



# A CHRONIC PAIN CRISIS

2022 SURVEY REPORT



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# MESSAGE FROM THE CEO

## The importance of shedding light on chronic pain



Research tells us that 50 million Americans live with chronic pain, or pain that lasts most days or every day for three months or more. Of this group, 20 million suffer from high-impact chronic pain, or pain that interferes with basic functioning and activities of daily living, like personal hygiene and household chores. Pain is the number one reason that Americans access the health care system, and the leading cause of long-term disability in the United States. Estimates suggest pain costs the nation at least \$560-635 billion a year in direct medical costs and lost productivity.

And yet we know very little about the epidemiology of chronic pain, including why acute pain sometimes becomes chronic or how many Americans are living with various causes of chronic pain. Nor do we have much data on what treatments work for the array of conditions that cause pain—and what does not. We also have scant information about the impact of pain on quality of life, especially its long-term effects on mental health, ability to work, and families at large.

Without this knowledge, it's hard to convey the true scope of the problem of chronic pain in America. It's even more difficult to try to solve it.

Meanwhile, patients are desperate for relief, for understanding, and for hope.

By surveying our community, we aim to pull back the veil on this public health crisis. In the following pages, you will read about trends across numerous areas related to pain, from strains on the patient-provider relationship to the increasing use of self-management tools.

We hope you will find the results as compelling as we do—and, most importantly, feel inspired to help fight for change for this vulnerable patient population.

Sincerely,

  
Nicole Hemmenway  
CEO

# KEY FINDINGS

Chronic pain has devastating consequences on function, quality of life, and mental health.

- More than half (52%) said their average pain level is 7 or more on a scale of 1-10.
- 99% said pain has restricted their ability to engage in routine activities, like exercise, household chores, sleeping, and socializing.
- 95% of respondents had at least one comorbidity.
- More than two-thirds (71%) of respondents said they considered themselves disabled.
- Only 18% are employed full-time.
- 60% said they feel anxiety-like symptoms daily or a few times a week, and a similar portion (59%) feel depression-like symptoms daily or a few times a week.
- **79% said they feel stigmatized** because of pain.



At best, people with pain feel their health care providers are not equipped to manage their pain effectively; at worst, people with pain feel unsupported and stigmatized.

- Approximately 63% of respondents felt stigmatized by their providers.
- Patients report that **core competencies expected of providers treating pain are lacking**.
  - 24% “rarely” or “never” felt validated or listened to;
  - 69% either did not feel, or only “rarely” or “sometimes” felt that their provider was on a team with them; and,
  - 53% answered “no” or only “sometimes” when asked if their provider helped them understand options for managing their pain.
- When asked about their top pain policy issue, the most common answer was increased pain education for providers (41%), tied with wanting new medications for chronic pain.
- 71% of caregivers said **“provider attitudes” are the top barrier to care**.

# KEY FINDINGS

Medications remain the most effective treatment option, but people with pain face significant barriers in accessing certain drugs.

- Nearly all respondents (79%) currently take prescription medications.
- A majority (77%) said prescription medications are the most helpful treatment in managing their pain.
- One-quarter (24%) said **no side effect would prevent them from trying a medication to manage pain.**
- Nearly half of respondents take opioid medications (47%), although three quarters of that group report a range of substantial barriers to obtaining their regular medication. Barriers faced by those taking opioid medications include decreased doses, stigmatization, and providers refusing to fill medications or outright refusing to treat the person with pain at all.
- Nearly all (94%) of those taking opioids said they attribute these barriers to the CDC Guideline for Prescribing Opioids for Chronic Pain — United States, 2016.
- Roughly one-fifth (19%) of people with pain currently use medical cannabis.
- 43% of individuals in states where it is illegal said **they would try medical cannabis if it were legalized.**



# KEY FINDINGS

Multidisciplinary approaches, particularly self-management techniques, are under-recognized components of effective pain management.

- Multidisciplinary approaches were widely employed, with the top strategies including activity restriction or modification (73%), stress reduction techniques (42%), heat therapy (41%), and meditation and mindfulness (40%).
- **Activity restriction or modification is the most-used specific “therapy” of any kind across all categories, aside from prescription medications as an entire category (79%).**
- Similarly, prescriptions were reported as the most helpful category of treatment (77%); self-management techniques as a whole were next at 31%, above OTC medications (27%), assistive devices or braces (24%), supplements, vitamins, or herbs (22%), medical cannabis (21%), mind-body and behavioral health options (20%), and interventional procedures and surgeries (17%).
- Less than one-fifth (19%) of people with pain had heard of the Pain Management Best Practices Report, a national set of recommendations that outlines the importance of multidisciplinary pain care.



Due to high out-of-pocket costs—coupled with pain’s drastic impact on the ability to work—cost remains the primary barrier to pain care.

- Approximately one-third (33%) of people with pain had a total annual household income of less than \$35,000.
- According to people with pain, **the leading barrier to treatment was cost** (49%).
- Nearly half (41%) of people with pain said they felt insurance coverage decisions are driven by cost, **not by what was in their best interest medically**.

# RESPONDENT DEMOGRAPHICS



A total of 2,378 individuals responded to the survey, which was open from March 29 to April 12, 2022. Respondents included 2,275 people with chronic pain (96%), defined as pain lasting three months or more, as well as 72 caregivers (3%) and 31 health care professionals (1%). The bulk of this report focuses on patient responses with a small summary pertaining to the caregiver experience.

Individuals had to be 18 years or older to be eligible to take the survey (U.S. Pain conducted a separate [survey on pediatric pain](#) last year). The average age of respondents with chronic pain was 54.

**Respondents were largely middle-aged, female, white, and non-Hispanics living in suburban areas.**

Nearly three-quarters of respondents had lived with pain for more than 10 years (74%), emphasizing that the population responding to this survey is individuals with severe, long-term pain. Interestingly, only 0.7% had lived with pain for less than one year. (Survey authors note this suggests opportunity to improve outreach to the newly diagnosed.)

The large majority of respondents were women at 85%. 13% were men, and 2% said they are gender variant, nonbinary, or an identity that was not listed. Less than 1% of respondents said they are transgender. Evidently, while women are known to be more likely to have chronic pain, they are widely overrepresented in this survey (according to the CDC, 21.7% of women have chronic pain vs. 19% of men)<sup>1</sup>. This may be indicative of women being more likely to engage with patient organizations, to respond to online surveys, or some combination of the two.

# RESPONDENT DEMOGRAPHICS



All 50 states and Washington D.C., Puerto Rico, the Northern Mariana Islands, and the Virgin Islands were represented. Roughly half of respondents were from suburban areas (52%); 26% were from rural areas, and 20% were from urban areas (2% said they prefer not to answer). This population density breakdown corresponds with the results of the 2017 American Housing Survey, which found that about 52% of Americans describe their neighborhood as suburban, 27% describe their neighborhood as urban, and 21% as rural<sup>2</sup>. A key difference is the higher percentage of individuals in rural areas in this survey, as chronic pain is more likely to affect those in rural areas.<sup>3</sup>

As far as race and ethnicity, respondents are largely non-Hispanic whites. 91% of respondents said they are white; 3.4% are American Indian or Alaska Native; 2.6% are Black or African American; 1.0% are Asian or Asian American; and 0.2% are Native Hawaiian or other Pacific Islander. 4.2% answered with “other,” and 3.7% said they prefer not to answer. (Respondents were able to select more than one answer.) Approximately 92% of respondents said they are non-Hispanic, 3.3% are Hispanic, and 4.4% said they prefer not to answer.

While, according to the CDC, non-Hispanic whites are slightly more likely to have chronic pain, non-whites and non-Hispanics are underrepresented in this survey. (A 2019 data analyzed by the CDC found that incidence in non-Hispanic whites is 23.6%; 19.3% in non-Hispanic Black individuals; 13% in Hispanics; and 6.8% in non-Hispanic Asians.)<sup>4</sup> This likely represents the demographics of this patient organization’s audience and suggests opportunity for more outreach to non-white and Hispanic communities.

The underrepresentation of key ethnic and racial groups, along with the underrepresentation of men, are important limitations to keep in mind throughout this report.

# THE INTERSECTION OF PAIN, DISABILITY, AND POVERTY

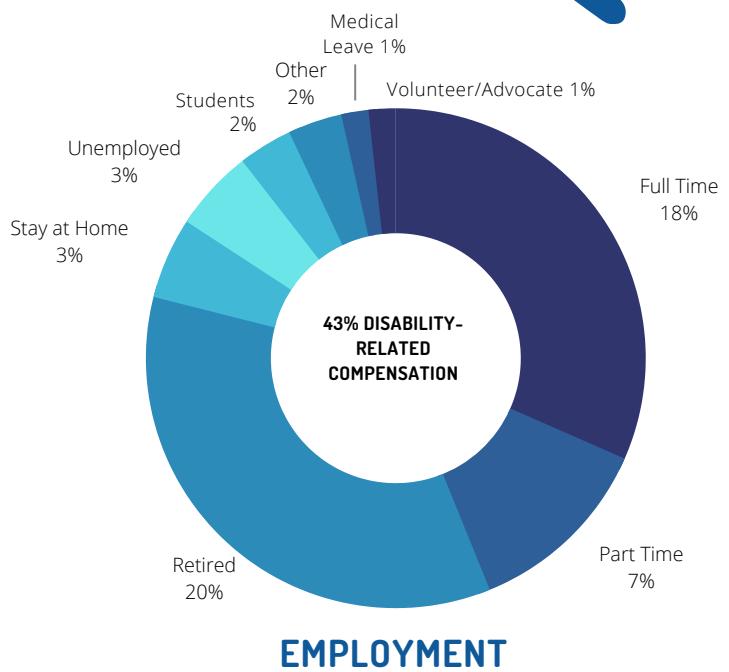
More than half of respondents (52%) report having an average pain level of 7 or more (on a scale of 0-10). Only 8% report pain of 3 or less. Nearly all of respondents—99%—said pain has restricted their ability to engage in routine activities. The most commonly impacted activities were exercise or sports (90%), household chores (87%), sleeping (85%), work (83%), hobbies (79%), socializing/maintaining friendships (78%), traveling (76%), and intimacy (73%).

In light of the almost universal impact on daily living, a significant portion (71%) said they considered themselves to be disabled. The term was not specifically defined in this instance.

When asked about employment, roughly 43% reported receiving some type of formal disability-related compensation, such as Social Security Disability Insurance (SSDI), worker's compensation, or Veterans Affairs disability compensation. Only one-quarter of respondents are employed, reflecting the impact of pain on ability to work: 18% are employed full-time (defined as 35 hours/week or more) and 7% are employed part-time (defined as 35 hours/week or less). One-fifth (20%) are retired; 3% are stay-at-home caretakers of children or other family; 3% described themselves as unemployed, 2% are students, and 1% are volunteers or advocates. Another 1% are on temporary medical leave and 2% responded 'other.'

Of the individuals receiving some type of formal financial disability support, 69% of them receive SSDI, 5% receive worker's compensation, and 5% receive Veterans Affairs disability compensation.

**Survey respondents are, by and large, individuals with high-impact chronic pain.**



The under- and unemployment of people with pain is reflected in income levels. Approximately 19% report their household income is less than \$20,000, and 14% said it was between \$20,000 to \$34,999. While this survey did not ask about household size, it is likely that many of these individuals fall under the poverty line. (In 2022, the poverty guidelines for a family of two is \$18,310; for a family of four, it is \$27,750.) A total of 10% reported their household income was \$35,000 to \$49,999; 24% said \$50,000 to \$99,999; 12% said \$100,000 to \$149,999; and 7% said \$150,000 or more.

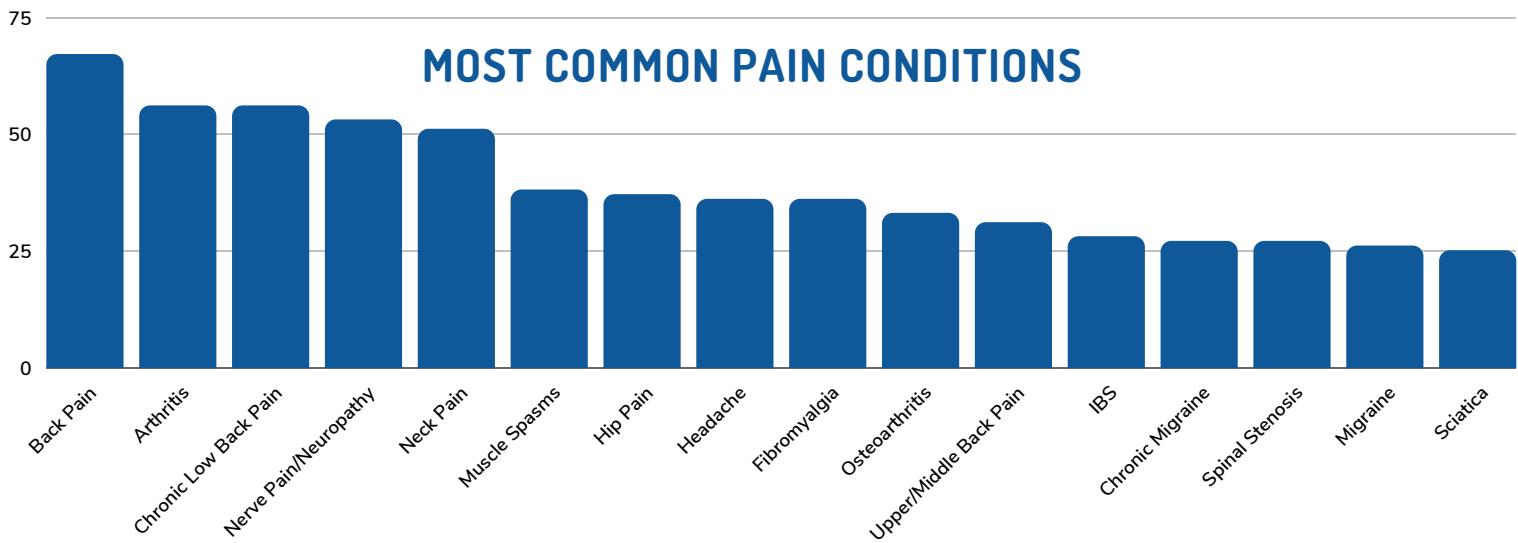
# THE INTERSECTION OF PAIN, DISABILITY, AND POVERTY

Health insurance status reflected income, employment, and age of respondents. The most common insurance was Medicare (46%), followed by employer coverage (37%), Medicaid (17%), military or veteran's insurance (5%), individual plan purchase via a state or federal health exchange ("Obamacare") (4%), and individual plan purchased outside of a state or federal health exchange (3%). While uninsured individuals represented a small portion—1.5%—it is concerning, given the level of pain and disability among respondents.

The most common pain conditions were primarily musculoskeletal in nature: back pain (67%), arthritis (56%), chronic low back pain (56%), nerve pain or neuropathy (53%), and neck pain (51%). Also prominent were muscle spasms (38%), hip pain (37%), headache (36%), fibromyalgia (36%), osteoarthritis (33%), upper/middle back pain (31%), irritable bowel syndrome (28%), chronic migraine (27%), spinal stenosis (27%), migraine (26%), and sciatica (25%).

Of note, 35% of respondents said one or more of their conditions is the result of trauma or injury, like a car accident or workplace injury.

While conditions varied widely, the commonality was the prevalence of comorbidities: only 5% of respondents had just one condition. In fact, 20% had 2-5 conditions; 30% had 6-10 conditions; 24% had 11-15 conditions; and 21% had 15 or more conditions, with the most conditions being 42 total. These enormous figures further underscore the complexity of the health of this patient population.



# IN CRISIS: THE STRAINED PATIENT- PROVIDER RELATIONSHIP

**59% of respondents said their provider doesn't, "sometimes," or "rarely" listens to and validates their concerns.**

Most respondents have at some point seen primary care physicians (PCPs) to manage their pain (88%), followed by pain specialists (73%). The next most common providers seen were neurologists (53%), physical or occupational therapists (53%), mental health professionals like psychiatrists and psychologists (44%), and chiropractors (42%).

When asked about the type of providers seen regularly, the responses were comparable but nuanced. 43% responded with PCPs, and 42% indicated pain specialists. Neurologists were seen 16% of time, followed by rheumatologists (9%), physical or occupational therapists (9%), and mental health professionals like psychiatrists and psychologists (8%).

The number of patients regularly seeing PCPs emphasizes the vital need for PCPs to be well-trained in pain management—which is not often the case. In fact, by and large, patients report that core competencies expected of providers treating pain (identify pain treatment options,

demonstrate empathy and compassion, assess patient preferences, demonstrate inclusion of patient in pain care decision-making<sup>6</sup>) were lacking, as the following table outlines.



# IN CRISIS: THE STRAINED PATIENT- PROVIDER RELATIONSHIP

## THE PATIENT-PROVIDER RELATIONSHIP

|  | Yes | Sometimes | No  | Rarely | Other | Prefer not to answer |
|--|-----|-----------|-----|--------|-------|----------------------|
| <b>Does your current health care professional help you understand different options for managing your chronic pain?</b>  | 42% | 33%       | 20% | N/A    | 3%    | 1%                   |
| <b>Do you feel your current health care professional listens and validates your symptoms, concerns, and pain?</b>  | 39% | 36%       | 16% | 8%     | N/A   | 2%                   |
| <b>Do you feel comfortable discussing new treatments, medications, therapies or procedures you learn about through other outlets (webinars, nonprofit organizations, internet, etc.) with your current health care professional?</b> | 52% | 29%       | 10% | 8%     | N/A   | 1%                   |
| <b>Do you feel you are a team with your current health care professional when it comes to managing your chronic pain?</b>  | 30% | 32%       | 26% | 11%    | N/A   | 1%                   |

# IN CRISIS: THE STRAINED PATIENT- PROVIDER RELATIONSHIP

In addition, only a little more than one-third of respondents (35%) said they have “high trust” in their providers’ ability to manage their pain; 36% said “somewhat trust,” and 27% said they had “low trust.” Further, when asked if they were hopeful that they would achieve the goals of their pain management plan, 38% said “sometimes,” 36% “no,” and 22% “yes.” Only 2% said they had actually achieved their pain management goals.

These are startling figures. Validation, patient-centered care, empathy and compassion, and a team approach are foundational components of effective pain management.

With this low trust in, and a lack of support from, their providers, it is concerning—but perhaps unsurprising—that 19% of respondents said they currently were not seeing any health care professional for pain. This is a troubling figure given the severity of pain experienced by this population. The most common reason, by far, was that respondents don’t feel supported by their providers (67%). Other reasons given were stigmatization (28%), lack of access nearby (23%), cost (19%), prefer to manage own care (13%), and COVID (8%).

In a similar vein, when asked about appointment frequency, the most common answer was “every other month or quarterly” (41%). This, again, is surprising given the severity of pain experienced, reiterating a possible disenfranchisement or disengagement from the health care system amongst pain patients.

The next most common answer was once a month (25%), followed by two to four times a month (17%). A small but significant total of 9% report seeing providers five times a month or more.



# PAIN MANAGEMENT THERAPIES: WHAT PATIENTS ARE TRYING—AND WHAT WORKS

Respondents were asked about treatments across 13 primary categories. Prescription medications were, by far, what patients reported as being most beneficial, at 77%. All other 12 categories were reported as helpful by less than one-third of respondents, which is quite low. The inadequacy of pain management in America today is perhaps best reflected by this statistic. This also reinforces the conclusions of the Pain Management Best Practices Inter-Agency Task Force Report that pain treatment must be individualized; each person is unique in terms of what treatments and combinations of treatments help their pain.

Interestingly, however, self-management techniques were second highest, at 31%.

This likely underscores dissatisfaction with traditional pain care and the need for alternative strategies that can be done on patients' own terms. It is interesting to note that although interventional procedures and surgeries for pain (e.g. injections) are commonly used despite the relative risk and often high cost, only 17% found them helpful.



# PAIN MANAGEMENT THERAPIES: WHAT PATIENTS ARE TRYING—AND WHAT WORKS

| Treatment options that most help manage patients' pain (could select multiple) |     |
|--|-----|
| Prescription medications   | 77% |
| Self-management techniques   | 31% |
| Over-the-counter medications   | 27% |
| Assistive devices or braces  | 24% |
| Supplements, vitamins, or herbs  | 22% |
| Medical cannabis   | 21% |
| Mind-body and behavioral health options  | 20% |
| Interventional procedures and surgeries  | 17% |
| I have not found any treatment options to help manage my chronic pain          | 13% |
| CBD-from-hemp-only products  | 12% |
| Complementary and integrative health options                                   | 10% |
| Other  | 9%  |
| Restorative treatments   | 9%  |
| External neuromodulation and stimulation devices                               | 8%  |
| Medical foods  | 2%  |

# PAIN MANAGEMENT THERAPIES: WHAT PATIENTS ARE TRYING—AND WHAT WORKS

Respondents were asked about specific therapies within these categories. These results are broken down in the following subsections:

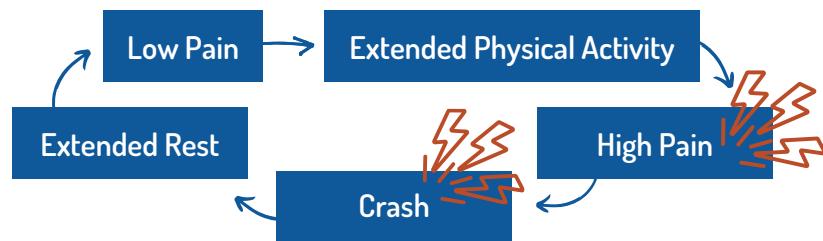
- Self-management
- Restorative, complementary, and integrative therapies
- Assistive and stimulation devices
- Mind-body and behavioral health
- Medications and supplements (including prescription, over-the-counter, and cannabis products)
- Interventional procedures and surgeries

## Self-management

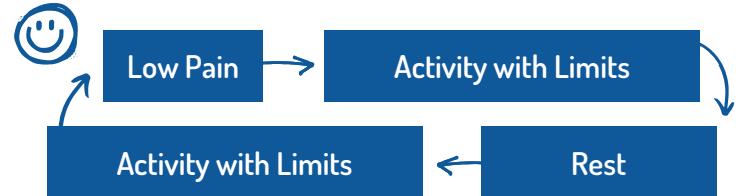
In the category of self-management, a high percentage of respondents generally found these techniques helpful. Respondents indicated the following specific strategies were most helpful, in descending order: activity restriction or modification (73%); stress reduction techniques (42%); meditation and mindfulness (40%); diet and nutrition (39%); sleep hygiene (37%); exercise practice (35%); assistive devices or technologies (35%); chronic pain support groups (27%); and other (13%). 22% said self-management techniques were not helpful to them.

The large number reporting that activity restriction or modification is helpful is very notable. In fact, it is the most-used specific “therapy” of any kind across all categories, aside from prescription medications as an entire category (79%). This suggests that teaching pacing, as well as determining and setting limits, early on after a chronic pain diagnosis would be extremely helpful.

### OVERDOING = HIGH PAIN



### PACING = LOW PAIN



While pacing was the most beneficial, benefit was high across all specific techniques in self-management, emphasizing this category as foundational to effective pain care. These strategies are not often introduced immediately after a chronic pain diagnosis, but given their benefit—and that they have low or no cost, little risk, and are fairly easy to access—they likely should be (in conjunction with traditional medical care).

An ideal model of care for pain would likely include some combination of introductory course, workshop, peer group, manual, and/or other materials that empower patients with training in self-management. This knowledge would serve them in perpetuity, an essential feature given the long-term and likely lifelong pain reported by this population.

# PAIN MANAGEMENT THERAPIES: WHAT PATIENTS ARE TRYING—AND WHAT WORKS

## Restorative, complementary, and integrative therapies

Many respondents found restorative treatments helpful, although 11% said they had not had access to them and 10% said they had not tried them.

Specific types of restorative treatments were ranked as helpful in the following order: heat therapy (42%); massage therapy (33%); physical therapy (30%); cold therapy (26%); pool or aquatic therapy (20%); exercise programs (19%); chiropractic care (17%); kinesiology taping (8%); other (7%); dry needling (7%); occupational therapy (7%); floatation therapy (5%); traction therapy (5%); postural training (4%); and osteopathic medicine (4%). 19% of respondents indicated these therapies were not helpful to them.

It is interesting to see that heat and cold therapy are ranked so highly, given their low cost, low risk, and ease of use.

Also of note is the one-third that find massage therapy helpful. Since massage is rarely covered by insurance, it is likely inaccessible to many, albeit beneficial.

Physical therapy, ranked at 30%, seems ranked rather low relative to its prevalence in traditional pain management. However, traditional physical therapy is often geared toward more acute pain and injury, rather than chronic pain and long-term issues. In fact, many insurers limit annual visits (in a later question, 10% of respondents said annual limits were a barrier to care) and/or may require specific benchmarks, like steady improvement, in order to continue covering visits. For patients with moderate or severe pain, steady improvement may not always be possible (as opposed to maintaining a baseline or staving off further decline).

It is also surprising to see occupational therapy ranked so low (7%) given the severity of respondents' disability. It is unclear from the results whether this is the result of a lack of benefit or a lack of awareness/access.

# PAIN MANAGEMENT THERAPIES: WHAT PATIENTS ARE TRYING—AND WHAT WORKS



**It is surprising to see acupuncture listed as low as it is given its increasing popularity in mainstream medicine...**



Regarding complementary and integrative health options, benefit, use, and access were somewhat low. Of the therapies listed, the most beneficial were as follows, from most to least: herbal and vitamin products (22%); acupuncture (16%); aromatherapy (12%); art, music, dance, and equine therapy (12%); acupressure (7%); cupping (7%); other (7%); reiki (7%); craniosacral therapy (7%); reflexology 5%; hypnosis (3%); traditional Chinese medicine (3%); and Ayurvedic medicine (3%). (Herbal and vitamin products will be further explored later in this report.) One-quarter of respondents said they had not found these therapies helpful. Another 21% said they had not tried them, and 19% said they have not had access to them.

It is surprising to see acupuncture listed as low as it is given its increasing popularity in mainstream medicine (Medicare recently began offering coverage for acupuncture for chronic low back pain). The low rates of other options in this category might be expected given that they are rarely covered by insurance, may be prohibitively expensive, and often lack robust clinical evidence.

# PAIN MANAGEMENT THERAPIES: WHAT PATIENTS ARE TRYING—AND WHAT WORKS

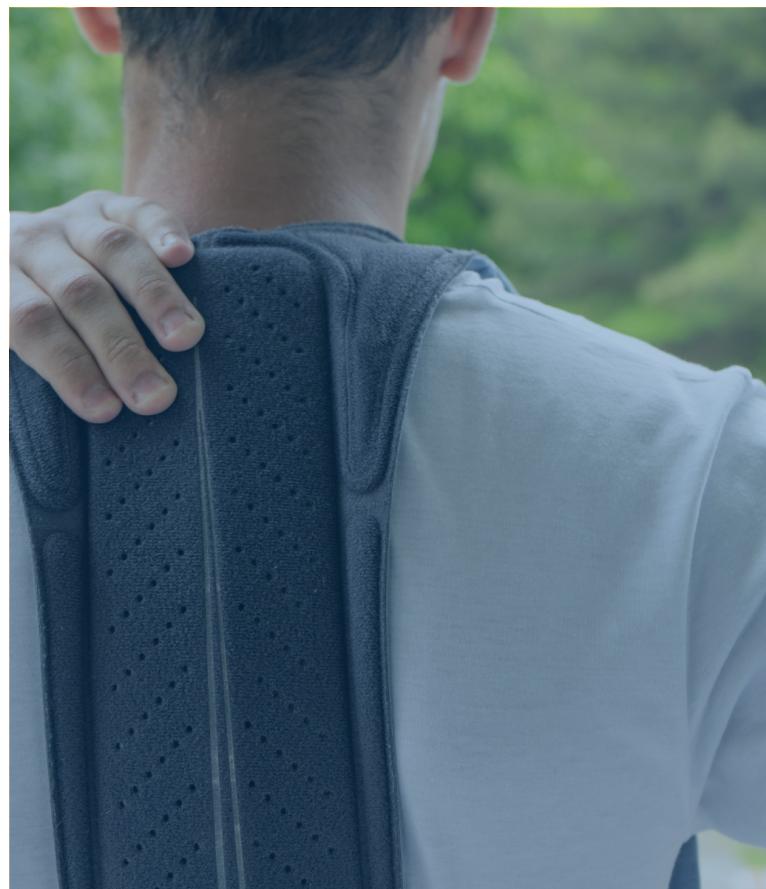
## Assistive and stimulation devices

This next section looked at two categories of devices in pain management: 1) assistive devices and braces and 2) external neuromodulation and stimulation devices. The first category may primarily be thought of as those instruments that support activities of daily living; the second relates to specific therapies that use some form of energy (stimulation) to relieve pain.

Approximately 70% of respondents indicate using some type of assistive device or brace. From most common to least used, they were: cane (37%); special cushion or seating (29%); back brace (23%); walker (22%); wrist brace (20%); orthotics (15%); adjustable bed (13%); neck brace (13%); ankle brace (12%); manual wheelchair (11%); leg brace (11%); other (10%); CPAP/BiPAP (9%); crutches (9%); SI joint belt (8%); adaptive technology (such as voice-to-text) (7%); blood glucose monitor (7%); arm brace (5%); power wheelchair (5%); handicapped-accessible motor vehicle (4%); catheter (2%); stair lift (1%); manual wheelchair with power assist (1%); prosthesis (1%); and gastric feeding tube (1%).

Though exact devices and braces vary widely, use of at least some type of device or brace was common. And though these tools often have associated costs, they are low risk and can provide long-term benefit, underscoring their important role in a pain management plan.

It is interesting, again, to consider that while use of assistive devices and braces was common, very few patients reported benefit from occupational therapy (7%). It is unclear whether this is from a lack of awareness of or access to occupational therapy, or actual inefficacy. In either case, there is likely room to improve and expand services to pain patients in this area. Similarly to self-management (especially pacing), employing adaptive tools and technologies—and emphasizing these tools earlier on in a chronic pain diagnosis—helps empower patients long-term and may reduce the impact of pain on daily activities and disability.

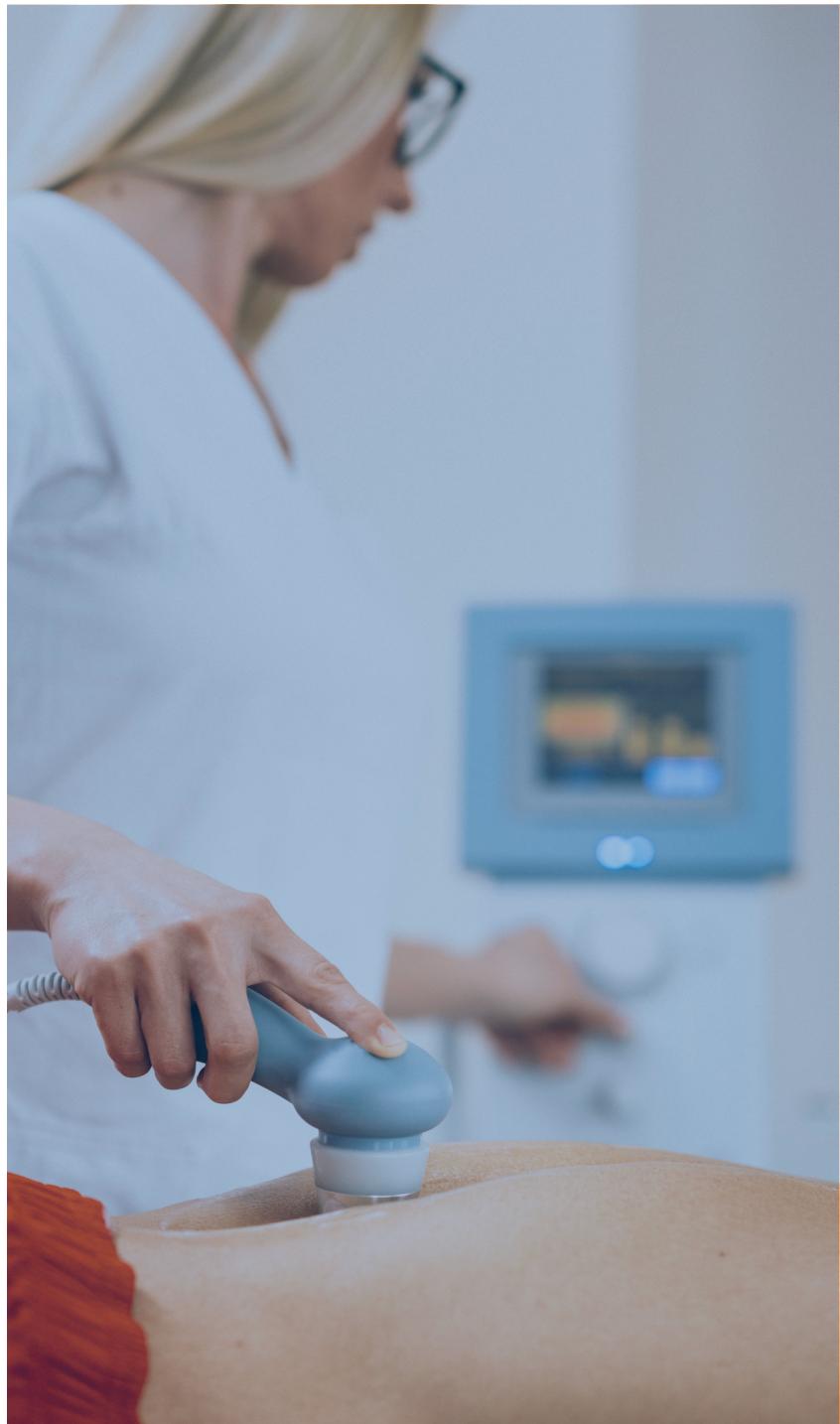


# PAIN MANAGEMENT THERAPIES: WHAT PATIENTS ARE TRYING—AND WHAT WORKS

In the second subcategory of devices, 80% of respondents had tried external neuromodulation and stimulation devices. By far, transcutaneous electrical nerve stimulation (delivered via TENS units) was the most common therapy tried (67%) with a steep dropoff for other therapies (all under 20%). Those therapies, in descending order, were: ultrasound therapy (18%); neuromuscular electrical stimulation (16%); infrared light therapy (12%); H-wave electrical stimulation device (7%); high-frequency impulse therapy (7%); laser therapy (6%); other (5%); vagus nerve stimulation (4%); percutaneous electrical nerve stimulation (4%); deep oscillation therapy (3%); pulsed electromagnetic field therapy (2%); interferential current (IFC) stimulation (2%); and scrambler therapy (1%).

While these other therapies were tried infrequently compared to TENS, they are still significant. Especially given that some types of stimulation are not well-known, their use is surprisingly high.

Future study might explore the benefit of these stimulation therapies; vagus nerve stimulation may be worth particular attention, as research has grown exponentially in this area in recent years.



# PAIN MANAGEMENT THERAPIES: WHAT PATIENTS ARE TRYING—AND WHAT WORKS

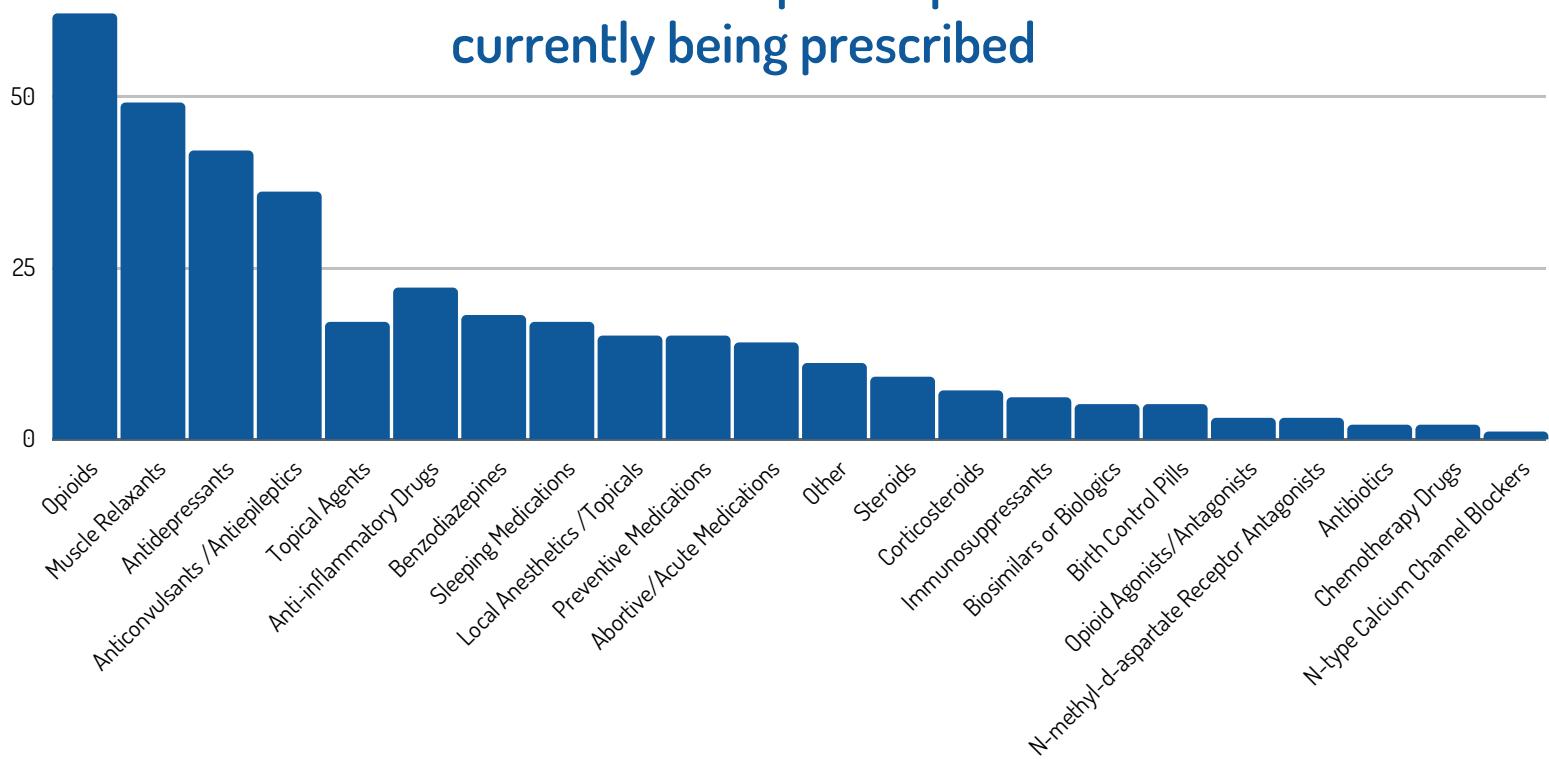
## Medications and supplements (including prescription, over-the-counter, and cannabis products)

Prescription medications are, by far, the most used category of treatment: more than three-quarters of respondents (79%) report currently taking some type of prescription medication. Additionally, 77% of respondents reported prescription medications to be the most helpful in managing their pain.

The most common prescriptions currently being prescribed were: opioids (62%); muscle relaxants (49%); antidepressants (42%); anticonvulsants and antiepileptics (36%); topical agents (22%); anti-inflammatory drugs (22%); benzodiazepines (18%); sleeping medications (17%); local anesthetics and topicals (15%); preventive medications—such as calcitonin gene-related peptide blockers, beta blockers, calcium channel blockers, onabotulinumtoxinA, or selective serotonin reuptake inhibitors (15%); abortive/acute medications—such as triptans, gepants, ditans, or dihydroergotamine (14%); other (11%); steroids (9%); corticosteroids (7%); immunosuppressants (6%); biosimilars or biologics (5%); birth control pills (5%); opioid agonists and antagonists (3%); N-methyl-d-aspartate receptor antagonists (3%); antibiotics (2%); chemotherapy drugs (2%); and N-type calcium channel blockers (1%).

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### Most common prescriptions currently being prescribed



# PAIN MANAGEMENT THERAPIES: WHAT PATIENTS ARE TRYING—AND WHAT WORKS

The fact that opioids are the most commonly prescribed type of prescription medication is likely related to the severity of pain in this patient population. However, three-quarters (76%) of patients using opioids report extensive barriers to treatment. Obstacles included decreased doses (65%), stigmatization (62%), providers refusing to prescribe (56%), fear of being targeted for prescription (44%), pharmacy unwilling to fill prescription (44%), outright abandonment with providers refusing to treat the patient (32%), and other (21%).

Nearly all (94%) of those taking opioids who have faced barriers said they attribute these barriers to the 2016 CDC Guideline for Prescribing Opioids for Chronic Pain.

Respondents were also asked about their experiences with pain contracts and urine drug testing. About half of respondents (47%) had signed a pain contract at some point.

When asked about their feelings on pain contracts, 49% said they understand it is to keep them safe and help their doctor treat them appropriately. Other respondents viewed them negatively, stating it made them feel judged, like a criminal, or like their doctor does not believe them.

Numbers were similarly mixed for urine drug testing. 53% said they had been asked to take a urine drug test (UDT) at some point. Roughly half said they didn't mind taking a test, as it proves their adherence, or understood it was to keep them safe. However, the other responses viewed UDT negatively, reporting that it makes them feel judged, like a criminal, or like their doctor does not believe them; or they felt the out-of-pocket cost was high.



# PAIN MANAGEMENT THERAPIES: WHAT PATIENTS ARE TRYING—AND WHAT WORKS

Over-the-counter (OTC) medications are taken by 63% of respondents. Of those taking OTCs, the most commonly used medications were: topicals (59%); NSAIDs (58%); acetaminophen (55%); combination medications with NSAID and acetaminophen (24%); OTC headache medications (21%); and other (11%). The high use of topicals is interesting and perhaps reflective of the musculoskeletal basis for pain for many in this population.

Almost as high as the number taking OTC medications is the number of respondents who said they use supplements, vitamins, or herbs (58%). Further research might inquire into types of supplements, vitamins, and herbs used.

Respondents were specifically asked about use of cannabidiol (CBD) supplements, which are increasingly popular but not closely regulated. A total of 22% said they are currently taking CBD-from-hemp-only products, a small but noteworthy portion.

Respondents were also asked a series of questions related to use of medical cannabis. There is clear, significant interest in and use of medical cannabis, though inconsistent laws regarding the use of medical cannabis continue to pose access issues. Of those who live in states where it is legal (68%), 70% reported using it currently—a huge portion. Of those who live in states where it is not legal (23%), a total of 43% said they would try medical cannabis if it became legal in their state, suggesting opportunity for improved access.

People with pain are clearly desperate for relief and open to whatever options are available. In fact, one question asked if there was any side effect that would prevent them from taking a medication and listed very serious side effects (like liver damage, kidney damage, trouble breathing, etc.). A total of 24% said no—no side effect would preclude them from using a medication if it helped their pain.



# PAIN MANAGEMENT THERAPIES: WHAT PATIENTS ARE TRYING—AND WHAT WORKS

## Interventional procedures and surgeries

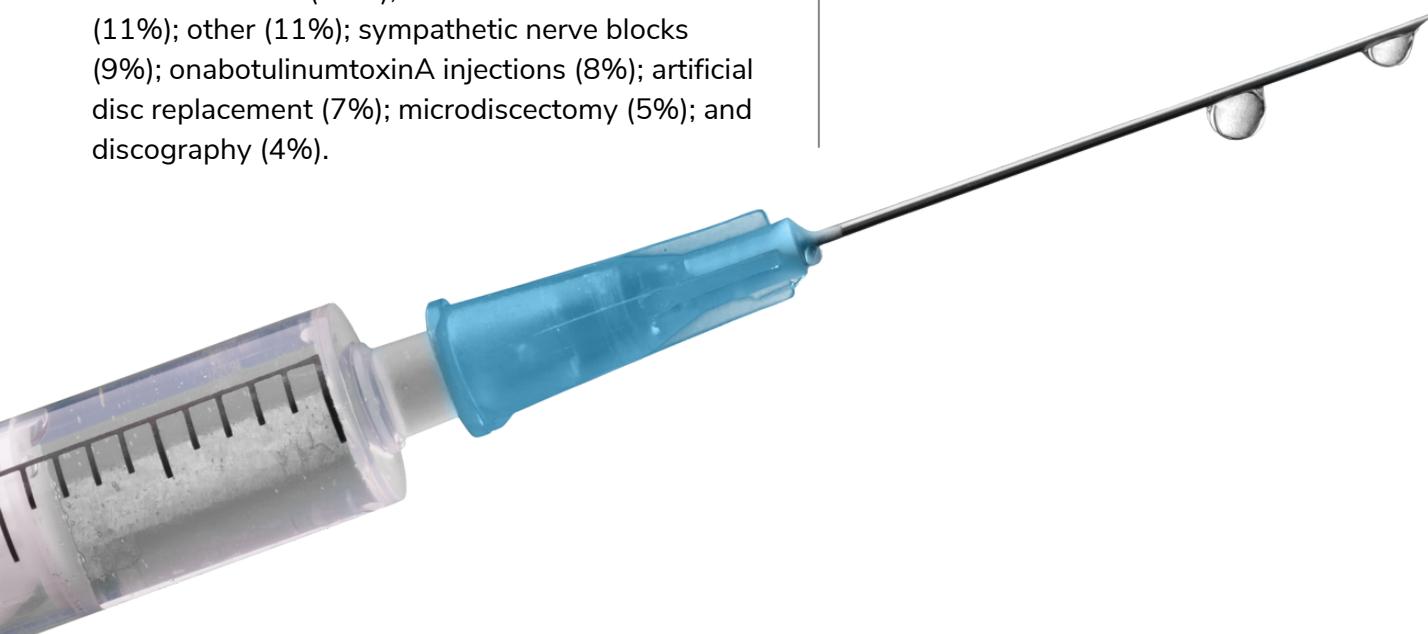
The final category of treatment looked at interventional procedures and surgeries. An overwhelming majority (87%) of respondents have tried this category; again, this likely reflects pain severity in this group. Injections topped the list of most commonly tried therapies, led by epidural injections (51%), trigger point injections (40%), joint injections (38%), and facet blocks (29%). All other options were tried by 20% or less of respondents.

Therapies in this category tried by 20% of respondents or less included spinal fusion (20%); peripheral nerve blocks (19%); nerve ablation or neurolysis (17%); laminectomy (16%); radiofrequency ablation/lesioning (15%); spinal cord stimulation (13%); medial branch blocks (11%); other (11%); sympathetic nerve blocks (9%); onabotulinumtoxinA injections (8%); artificial disc replacement (7%); microdiscectomy (5%); and discography (4%).

At 3% or less were: platelet-rich plasma injections (3%); hyaluronic acid injections (3%); microvascular decompression (2%); prolotherapy (2%); dorsal root ganglion stimulation (2%); stem cell therapy (2%); interspinous spacer (2%); peripheral nerve surgery (1%); peripheral nerve and field stimulation (1%); nerve repair (1%); laminoplasty (1%); and nerve capping, nerve connecting, or nerve protecting (1%).

At 0.5% or less were: chemical sympathectomy; thermal intradiscal procedures; chemical neurolysis; cryoneurolysis or cryoablation; deep brain stimulation; and stereotactic radiation.

While these lesser-used procedures and surgeries were tried infrequently, they remain important statistically given that they are mostly high-risk, high-cost, invasive procedures.



# RESTRICTED ACCESS: KEY BARRIERS TO EFFECTIVE PAIN CARE

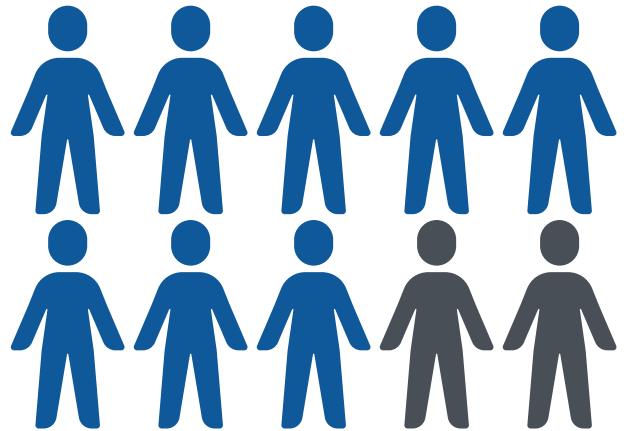


**81% of respondents reported barriers to treatment.**

With the severity of pain and disability in this population, access to care is essential. But 81% of respondents reported barriers to treatment.

Perhaps unsurprisingly in light of respondents' limited ability to work and low incomes, cost was the most commonly reported barrier at 49%. Next was prior authorization (39%); lack of options nearby (31%); high copays (27%); other (18%); fail first/step therapy practices (17%); annual visit limits (10%); and non-medical switching practices (5%). In "other," answers often mentioned the 2016 opioid prescribing guideline having a chilling effect on their care.

When asked if their insurance covers what they and their doctor believe is the best treatment option, only 36% of respondents reported feeling that insurance coverage decisions regarding their treatment options were primarily driven by their health care provider's recommendations, rather than cost.



These figures should raise alarm. Individuals with high-impact chronic pain face so much suffering; they are amongst the most vulnerable patients in our health care system. The idea that treatment may exist that could alleviate that suffering—but cost and insurance cost-saving tactics stand in the way—is devastating. Furthermore, we, as a society, undoubtedly pay the costs in other ways, whether in terms of disability payments, lost productivity, etc.

Finally, 40% of respondents said that mobility issues had limited their physical access to care. In this group, the three most common challenges were difficulty driving (70%), difficulty walking (59%), and difficulty waiting in line (48%). These results underscore the importance of accessible care, particularly telehealth, which is discussed more later in this report.

# PATIENT SAFETY: CONCERNs AND QUESTIONS

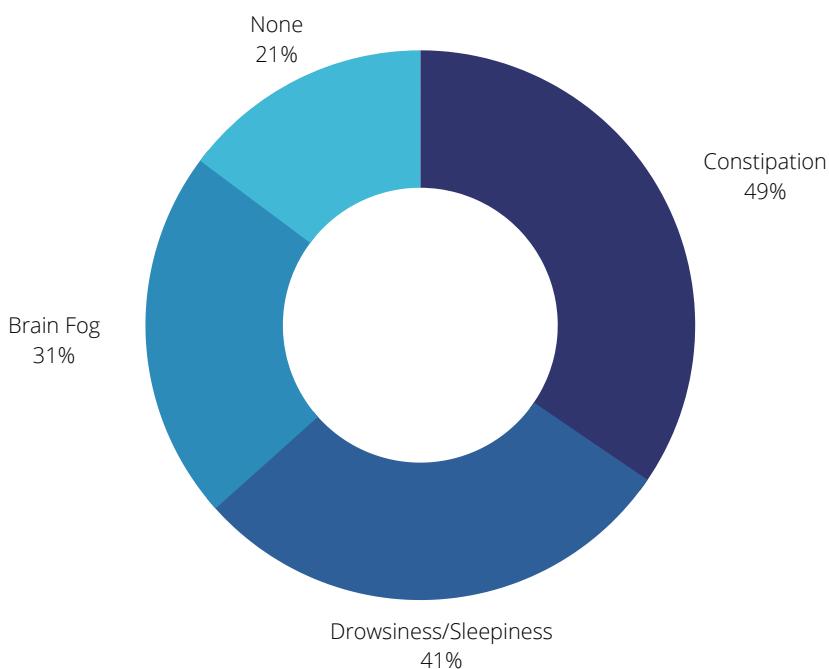
A series of questions in the survey asked about safety related to medications and procedures.

In the realm of medications, the most common side effects for those using prescription medications were constipation (49%); drowsiness/sleepiness (41%); and brain fog or trouble concentrating (31%). 21% of patients taking prescription medications said they did not experience side effects from their drugs.

Of those who reported side effects from using prescription medications, 72% of respondents said they tell their provider about side effects. This is heartening, but 23% said only “sometimes” and 5% said “rarely” or “no”—a smaller but important portion. Reasons for only “sometimes,” “rarely,” or not discussing side effects were: not thinking the side effect was bad enough (71%); fear of being taken off medication (35%); provider never asked (28%); did not know it was a side effect (25%); other (10%); and embarrassment (7%). These perspectives may be helpful for providers to keep in mind to help limit side effects and ensure adherence.

Positive news was that 91% of patients said they had told their provider about their use of OTC medications, though slightly less said their provider knew about their use of supplements, vitamins, or herbs (86%). Conversely, only 58% of respondents said their providers had ever discussed the safe use of OTCs with them—a concerning figure.

## MOST COMMON SIDE EFFECTS



Another identified gap is that despite widespread use of and interest in medical cannabis, guidance on its use is not easy to come by. Roughly half (55%) of current medical cannabis users said their doctor had suggested they try it; however, in learning what dose to take, the most common answer was trial-and-error (27%).

# PATIENT SAFETY: CONCERNs AND QUESTIONS

Trends in safe storage of medication were concerning as well. While 24% said they store their medications in a lock box and 16% said they put them up out of reach of others, most stored them in places that aren't fully secure like a nightstand (37%), kitchen cabinet (22%), bathroom (19%), in a purse or bag (17%), or in the refrigerator (7%). In addition, when asked about disposal of drugs, 37% said they never have extra medication—while 34% said they save it for later. A total of 35% said they bring it to a drug disposal location or bring it back to the pharmacy, but improper disposal was reported by 13% (throwing away, flushing down the toilet, or giving to someone else that needs it). (Respondents could select all that applied.)

In the area of interventional procedures and surgeries, there were also some troubling data. In the group that had tried interventional procedures and surgeries, when asked if the providers discussed the risks and benefits of these options, less than half said they discussed them "in-depth" (46%). More than one-third (37%) said the risks and benefits were "briefly mentioned," and 14% said "no."

When asked if their providers listened when they had concerns about risks with procedures, 37% said somewhat or no. In addition, more than one-quarter (28%) said their provider did not discuss other, non-interventional alternatives.

These figures are extremely concerning given the relative risk of this category of treatment compared to other categories.



# COVID-19 AND PAIN: RIPPLE EFFECTS CONTINUE

While the bleakest days in the COVID-19 pandemic have faded, challenges remain.

A total of 3% of respondents indicated they were experiencing long-COVID. The most common symptoms respondents associated with long-COVID were fatigue (71%), brain fog (58%), change in smell or taste (50%), palpitations (45%), joint or muscle pain (42%), and sleep problems (41%).

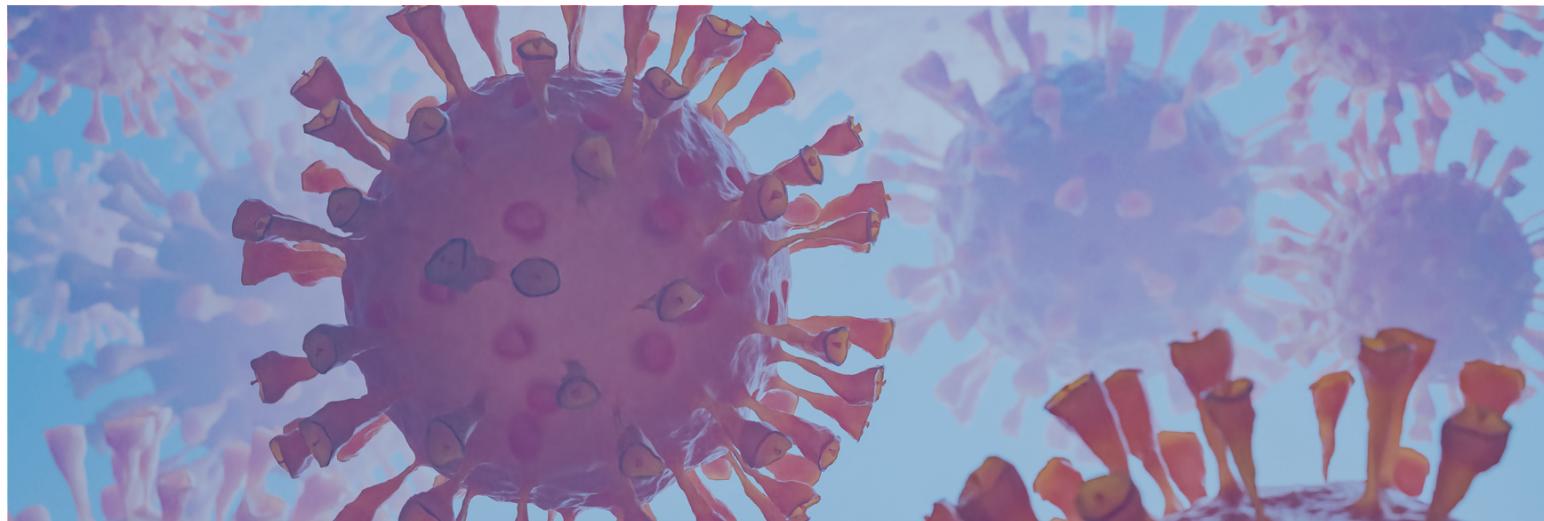
When asked if the COVID-19 pandemic had increased their pain in any way, 35% said yes. (This marks steady improvement over time: The rate was 64% in U.S. Pain's 2020 COVID-19 and Pain survey and 46% in its Understanding Barriers to Multidisciplinary Care survey.)

Similarly, 34% said the pandemic had impacted their ability to access pain care, an improvement from last year, when the rate was 53%. While the improvement is reassuring, however, one-third is still a sizable portion of respondents.

When asked how the pandemic had impacted their care, the three most common answers were: stress about COVID-19 had increased their pain (25%), contracting COVID (17%), and concern about contracting COVID preventing routine care (16%).

One bright spot out of the pandemic is the uptick in telehealth services. A large majority (80%) said they have used telehealth services during the pandemic. In that group, 59% said their providers have continued to offer telehealth—a positive figure, but ideally it would be higher in light of the severity of pain and disability in this patient population.

88% of patients said they hope their provider will offer telehealth options beyond the COVID-19 pandemic.



# FILLING THE GAPS: THE ROLE OF THE CAREGIVER/CARE PARTNER

Chronic pain affects entire families. As such, a portion of the survey focused specifically on caregivers or care partners; 72 individuals responded.

Most were spouses or partners (47%), followed by parents (28%), children (14%), other family members (4%), friends, neighbors, or other non-related individuals (3%), and siblings (1%).

The caregivers/care partners are quite closely involved in care. 56% reported accompanying the person they are caring for to medical appointments. Three-quarters (76%) reported discussing treatment options with the person living with pain.

But when asked about how confident they were in helping the person manage their pain safely, answers varied. More than half (54%) said they were not confident or only somewhat confident. In fact, nearly all—94%—face barriers in helping care for the person with pain. The most common challenges faced were provider attitudes (71%), insurance barriers (56%), other (25%), geographic barriers (18%), decision-making (14%), patient cognition (13%), and lack of transportation (11%).

That provider attitudes were easily the largest barrier underscores patients' reports on feelings of stigmatization and marginalization.

Sadly, 96% of caregivers and care partners reported feeling helplessness, and 80% reported feeling overwhelmed. Sizeable portions (roughly half to two-thirds) also reported feeling exhaustion, fear, stress due to financial concerns, and guilt. Further, support for care partners is significantly lacking. Approximately 54% of care partners said they either do not have a good support system in place or keep everything to themselves, and 79% said they have never participated in a support group for care partners.

More should be done to empower them to take better care of their loved ones—without such significant burdens on their own quality of life.

**When asked what resources might help, responses were:**

- **Case manager, social worker, or patient advocate (44%)**
- **More engagement with health care professional of the person they are caring for (42%)**
- **More affordable health care (40%)**
- **Time for self-care (31%)**
- **Other (28%)**
- **Accessible home care or assisted living options (22%)**
- **Transportation (15%)**
- **Another caregiving partner (13%)**

# WHAT'S NEXT: RECOMMENDATIONS

There is much work to be done to improve care for this underserved and vulnerable patient population, many of whom are in serious crisis due to the failures of our health care system.

We have several recommendations for a path forward.

1

## **Increase pain education for health care professionals, including through the dissemination of the Pain Management Best Practices Report.**

The Pain Management Best Practices Report, released under the Department of Health and Human Services in 2020, is a roadmap for improved pain management. But the report's dissemination has been limited at best. Despite its positive reception, many individuals outside of national pain experts seem unaware of its existence. It must be widely distributed, not just to pain management providers, but to general practitioners, including primary care physicians, who so often end up managing pain.

2

## **Invest more dollars into research on safe, effective treatments for chronic pain.**

Patients are desperate for relief. They typically must endure a painful, years-long process of trial-and-error to find treatments that work. No treatment is fully effective, and many come with significant risks. Some individuals never find relief at all. More research must be done into safe, effective, targeted treatments for the diverse range of pain conditions.

3

## **Develop patient education programs with an emphasis on self-management skills and offer them early on in the chronic pain diagnosis.**

Chronic pain management is a marathon, not a sprint. Especially with the paucity of effective treatment, patients need tools that empower them to take control of their pain on their own terms. But living with chronic pain not only turns an individual's world upside down physically—it has enormous ramifications emotionally. People with pain need specialized support and education to help them and their families navigate their new reality.

# WHAT'S NEXT: RECOMMENDATIONS

4

## **Further revise the Center for Disease Control and Prevention's update to its opioid prescribing guideline.**

The 2016 CDC Guideline for Prescribing Opioids for Chronic Pain undoubtedly has had a chilling effect on pain care and increased stigma surrounding chronic pain. While the CDC is revising its guideline, more must be done to improve the guideline's focus on individualized, multidisciplinary care. The guideline should take into account the full scope and recommendations of the Pain Management Best Practices Inter-Agency Task Force.

5

## **Implement a public awareness campaign about chronic pain to reduce stigma.**

The stigma faced by this group of patients is tragic and heart-wrenching—and completely preventable. Myths perpetuate that people with pain are dramatic, lazy, or drug-seeking, instead of humans suffering from horrific, debilitating conditions and injuries who are in need of help. This stigma significantly impedes the care and support they receive, which is scarce to begin with. Worse yet—people living with pain internalize this stigma, preventing them from fully seeking out the care and support they deserve. A public awareness campaign would undoubtedly help improve the quality of life of millions by promoting empathy and understanding for the unique challenges of chronic pain.

# WHAT'S NEXT: RECOMMENDATIONS

These recommendations are underscored by patients' responses when asked what top three policy issues are most important to them. The following answers were selected by 10% or more of patient respondents.

| Top 11 pain policy issues   |     |
|---|-----|
| Increased pain education for health care providers  | 41% |
| New medications for chronic pain  | 41% |
| Taking action on CDC Prescribing Guideline for Opioids  | 33% |
| Balanced approaches to opioid prescribing and dispensing  | 32% |
| Coverage of integrated, multidisciplinary pain care, including complementary treatments such as massage and acupuncture   | 30% |
| Improved access to wide range of treatments, including novel therapeutics, medical device innovation, and complementary treatments  | 20% |
| Medical cannabis access   | 20% |
| Telehealth coverage expansion   | 17% |
| Overall drug pricing  | 12% |
| Dissemination of the Pain Management Best Practices Report  | 11% |
| Putting curbs on pharmacy benefit and utilization management practices, including step therapy, prior authorization, non-medical switching, co-pay accumulators, Medicare Part B and D access, and cost | 10% |

# WHAT'S NEXT: RECOMMENDATIONS

Under 10% were: issues impacting headache disease; population health data collection, analysis, and reporting on chronic pain (i.e.: to find out how many people have different types of pain, age, gender, and race of those with pain, and the cost of pain care); coverage of biologics and biosimilars; and access to medical foods as a treatment approach to pain.

It is incredibly telling to see “increased pain education for health care providers” and “new medications for chronic pain” tied for the top two policy issues. These are foundational components of effective pain care, which this survey indicates is largely lacking.

Patient organizations like the U.S. Pain Foundation certainly have a role to play in these efforts. Respondents were asked to indicate the top three nonprofit services that are most helpful to them.

They are, in order: informative articles with key experts (56%); support groups (48%); advocacy efforts (40%); educational webinars (29%); educational handouts and infographics (23%); awareness campaigns (21%); patient-focused magazines (11%); other (6%); and volunteer opportunities (3%).

The survey authors will use this information to further tailor the U.S. Pain Foundation’s offerings and fill the gaps for this patient population. But we cannot do it alone. We are sounding the alarm on the crisis of pain in America and all hands on deck are required—policymakers, providers, researchers, caregivers or partners, industry members, employers and teachers, and advocates—to create much-needed, long-overdue change.



# ACKNOWLEDGEMENTS

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# ACKNOWLEDGEMENTS

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Association of Migraine Disorders  
CHAMP (Coalition for Headache And Migraine Patients)  
Clusterbusters  
Danielle Byron Henry Migraine Foundation  
The Ehlers-Danlos Society  
For Grace  
International Foundation for Autoimmune and Autoinflammatory Arthritis  
Interstitial Cystitis Association  
Lupus and Allied Diseases Association  
LupusChat  
Migraine Meanderings  
Miles for Migraine  
National Headache Foundation  
National Vulvodynia Association  
Rhode Island Patient Advocacy Coalition  
Sick Cells  
... and to the many other groups who helped share this survey

FOR MORE INFORMATION ABOUT THE U.S. PAIN FOUNDATION, VISIT: [USPAINFOUNDATION.ORG](http://USPAINFOUNDATION.ORG)

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