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Executive Summary

LOST IN CHAOS:

The State of
Chronic Pain in 2016

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

Millions of Americans living with chronic pain struggle because two important public health issues— chronic pain and opioid addiction—are misunderstood and have been conflated. Until these two health conditions are properly distinguished, studied and addressed, the problems associated with both will continue. Tension and misunderstanding surrounding chronic pain and opioid addiction characterize the state of pain in 2016.

How we got here

Weighing in on the matter with differing claims, perspectives and recommendations, a virtual alphabet soup of governmental, professional and pain advocacy groups has created a Tower of Babel. Voices include those of the National Academies' Institute of Medicine (IOM), Department of Health and Human Services (HHS), Centers for Disease Control (CDC), American Medical Association (AMA), Federal Drug Administration (FDA), Drug Enforcement Agency (DEA), American Academy of Family Physicians (AAFP), American Academy of Pain Medicine (AAPM), Academy of Integrative Pain Management (AIPM) and the National Fibromyalgia & Chronic Pain Association (NFMCPA) among others. The lack of coordination among these groups and the paucity of funding has resulted in a state of confusion and chaos.

In 2011, the IOM report, *Relieving Pain in America*, recommended developing a national pain strategy by the end of 2012—one that would address and resolve the many interrelated aspects of the pain problem. Pain advocates believed a national plan would bring much-needed attention to the problem of chronic pain. In addition, advocates thought it would bring order, direction and resources needed to address this public health issue in a rational, effective way.

In March 2016, HHS published its long-awaited *National Pain Strategy* promoting and amplifying the IOM's perspectives and advancing the notion that a "cultural transformation in the way pain is perceived, judged and treated" is needed. HHS's strategy includes shifting

from the traditional biomedical pain care model, i.e., one relying upon prescription medications, interventional procedures and surgeries, to a comprehensive biopsychosocial chronic disease management model. A model that:

- takes into account the wide variety of reasons why people experience chronic pain
- includes biomedical approaches, behavioral health and consideration of the social aspects of pain
- assures that people with chronic pain have timely access to appropriate, safe pain management including opioid therapy when appropriate
- includes noninterventional and complementary treatment approaches

Unfortunately, just days before the *National Pain Strategy* was published, a firestorm arose around the *Guideline for Prescribing Opioids for Chronic Pain* developed and promulgated by the CDC. The *Guideline* focused on reducing opioid prescribing rather than improving chronic pain care. Although framed as voluntary, state legislators, medical boards and others quickly moved to codify this powerful agency's recommendations restricting the use of opioids for chronic pain and limiting dosage and duration of opioid prescriptions. Unfortunately, to many the *Guideline* was perceived as blaming primary care providers (PCPs) for the opioid epidemic. The pain advocacy community expressed serious concerns about the *Guideline's* impact, especially its low evidence base.

Throughout 2016, the attention of the media, the public, healthcare providers and policymakers was on the opioid epidemic, not chronic pain. To the extent that chronic pain received any attention, it was confused and conflated with the opioid epidemic, further stigmatizing those who live with chronic pain. In the five years following publication of *Relieving Pain in America*, the abuse of opioids has come to be considered by both policymakers and the public as one of the most pressing public health concerns in America—more urgent than addressing chronic pain. Consequently, HHS's balanced and thoughtful *National Pain Strategy* has received little attention and virtually no funding.

The Pain Action Alliance to Implement a National Strategy (PAINS), the author of this report, recognizes the importance of addressing the opioid epidemic and is attempting to build collaborations with addiction advocacy groups. PAINS' reason for being, however, is to promote comprehensive chronic pain treatment. We strongly believe that comprehensive chronic pain treatment will improve the lives of millions of Americans, save billions of dollars and reduce opioid misuse. Comprehensive chronic pain treatment warrants equal attention.

Who's getting hurt

The CDC's *Guideline* has adversely impacted the ability of people living with chronic pain, especially those living with "high-impact" chronic pain (pain that is unrelenting and disabling), to access needed care. Following its publication, some PCPs, fearing action by their state medical board or the DEA, prosecution, or worse, the death of a patient, decided simply NOT to prescribe opioids under any circumstances. People living with chronic pain who had been well-managed with medication therapy found themselves having to look for new physicians to address their needs, including prescribing opioids when necessary. Many of these individuals had relied on opioids for years to function maximally and maintain their quality of life. Ironically, care for those living with chronic pain, which the reports by the IOM and HHS were intended to improve, declined precipitously in 2016, and anxiety and desperation among those living with this disease escalated dramatically.

Underlying issues

Unfortunately, and without justification, many in Congress, the media and elsewhere have pitted these two important public health issues—chronic pain care and opioid addiction—against one another as problems competing for attention and resources. As a result, public health issues, important to both patient populations, are currently being neglected. Some of those issues include:

- understanding chronic pain and opioid addiction as diseases
- stereotyping, stigmatizing and underserving both populations
- underfunding research, data collection and analysis for both
- continuing a law enforcement based policy approach to opioid addiction in lieu of a public health response

Adding to the complexity of this conundrum is the reality that some individuals have dual diagnoses—they live with both chronic pain and addiction. Though the size of this population overlap is not currently known, it does exist and needs to be defined and understood.

PAINS believes that both advocacy groups are more likely to achieve their stated goals by collaborating on these common concerns.

What's needed

In the next five years, if not sooner, the federal government must provide leadership and resources to transform the balanced vision first articulated by *Relieving Pain in America* and reiterated in the *National Pain Strategy* into reality. In this shared vision, “People experiencing pain would have timely access to patient-centered care that meets their biopsychosocial needs and that considers individual preferences, risks, and social contexts, including dependence and addiction.” (NPS)

Bringing this change into reality will require significant collaborative effort by organizations and leaders across the U.S. concerned about both public health issues. A paradigm shift in the way chronic pain, those who live with it, and those who care for them, are perceived by the American public will be required. Clarifying the relationship

between chronic pain and opioid addiction and addressing these two related, but separate, issues with a public health approach rather than a medical treatment or law enforcement mindset will be essential to change. Both issues are important, and each deserves a systematic, research-based response. Balance between these two issues is essential if chronic pain management is to be appropriately funded and understood as part of, but distinguished from, the campaign to curtail the opioid epidemic.

PAINS recommends for all those involved to call on the new administration to hold a White House Summit in 2018 to address both public health issues.

The Pain Action Alliance to Implement a National Strategy (PAINS) is a consortium of leaders from professional societies, patient advocacy organizations, policy groups, consumers, third party-payers and the private sector collaborating to achieve a common vision and mission. PAINS is a program of the Center for Practical Bioethics, a private, nonprofit organization that has a broad-based stream of revenues, including institutional memberships, endowments, grants and contributions from individuals, corporations and foundations (both public and private), and fee-for-service. The Center brings a wealth of experience in coordinating national programs. Its staff includes nationally recognized leaders in chronic pain.

Learn more at painsproject.org.

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