



# Achieving Balance in State Pain Policy

A Report Card



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# Executive Summary

As policymakers continue to consider options to address the opioid crisis, they must also consider the legitimate need patients still have for treatment of debilitating pain and other symptoms of serious illness. Many cancer patients, cancer survivors and other patients with serious illness need access to opioid medications to alleviate pain and maintain their quality of life.

Unfortunately, a recent American Cancer Society Cancer Action Network (ACS CAN) survey showed that patients are experiencing problems accessing opioid medications prescribed by their doctors. Of those surveyed, **nearly one-half of cancer patients** (48%) and more than one-half

of those with other serious illnesses (56%) **said their doctor-indicated treatment options for their pain were limited by laws, guidelines or insurance coverage in 2018**. More than one-quarter (27%) of cancer patients and survivors reported being unable to get opioid prescription pain medication because a pharmacist would not fill the prescription even though the drug was in stock, which more than doubles the number (12%) who reported such issues in 2016. **Similarly, 30% of cancer patients and survivors reported being unable to get the pain medicine their doctor prescribed this year because their insurance plan would not cover it – a 19% jump from 2016.**

## A Balanced Pain Policy Agenda

ACS CAN supports policies at federal, state and local levels that take a balanced approach to addressing the opioid problem without harming patients who are using the medications appropriately to treat their pain or other symptoms. These policies include:

- Increasing access to and training in palliative care, which includes a focus on coordinated symptom management including managing pain for patients with serious illness
- Exempting patients who are actively being treated for cancer-related pain and other patients with serious illness from opioid prescribing limits and lock-in programs
- Creating and maintaining prescription monitoring programs<sup>1</sup> (PMPs) that allow doctors and pharmacies to work together to curb misuse and abuse (including across state lines), while also helping to ensure care coordination
- Funding research to develop new evidence-based pain treatments – pharmacological and non-pharmacological
- Increasing provider education on pain management
- Ensuring that public and private insurance programs cover the range of evidence-based pain treatments in a way that is accessible and affordable for patients
- Creating effective drug take-back programs or methods that provide cancer patients and other patients with a safe way to dispose of unused medication

## 2018 State Pain Policy Report Card

For decades, ACS CAN, the American Cancer Society and the University of Wisconsin have tracked and rated state pain policies. For 2018, states have been rated according to a new methodology.

This year's report card showed that:

- Four states were doing well – having pain policies that followed model policy closely (above 80% match): New Hampshire, New Mexico, Vermont and Virginia.
- Eight states missed the mark – having pain policies that matched model policy 50% or less of the time: Arkansas, Illinois, Indiana, Maryland, Missouri, Montana, North Dakota and South Dakota.
- Thirty-nine states fell in the middle – matching model pain policies 51% to 80% of the time.

It is well-documented that unrelieved pain is still a serious problem for many people in the U.S., including for cancer patients, cancer survivors and other patients with serious illness.<sup>2</sup> Yet, pain medications – opioids in particular – also have a potential for abuse, and the misuse and abuse of opioids have been declared a public health emergency.<sup>3</sup> As policymakers, health care professionals and other decisionmakers continue to consider options for responding to this emergency, we cannot ignore the fact that many Americans legitimately need access to opioid medications to treat pain and other symptoms of serious illness.

Seriously ill patients commonly experience pain caused by their underlying illness(es) or the effects of treatment (e.g., surgery or chemotherapy treatments can cause pain). For example, nearly 60% of cancer patients in active treatment and 30% of patients who have completed treatment experience pain.<sup>4</sup> Managing this pain is an integral part of care for many of these patients,<sup>5</sup> and providing palliative care that includes pain management has been shown to prolong patient survival.<sup>6</sup>

### From This Year's Report Card:

- Updated methodology reflecting current trends in pain and opioid policies, including restrictions on opioid dosing and prescription durations for long-term treatment
- New section on state prescription monitoring programs
- In-depth information and direct links to the laws, regulations and policies evaluated for each state available in an interactive database <http://lawatlas.org>
- State-specific report cards with details about state ratings, available at [www.acscan.org/painreportcard](http://www.acscan.org/painreportcard)



Pain and other symptoms tend to be under-recognized and undertreated as part of regular care.<sup>7</sup> Poorly managed pain in seriously ill patients can contribute to decreased productivity, poorer quality of life, increased health care utilization and even increased mortality.<sup>8</sup>

## Treatments for Pain and Serious Illness Symptoms

Opioids are frequently used to treat both acute and non-acute pain. An estimated 1 out of 5 patients with chronic pain receives a prescription for opioids.<sup>9</sup> However, opioid prescriptions began to decline nationwide in 2013.<sup>10</sup>

Opioids are also used to treat other symptoms of serious illness, especially by palliative care clinicians. For example, opioids are widely accepted as the first line treatment of dyspnea (severe shortness of breath) after other disease-targeting or modifying therapies are optimized.<sup>11,12</sup> This symptom occurs in over 50% of patients with underlying serious illness (e.g., chronic obstructive pulmonary disease, heart failure or chronic lung disease) and is correlated with lower quality of life and with physical, emotional and cognitive changes including anorexia, fatigue, poor concentration, depression and memory loss.<sup>13</sup>

Opioids are not the only treatment option for pain or other symptom management. Non-opioid medications, like anti-inflammatories, are also used to treat pain in some patients. There are also evidence-based pain treatment options beyond medications, including physical, behavioral and intervention treatments like physical therapy, weight loss programs, cognitive behavioral therapy and steroid injections.<sup>14</sup> Many patients benefit from using more than one treatment type. Unfortunately, many insurance plans do not cover the breadth of non-opioid pain treatments – or if they do, the coverage is severely limited, hard to access and/or involves high cost-sharing for the patient.<sup>15</sup>

# What Patients Need

Patients with serious illness need access to treatments for their pain and other symptoms – including prescription opioids.

Patients with Serious Illness Need:	Barriers
<p><b>Doctors and other health care professionals willing to take their pain and other symptoms seriously and treat these symptoms with proven therapies</b></p>	<ul style="list-style-type: none"> <li>• Policies that punish clinicians for using opioids even when that is the appropriate clinical decision</li> <li>• Policies that place so many restrictions on clinicians' ability to prescribe opioids that they are unable to use them as a treatment option</li> <li>• Requirements for clinicians to follow guidelines without any allowance for exceptions</li> </ul>
<p><b>Insurance coverage for the treatments they need</b></p>	<ul style="list-style-type: none"> <li>• Policies that limit or prohibit coverage of opioids without exemptions for patients with serious illness</li> <li>• Policies that require patients to try non-opioids first, without exception, when it is not medically appropriate</li> <li>• Insurance policies that do not cover alternatives to opioids (physical, behavioral or intervention therapies), or cover them with significant barriers to access or at much higher costs</li> </ul>
<p><b>To be able to obtain prescriptions from their pharmacy without fear of being turned away or stigmatized</b></p>	<ul style="list-style-type: none"> <li>• Policies that universally require pharmacists to obtain permission from the insurance plan before dispensing opioids</li> <li>• Policies that severely limit the supply of opioids and cause drug shortages</li> <li>• Policies that require pharmacists to reduce the quantity, duration or dose of a patient's opioid prescription without consulting the prescriber</li> </ul>



## Cancer Patients and Survivors Are Increasingly Having Problems Accessing Opioids

Recent results from a nationwide survey of patients showed that the use of opioids is declining for some patient populations, and that many patients are experiencing problems accessing the opioid medications prescribed by their doctors.

On behalf of ACS CAN and the Patient Quality of Life Coalition,<sup>16</sup> Public Opinion Strategies conducted national online surveys among key patient populations that took opioid prescription medications in 2016 and 2018.

The surveys showed that since 2016, opioid use has declined for certain populations.

Percentage of Patients Who Are Currently Taking Opioid Prescriptions		
	2016	2018
Cancer Patients	43%	43%
Cancer Survivors	24%	10%
Chronic Pain Patients	48%	34%
Other Serious Illness Patients <sup>17</sup>	N/A	18%

The surveys also found there has been a significant increase in cancer patients and survivors being unable to access their opioid prescriptions since 2016.

Problems with Insurance			
<i>Among Cancer Patients/Survivors Ranked by Net Difference</i>	December 2016	May 2018	Net Difference
Have you been unable to get your opioid prescription pain medication because your insurance would not cover it?	11%	30%	+19%
Has your insurance company limited you to just one pharmacy to go to for filling your opioid prescription pain medication?	14%	32%	+18%
Has your insurance company reduced the number of times your opioid prescription could be refilled?	21%	36%	+15%
Has your insurance company reduced the number of pills in your opioid prescription pain medication?	19%	25%	+6%

<b>Problems at the Pharmacy</b>			
<i>Among Cancer Patients/Survivors Ranked by Net Difference</i>	<b>December 2016</b>	<b>May 2018</b>	<b>Net Difference</b>
Have you been unable to get your opioid prescription pain medication because the pharmacy did not have the particular drug in stock?	16%	41%	+25%
Have you been questioned by a pharmacist about why you needed your opioid prescription pain medication?	16%	35%	+19%
Have you been unable to get your opioid prescription pain medication because the pharmacist would not fill it for whatever reason even though they had it in stock?	12%	27%	+15%

In 2018, the survey asked patients about additional barriers to access, and many reported experiencing these problems.

<b>Additional Access Problems</b>			
	<b>Cancer</b>	<b>Chronic Pain</b>	<b>Other Serious Illness</b>
Has your doctor indicated his or her treatment options for your pain were limited by laws, guidelines or your insurance coverage?	48%	40%	56%
Has your insurance company or pharmacy required you to only have opioid prescriptions from one doctor?	36%	25%	26%
Has your doctor refused to give you a prescription for an opioid pain medication?	35%	25%	36%
Has the pharmacist given you only part of your opioid prescription (for example: for 7 days instead of 30 days the prescription was written), and told you to call your doctor for a new prescription if you need more?	31%	18%	21%
Have you been unable to get your opioid prescription pain medication because the pharmacist or pharmacy sent you home without your prescription because they had to contact your doctor before filling the prescription?	26%	30%	22%
Has the pharmacist given you only part of your opioid prescription (for example: for 7 days instead of 30 days the prescription was written), and told you to come back if you need more?	25%	26%	26%
Has your doctor or pharmacist told you that you have been flagged in their system as a potential opioid abuser?	21%	14%	11%

## The Need for Balanced Policy Solutions

ACS CAN is concerned about the current public health emergency resulting from inappropriate use of prescription opioids. As a nation, we must take steps to address the issue, and ACS CAN welcomes the opportunity to represent the voices of cancer patients and survivors in such efforts. Many cancer patients and survivors legitimately need access to opioids to treat their pain. ACS CAN supports policies that take a reasonable, balanced approach to addressing the opioid addiction epidemic and its associated risks, without harming patients who are using the medications appropriately to treat their pain.

### Exempting Certain Patients from Opioid Prescribing or Access Limits

Policy changes that have the most potential to harm patients with serious illness are prescribing limits (e.g., a limit on the number of days for which a doctor can write an opioid prescription, or a limit on the dosage) and “lock-in” policies (e.g., requiring a patient to receive their opioid prescriptions from only one doctor or only one pharmacy). These policies would directly limit patient access, and ACS CAN remains very concerned about such changes. When implementing such prescription or access limits, ACS CAN urges policymakers to provide exemptions for people with pain and other symptoms due to cancer and other serious illnesses within any legislative or regulatory changes imposing opioid restrictions and limits according to the following guiding principles:

#### Guiding Principles for Serious Illness Exemptions to Opioid Prescription Limits

In general, exemptions to opioid restrictions should:

- Include cancer patients in active treatment and cancer survivors who continue to receive treatment for pain because of the effects of cancer treatment or the cancer.
- Include patients receiving hospice care.
- Include other non-cancer patients experiencing pain or other symptoms related to a serious illness who are receiving, or would be eligible for, palliative care services.
- Be standardized in definition and application across all plans or programs affected by the policy.
- Be applied as early in the process as possible so that a patient who qualifies for an exemption will experience little or no disruption to treatment – and to minimize the time plans, prescribers and pharmacists must spend in resolving restrictions for patients who are ultimately exempted.
- Be clearly explained and included in aggressive outreach and education efforts to prescribers so they can anticipate access challenges for their patients and proactively minimize these obstacles.
- Include a clear and timely appeals process for patients who should be exempt but are not.



These guiding principles for holding cancer patients, survivors and other patients with serious illness harmless from opioid prescription limits are applicable to local, state and national laws. Carefully constructed exemptions from opioid restrictions will protect these vulnerable patients and their access to opioid treatment. ACS CAN encourages all policymakers to carefully consider these principles.

## Other Balanced Policy Solutions to the Opioid Crisis

ACS CAN supports other balanced policies that address the public health concerns relevant to the opioid epidemic, while not harming patient access to medications that they need to treat pain appropriately, such as:

- Increasing access to palliative care, which includes a focus on coordinated symptom management including managing pain for patients with serious illness
- Creating and maintaining PMPs that allow doctors and pharmacies to work together to curb misuse and abuse (including across state lines), while also helping to ensure care coordination
- Funding federal research to develop new evidence-based pain treatments – pharmacological and non-pharmacological
- Increasing provider education on pain management
- Ensuring that public and private insurance programs cover the range of evidence-based pain treatments in a way that is accessible and affordable for patients
- Creating effective drug take-back programs or methods that provide cancer and other patients with a safe way to dispose of unused medication

These policies are part of larger efforts to address the opioid crisis that include actions to reduce the supply and trafficking of illegal opioids in the U.S., increase access to treatment for substance abuse and improve such treatments and better deal with the consequences of addiction. ACS CAN focuses its efforts on advocating for cancer patients, survivors and caregivers; as such, we maintain a focus on policies that could impact patient access to prescription opioids.

## Federal Pain Policy

Over the past few years, policymakers at all levels of government have taken steps to address the opioid misuse and abuse epidemic. At the federal level, ACS CAN is working with the administration, members of Congress and federal agencies to institute balanced pain policy that does not harm access to needed treatment for cancer patients and survivors.

**CDC Prescribing Guideline:** In 2016, the Centers for Disease Control and Prevention released a new *Guideline for Prescribing Opioids for Chronic Pain*<sup>18</sup> (Guideline). ACS

CAN expressed strong objections to the CDC Guideline when it was drafted,<sup>19</sup> including the lack of evidence on which the Guideline is based, the methodology used to develop

the document and concerns about how the Guideline would be used in policymaking. We continue to have these concerns, and caution policymakers that the document was written as a guideline, and is only meant to apply to primary care clinicians for treatment of chronic pain “in outpatient settings outside of active cancer treatment, palliative care and end-of-life care.”<sup>20</sup>

ACS CAN continues to monitor the CDC’s promotion of the Guideline and its use to justify prescribing limits for which it was not intended.

**CARA:** The Comprehensive Addiction and Recovery Act (CARA, P.L. 114-198<sup>21</sup>) was signed into law on July 22, 2016. CARA was the first major legislative effort focused on addressing the opioid epidemic in the U.S. It authorized over \$181 million in new funding to create a coordinated response to the epidemic through prevention, treatment, recovery, law enforcement, criminal justice reform and overdose reversal. ACS CAN supported the passage of CARA<sup>22</sup> and continues to monitor its implementation.

**Increasing Research:** ACS CAN continues to support efforts at the National Institutes of Health and elsewhere to focus research on improving pain management treatments and finding new, non-addictive treatments for pain. Such research will help patients with serious illness better maintain their quality of life while dealing with debilitating symptoms and side effects. It will also give health care professionals more options in treating their patients and will reduce reliance on pain treatment with opioids. We support efforts to implement the Federal Pain Research Strategy,<sup>23</sup> which

includes research on novel drugs and non-pharmacological pain treatments, improved screening tools to help providers assess pain, national registries and research networks for diverse pain conditions, effective models for pain management and care delivery and precision medicine methodology for preventing and treating pain.

**Addressing Opioids in Medicare:** In 2018, the Centers for Medicare and Medicaid implemented several new policies addressing opioid use in the Medicare population, including a seven-day limit on first-time prescriptions for acute pain, and a drug management program for Medicare Part D enrollees that restricts access to opioids for patients who have been identified as potentially at-risk for misuse or abuse. These policies nominally exempt cancer patients, but ACS CAN is monitoring implementation of these policies in light of the exemption principles referenced above.<sup>24</sup>

**FDA Activity:** The U.S. Food and Drug Administration and its Opioid Policy Steering Task Force have put a serious regulatory focus on opioids, including considering how it should make decisions about future drug approvals, re-examining the Risk Evaluation Management System process to mitigate the risk of opioids and what changes it could require in opioid packaging to make disposal of unused medication and prescribing short doses easier.<sup>25</sup> ACS CAN continues to monitor this activity and urge the agency to base their decisions in strong evidence and always consider patient access to the drugs they are regulating.

**Congressional Activity in 2018:** Several committees in Congress have considered legislation this year to address opioids. On June 22, 2018, the House passed the Substance Use Disorder Prevention that Promotes Recovery and Treatment for Patients and Communities Act with strong bipartisan support.<sup>26</sup> The legislation takes significant steps toward responding to the opioid crisis. It includes key provisions that encourage the development and use of non-opioid medications; improves federal support of state-run PMPs; increases critical resources for researchers; and encourages the safe disposal of unused opioid medications by medical professionals and hospice workers. The bill moved to the Senate where further action is expected. Several Senate committees are working on comprehensive legislation to address the opioid crisis including the Senate Health, Education, Labor and Pensions Committee, which passed its Opioid Crisis Response Act of 2018 out of committee with bipartisan support in April, and the Senate Finance Committee, which marked up its bipartisan package –

the Helping to End Addiction and Lessen (HEAL) Substance Use Disorders Act – favorably out of committee in mid-June.

**Palliative Care Hospice Education and Training Act (PCHETA):** ACS CAN supports efforts to increase patient access to palliative care, which includes a focus on pain management for many patients. On July 23, 2018, the House of Representatives passed this bill unanimously.<sup>27</sup> We urge Congress to consider including this bipartisan legislation, which addresses the proactive need to expand research in pain, palliative care and symptom management at the National Institutes of Health, and expand education and training of providers in the medical subspecialty of palliative care who are on the front lines of treating patients with serious illness in a final opioid bill package. PCHETA has strong bipartisan support in both chambers, and has been identified as legislation that includes balanced policy solutions that would positively impact care for patients with serious illness who live with pain and other symptoms due to a serious illness.

## State Pain Policy

States are also taking action to address the opioid epidemic while ensuring patient access to pain treatment. They regulate the health professionals practicing within their borders, as well as the facilities at which patients receive treatment and some health insurance plans covering state residents. The opioid epidemic also has important regional implications, with some states and areas being harder hit than others. For these and other important reasons, much of the recent activity around changing policy related to pain care has been at the state level. In its 2018 *How Do You Measure Up?* report, ACS CAN reported that over 470 pieces of state legislation related to pain management/opioid issues were proposed in 2018,<sup>28</sup> and this does not include many other policies proposed and implemented through the regulatory process.

For over a decade, ACS CAN, the American Cancer Society and the University of Wisconsin<sup>29</sup> have tracked and rated state pain policies. State ratings were most recently published in 2015. In 2017, the organizations underwent a process to update the methodology of this analysis to better reflect the current policy environment. This new methodology was used to evaluate state policies in place as of December 31, 2017, in the following ratings.

### **From the State Pain Policy Ratings This Year:**

- Updated methodology reflecting current trends in pain and opioid policies, including opioid dosing amounts and prescription durations for long-term treatment
- New section on state prescription monitoring programs
- In-depth information and direct links to the laws, regulations and policies evaluated for each state available in an interactive database <http://lawatlas.org/datasets/state-laws-and-other-regulatory-policies-related-to-pain-care-final>
- State-specific ratings, with details about the criteria contributing to those ratings, available at [www.acscan.org/painreportcard](http://www.acscan.org/painreportcard)

Researchers from the Sonderegger Research Center at the University of Wisconsin School of Pharmacy evaluated state policies (including laws, regulations and official guidelines or policy statements) based on their conformity with model policy statutes or regulatory policies. States were evaluated in the following categories:

#### ***Policy Definitions and Prescription Limits***

How does the state define key terms, like “addiction,” “practice of medicine” or “unprofessional conduct” that could affect the provisions of pain management? Are there limits on the amount, length or strength of prescriptions for controlled substances and/or opioids? Are these definitions or limits reasonable and based on policy models?

#### ***Efforts to Assess and Improve Pain Treatment***

Does state policy recognize that reducing controlled substance-related harms, while

essential, should not cause barriers for patients legitimately in need? How is pain management officially evaluated by regulatory agencies? What resources does the state provide to practitioners and facilities to improve the treatment of pain?

#### ***Expectations of Health Care Practitioners for Pain Treatment***

Is the standard of practice for practitioners to integrate treatment options, individualize plans for care and assess patient functioning? Do these expectations incentivize appropriate treatment that actively involves the patient? Are benefits and risks of treatment considered and monitored?



## Trends

- In recent years, many states have considered policies limiting the dosage strength, amount of pills or duration of opioid prescriptions. ACS CAN remains very concerned about such prescribing limits, as they are often focus solely on controlling the number or strength of opioid pills in circulation, are often not based on any scientific evidence regarding pain treatment and directly limit patient access to their treatments. However, while six states have recently enacted such prescribing limits for long-term pain, each of these policies either provides the prescriber with the option to exceed the limit if it is medically justified for the patient or maintains at least a 30-day supply (which is the standard length of one fill at a retail pharmacy). These types of exceptions, and/or the exceptions discussed above, are important because they allow cancer patients and survivors to maintain access to their pain medication.
- As policymakers continue to focus on how to improve PMPs, clear consensus from providers, pharmacists and the public is that these programs should be interoperable – i.e., allowed and able to share data with other state PMPs. This analysis shows that 34 states' PMPs provide specific authority for interoperability, even though many more states' PMPs have become participants in interoperability agreements. This highlights the periodic disconnect in some states between written policy and implementation.
- Note that because of the 2017 change in methodology for this analysis, these results cannot be compared to previous state ratings.



As state policymakers continue to consider legislation and regulations to address the opioid epidemic, ACS CAN urges an approach based on model policies, which seek to address medication harms while protecting access to needed pain treatments for cancer patients, survivors and others who are seriously ill.



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- (25) See ACS CAN comments on FDA efforts here: <https://www.acscan.org/sites/default/files/ACS%20CAN%20comments%20to%20FDA%20Opioid%20Policy%20Steering%20Committee%20-%20Final.pdf> (December 19, 2017).
- (26) See ACS CAN's press statement on the passage of this bill here: <https://www.acscan.org/releases/cancer-patients-and-survivors-call-balanced-comprehensive-opioid-package>
- (27) See ACS CAN's press statement on this action here: <https://www.acscan.org/releases/house-energy-and-commerce-committee-approves-palliative-care-bill>
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