for Disease Control and Prevention. 64: 1378-1382
- 10) Carr, Daniel B., MD, DABPM, FFPANZCA (HON). "President's Message: NPS Versus CDC: Scylla, Charybdis, and the 'Number Needed to [Under-] Treat'." *Pain Medicine* 17.6 (2016): 999–1000.
- 11) Ibid.
- 12) "HHS takes strong steps to address opioid-drug related overdose, death and dependence." U.S. Department of Health & Human Services. 26 Mar. 2015. <<https://www.hhs.gov/about/news/2015/03/26/hhs-takes-strong-steps-to-address-opioid-drug-related-overdose-death-and-dependence.html>>.
- 13) "FACT SHEET: Obama Administration Announces Public and Private Sector Efforts to Address Prescription Drug Abuse and Heroin Use." The White House. Office of the Press Secretary. 21 Oct. 2015. <<https://www.whitehouse.gov/the-press-office/2015/10/21/fact-sheet-obama-administration-announces-public-and-private-sector>>.
- 14) "12-3-15 Meeting Minutes." National Institutes of Health: The Interagency Pain Research Coordinating Committee. U.S. Department of Health & Human Services. <https://iprcc.nih.gov/meetings/12-3-15_Meeting_Minutes.htm>.
- 15) "CDC Guideline for Prescribing Opioids for Chronic Pain—United States, 2016." *Morbidity and Mortality Weekly Report (MMWR)* (2016): 1–49. <<https://www.cdc.gov/mmwr/volumes/65/rr/rr6501e1.htm>>.
- 16) "FDA announces enhanced warnings for immediate-release opioid pain medications related to risks of misuse, abuse, addiction, overdose and death." U.S. Food & Drug Administration, 22 Mar. 2016. <<http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm491739.htm>>.
- 17) "May 3-4, 2016: Joint Meeting of the Drug Safety and Risk Management Advisory Committee and the Anesthetic and Analgesic Drug Products Advisory Committee Meeting Announcement." U.S. Food & Drug Administration. U.S. Department of Health & Human Services. <<http://www.fda.gov/AdvisoryCommittees/Calendar/ucm490628.htm>>.
- 18) S. S.524, 114th Cong., 695 (2016) (enacted). <<https://www.congress.gov/bill/114th-congress/senate-bill/524/text>>.
- 19) "Surgeon General's Call to End the Opioid Crisis." TurnTheTideRX. 24 Aug. 2016. <<http://turnthetiderx.org/>>.
- 20) "DEA Reduces Amount of Opioid Controlled Substances to be Manufactured in 2017." United States Drug Enforcement Administration. 4 Oct. 2016. <<https://www.dea.gov/divisions/hq/2016/hq100416.shtml>>.
- 21) 21st Century Cures Act, S. H.R.6, 114th Cong., 1-362 (2015-2016). <<https://www.congress.gov/bill/114th-congress/house-bill/6/text>>.
- 22) "Resolution 117 - Multidisciplinary Pain Management Center Reimbursement." Report of Reference Committee A. Proc. of American Medical Association House of Delegates Annual Meeting 2016. (2016): 27–29. <<http://www.mag.org/sites/default/files/downloads/a16-refcomm-a-annotated.pdf>>.
- 23) Udekwu, Pascal O., M.D. "Coming to terms with opioid prescribing: Safe treatment is the goal." *North Carolina Medical Board Forum*. (2016): 1–2.
- 24) Cosio, David. "Practice-based evidence for outpatient, acceptance & commitment therapy for veterans with chronic, non-cancer pain." *Journal of Contextual Behavioral Science*. 5.1 (2016): 23-32.
- 25) Hoffman, Jan. "Patients in Pain, and a Doctor Who Must Limit Drugs." *The New York Times*. 16 Mar. 2016.
- 26) National Center for Complementary and Integrative Health. "NIH Analysis Shows Americans Are In Pain." National Institutes of Health (2015).
- 27) Hooten, W.M. "Chronic Pain and Mental Health Disorders: Shared Neural Mechanisms, Epidemiology, and Treatment." *Mayo Clinic Proceedings*, Vol. 91, No. 7. (2016): 955–970.
- 28) Data provided by Jan Chambers, President of the National Fibromyalgia & Chronic Pain Association.
- 29) Alford, Daniel P. "Opioid Prescribing for Chronic Pain—Achieving the Right Balance through Education." *The New England Journal of Medicine*, vol. 374, no. 4, (2016): 301–303.
- 30) "National Pain Strategy". (2016). p.5

This copy is made available to you by:



USPAINFOUNDATION.ORG

TOLL-FREE NUMBER
(1-800-9102462)

Contributors:

Myra Christopher

Kathleen M. Foley Chair in Pain and Palliative Care
Center for Practical Bioethics

Cindy Leyland

Project Director
Center for Practical Bioethics

Richard Payne

John B. Francis Chair
Center for Practical Bioethics

Clint Cole

Research Intern
Center for Practical Bioethics

Tracie Mattivi Thomas

Director of Strategic Communications
PAINS

For an annotated bibliography and sample of additional articles focused around pain in 2016, go to painsproject.org.