

BEHIND THE NUMBERS

WHAT IT REALLY MEANS TO LIVE WITH CHRONIC PAIN

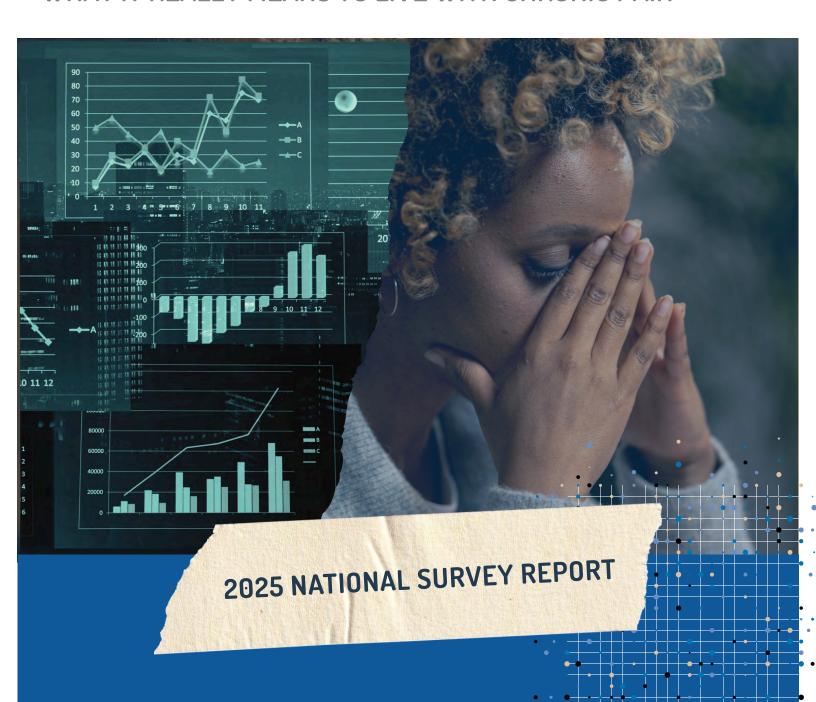


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INTRODUCTION & METHODOLOGY

Chronic pain affects nearly one in four Americans. Yet, its complexity and far-reaching consequences remain largely unaddressed in health policy and care delivery. According to November 2024 CDC data, 24.3% of adults live with chronic pain, a figure that reflects more than medical discomfort —it signals a national public health crisis.

Beyond its physical toll, chronic pain deeply impacts emotional health, relationships, school and employment, and daily independence. Pain reshapes lives—but those living with it remain marginalized, misunderstood, and undertreated.

To illuminate the realities behind these numbers, the U.S. Pain Foundation conducted a nationwide survey from May 5–25, 2025. A total of 2,420 individuals responded, including those living with chronic pain, caregivers, parents of children with pain, and health care professionals—as well as many individuals falling into multiple categories. This report focuses on the 2,098 respondents who completed the chronic pain-specific section of the survey. Findings from caregivers, children with pain and their parents, and health care professionals, who completed other sections of the survey, are summarized in separate reports to ensure their unique perspectives are fully represented.

These individuals' stories—and the data they provided—paint a vivid and urgent picture: chronic pain is not sporadic, not imagined, and certainly not a niche concern. It is a multidimensional lived experience shaped by stigma, gaps in care, and persistent systemic failures.

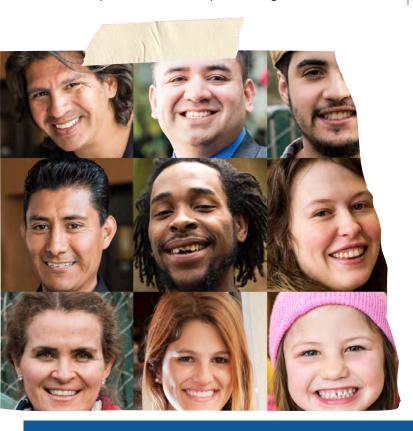


CHRONIC PAIN IS NOT SPORADIC, NOT IMAGINED—AND NOT A NICHE CONCERN.

SCOPE AND SCALE OF PAIN

Respondents ranged from 18 to 89 years old, with a median age of 57. They represented all 50 states, the District of Columbia, Puerto Rico, Guam, the Northern Mariana Islands, and 32 international locations. A striking 81% identified as women, 16% as men, and 3% as nonbinary or gender-diverse. Most were white, while 13% identified as Black, Latino, Indigenous, multiracial, or other communities of color.

While this demographic profile aligns with known trends in some aspects—chronic pain disproportionately affects women and older adults —it also reveals gaps in outreach and research. Future studies must ensure more inclusive representation, including among men, nonbinary or gender-diverse individuals, and communities of color—particularly since the latter two populations often experience chronic pain at higher rates.



Key Findings:

- **87%** have lived with chronic pain for over five years
- 32% have lived with it for over 25 years
- Respondents reported an average of 10 distinct diagnoses per person
- Conditions like back pain (64%), arthritis (53%), neuropathic or nerve pain (48%), osteoarthritis (42%), and fibromyalgia (37%) were among the most reported

Pain Is Multifaceted—And Rarely Isolated

Most people experience multiple overlapping pain types:

- 84% of those with **inflammatory pain** also had **musculoskeletal pain**
- 83% of those with **nociceptive pain** also had **neuropathic pain**
- 79% of those with **musculoskeletal pain** also had **neuropathic pain**

These patterns highlight the inadequacy of "one-size-fits-all" care. Pain is not just felt in the nerves, joints, or tissues—it often spans all of these. Effective care must address this complexity through integrated, multimodal treatment plans.

Specific Patterns of Overlap Reveal the Need for Comprehensive Care

Survey data also reveal striking multi-mechanism overlap—challenging assumptions about "typical" pain presentations. These findings confirm that many forms of chronic pain do not have a single root, but exist within an intricate interaction between musculoskeletal, neuropathic, inflammatory, nociceptive, and nociplastic processes. For example, individuals living with the following conditions reported experiencing multiple types of pain:

- Hip and knee pain almost always presented with musculoskeletal pain, with inflammatory pain not far behind. But almost 85% of each group also had neuropathic involvement, at similar rates to the inflammatory overlap challenging the notion that joint pain is solely joint-specific or tissue-based.
- CRPS (complex regional pain syndrome) showed the highest neuropathic involvement (92%) of all conditions, with significant musculoskeletal (70%) and inflammatory (72%) features.
- Fibromyalgia typically involved multiple classes of pain, including several at similarly high rates—musculoskeletal (87%), neuropathic (81%), inflammatory (80%).
- Rheumatoid and psoriatic arthritis were overwhelmingly associated with inflammatory pain (93% and 95%, respectively) but also showed significant musculoskeletal and neuropathic overlap.
- Sciatica, commonly considered a nerve condition, also exhibited high musculoskeletal involvement (87%)—underscoring the common back-nerve-joint interaction.

While living with multiple conditions and comorbidities certainly contributes to overlaps in pain types, these patterns also indicate that chronic pain is almost never "just nerve" or "just inflammation." It is a multi-pathway condition that demands integrated care: medication, restorative and complementary therapies, injections or surgeries, psychosocial support, and more. Programs, policies, and education must evolve to reflect this complexity—because people with pain are already living it every day.

CHRONIC PAIN IS ALMOST
NEVER 'JUST NERVE' OR
'JUST INFLAMMATION'—IT IS
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INTEGRATED CARE.

THE FULL IMPACT OF CHRONIC PAIN

Chronic pain is not confined to a physical sensation. It ripples through every corner of a person's life—limiting movement, affecting mental health, straining relationships, impacting income, and reshaping identity. For most respondents, pain is not only a medical issue. It is a pervasive experience that alters how they live, work, and connect.

Physical and Functional Impact

- 93% said pain significantly limited physical activity or hobbies
- 79% struggled with household chores
- 76% reported serious sleep disruption
- 76% missed work or school regularly
- 74% said pain significantly interfered with employment or job performance
- **61%** were unable to care for children or dependents due to pain

Chronic pain also pushes many out of the workforce entirely—eliminating not just income, but a sense of purpose and agency. These disruptions reinforce a cycle of economic instability and emotional strain.



Emotional and Social Disruption

The psychological toll is also severe:

- 72% reported a significant impact on their mental and emotional health
- 73% felt socially isolated or misunderstood
- 50% lacked emotional support from others

Relationships are deeply affected. Nearly all respondents (97%) said chronic pain has impacted their ability to socialize with family and friends in the past year. 70% reported a significant impact on romantic relationships and intimacy, while 40% also said pain caused tension or frustration in romantic relationships.

Pain isolates. It can sever bonds and foster silence instead of support. These patterns often go unseen—but they shape whether people feel loved, understood, or supported.



PAIN ISOLATES. IT SEVERS
BONDS AND FOSTERS
SILENCE INSTEAD OF
SUPPORT.



Differences Across Populations

- Women often reported higher social and emotional impact across all ages in many categories
- Nonbinary or gender-diverse respondents reported the greatest emotional burden—83% said their mental health was significantly affected
- Adults between the ages of 35 and 64
 experienced the most disruption to
 employment, relationships, and household
 chores
- Adults who were 50 and older continued to face physical limitations, sleep disruptions, and challenges with household chores

These findings reflect a powerful truth: Chronic pain changes everything—not just how people feel, but how they live.



Stigma Still Shapes the Pain Experience

Stigma was an all-too-common experience for respondents. Whether related to their condition or the treatments they use, individuals experienced stigma from a range of sources: friends, employers, family members, and even health care providers.

Stigmatization impacted respondents in a variety of ways: **61%** have experienced stigmatization from providers or pharmacies related to opioid prescriptions; **21%** are concerned about using medical cannabis or CBD for pain management because of associated stigma; and **79%** believe that stigma around chronic pain and its treatments are a major barrier to improving pain-related policies.

Common experiences included being labeled:

- "Drug-seeking"
- "Difficult"
- "Dramatic" or exaggerating their condition

Such judgment reinforces isolation, discouraging individuals from advocating for the care they need or openly sharing their realities with others.

THE MENTAL HEALTH TOLL—AND THE POWER OF PEER SUPPORT

Chronic pain is not only a physical condition—it is a **biopsychosocial** one. It touches every part of a person's identity, well-being, and relationships. The mental health consequences of living with persistent pain are deep, complex, and often invisible.

Psychological Distress Is the Norm, Not the Exception

- 95% of respondents reported feeling emotionally drained or irritable due to pain
- 88% said they experienced anxiety or depression due to their pain
- 85% felt overwhelmed by the combined weight of pain and mental health symptoms
- 78% said chronic pain had significantly impacted their mental health
- 57% noted that their mental health conditions (e.g., anxiety, depression) made pain harder to manage

These findings reveal a **detrimental feedback loop:** mental distress heightens physical symptoms, and pain deepens emotional struggle. Yet, few respondents reported receiving support that integrated both components.

Emotional Isolation and Lack of Support

The emotional burden of chronic pain is intensified by social isolation. **90%** of respondents said they had missed social events in the past year due to their pain. Even more concerning, only **28%** said their family and friends are **very supportive**.

This means the **vast majority** of people with chronic pain navigate their daily lives—managing symptoms, responsibilities, and emotional distress—**without consistent personal support.**

Isolation is unhealthy. It reduces emotional resilience, increases pain perception, and weakens the ability to cope.

- 73% of respondents felt socially isolated or misunderstood
- **79%** said their pain makes it **difficult to spend time** with family or friends
- 65% reported difficulty communicating with loved ones about their pain or limitations
- 70% said their romantic relationships were significantly impacted

These experiences paint a picture of disconnection—where people feel unseen, silenced, and emotionally alone, even in relationships meant to provide care.



Peer Support: A Path to Belonging and Validation

In this context, **peer support** emerges as a uniquely powerful intervention. It offers not just information—but **connection and belonging**.

Utilization and Impact

- Only 42% of respondents had ever joined a peer support group
- But of those who did, 77% found it helpful

Reported benefits included:

- Reduced feelings of isolation
- Emotional validation
- Sharing experiences with others who understand
- Resources and practical coping tools shared from lived experience

PEER SUPPORT CREATES CONNECTION, VALIDATION, AND A SENSE OF BELONGING.

Who's Participating—And Who's Missing Out

Peer support serves as a resource for lower-income individuals who may have less access to other resources; **40%** of survey respondents with a household income under \$25,000 have participated in a support group. But this type of support also emerged as a preferred resource even for those with more financial stability; **42%** of respondents with a household income of \$100,000-200,000 had also joined a group.

However, a majority still had **not participated**, despite clear interest.

Why People Haven't Joined

Barrier	% of Nonparticipants
No local options	37%
Didn't know support groups existed	31%
Unsure what to expect	19%
Struggled to find a good fit	19%

Encouragingly, 73% of those who hadn't joined a group said they would consider it in the future—especially if groups were flexible, welcoming, and confidential. Online formats were especially valued by those facing mobility challenges, health limitations, or geographic barriers—suggesting virtual models are critical to equitable access.

When asked what made a peer support group effective, respondents emphasized:

- Compassionate, understanding participants (88%)
- Safe, nonjudgmental environments (81%)
- Experienced facilitators (73%)
- Access to helpful resources (71%)
- Confidentiality and privacy (69%)

The U.S. Pain Foundation offers more than 60 free online peer support groups each month—yet participation continues to lag behind need. This gap is not just a missed opportunity—it's a solvable problem.

Increasing awareness, simplifying access, and improving outreach could dramatically expand participation. Strengthening the connection between people with pain and the support systems designed for them isn't just helpful—it's essential. Empowering individuals to feel seen, heard, and supported may be one of the most effective tools we have to improve quality of life.

CAREGIVING AND THE INVISIBLE WORKLOAD



For individuals living with chronic pain, even routine activities—bathing, cooking, driving, managing medications—can become overwhelming. Many need help. But too often, they go without it.

The Support Gap

- 56% said they **need caregiving assistance**
- Yet only 32% currently receive it (through family, friends, or paid caregivers)
- 24% of all respondents go without support they know they need

This gap is not evenly distributed. Among those with a household income of **under \$25,000/year**, one in three **(33%)** reported unmet caregiving needs. In contrast, only **11%** of those with a household income of **\$100,000 or more** faced the same issue. Income strongly shapes access to help.

At the same time, 40% said they **don't need caregiving**. But that number deserves scrutiny: given that 93% of respondents **face physical limitations** and 79% **struggle with chores**, many are likely managing without the support that could truly make a difference for them—perhaps due to pride, financial constraints, lack of availability, or limited knowledge about available resources and how to access them.

Caregiver Access by Income

Income Level	Receive Help	Need But Don't Get Help	Report No Need
Under \$25K	34%	33%	29%
\$25K-\$50K	31%	29%	35%
\$50K-\$100K	35%	23%	40%
\$100K+	31%	11%	54%

Without caregiving assistance, people with chronic pain are left to manage physical limitations alone—fueling a **vicious cycle** of greater pain, reduced capacity, and declining economic stability. Caregiving is not a luxury. It is a lifeline.

THE DIAGNOSTIC JOURNEY: TRUST, DELAYS, AND DISMISSAL

For many respondents, the path to a diagnosis was long, confusing, emotionally taxing, and not always successful. Even when pain was severe or constant, providers were slow to offer answers and validation.

How Long It Took

- Only 15% received a diagnosis within 6 months of symptoms
- **33%** waited 1–5 years
- 29% waited more than 5 years
- Others were never diagnosed at all

Delays in diagnosis aren't just frustrating—they're harmful. They often lead to worsening symptoms, unnecessary procedures, emotional suffering, economic hardship, and a loss of trust in the medical system.

Delayed diagnosis appears to be a generational problem, not just a one-off barrier. Younger respondents—especially those under 35—were more likely to report waiting three or more years for a diagnosis. This suggests systemic dismissal of younger people's pain, lack of access to specialists early on, or the bias that pain in youth or young adulthood is "psychosomatic" or temporary.

Adults who were 55 and older were more likely to receive a diagnosis within a year of symptom onset, possibly reflecting more-frequent health care interactions, higher likelihood of belief from providers, or more obvious physical correlations with aging.

However, those between the ages of 35 and 54 also showed meaningful rates of diagnostic delays, confirming that this issue cuts across generations.

The "never-diagnosed" category appeared across all age groups—but especially among younger respondents, highlighting critical gaps in early recognition and validation of pain.

The road to obtaining a diagnosis often includes significant detours for those living with pain:

- 21% had seen more than 10 providers in search of answers
- Another 32% had seen between 6 and 10 providers

And for many, that road is unending.

FOR MANY, THE ROAD
TO DIAGNOSIS IS LONG,
CONFUSING,
EMOTIONALLY TAXING
—AND SOMETIMES
UNENDING.

Most Common Suspected But Undiagnosed Conditions

Even after years of seeking answers, many individuals continue to live with **unexplained symptoms** and a sense that something important has been overlooked. In fact, 38% of respondents—even those with a diagnosis—or their providers believe they **still have undiagnosed conditions**.

When asked which conditions they **suspect but** have never been formally diagnosed with, respondents cited a range of pain-related disorders:

- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)
- Fibromyalgia
- Arthritis
- Neuropathic pain
- Ehlers-Danlos syndrome (EDS)
- Postural orthostatic tachycardia syndrome (POTS)

These are complex, overlapping conditions—some frequently dismissed as psychological, especially in women and youth. These suspected diagnoses reflect both the complexity and the overlapping nature of chronic pain. Many respondents are living with multiple coexisting pain-related conditions—further complicating the diagnostic picture and highlighting how pain often manifests as a web of interconnected disorders rather than a single identifiable illness.

What Delays Diagnosis?

Reported Barriers	% of Respondents
Dismissive attitudes from providers	71%
Lack of access to specialists	43%
Financial constraints	31%
Insurance limitations	20%

Diagnosis is not just a clinical event—it is often a milestone of validation and a road forward. And too often, people living with pain are denied that validation.

However, even after a diagnosis, the journey does not get easier:

- Only 12% felt their providers fully understood their pain
- 60% said others (medical and non-medical) don't understand at all
- Only 3% felt very well understood

When diagnosis is delayed or dismissed, people are not only denied treatment—they are denied trust, clarity, answers, and hope.

FOR SOME, DIAGNOSIS REMAINS AN UNFINISHED PUZZLE.

GEOGRAPHIC AND STRUCTURAL BARRIERS TO PAIN CARE

Access to effective, affordable pain care remains deeply uneven across the United States.

Respondents—urban and rural alike—described a common challenge: finding nearby pain specialists, clinics, or comprehensive services.

More than one-third (35%) of respondents cited a lack of nearby providers as a barrier to care. This is particularly consequential in rural or underserved areas, where geographic isolation and transportation challenges make delays in care even more detrimental.

States with the Highest Reported Geographic Gaps

- Alabama (55%)
- lowa (41%)
- Colorado (40%)
- **Oregon** (39%)
- Texas (38%)

These gaps potentially stem from multiple causes: rural hospital closures, limited pain specialists, lack of Medicaid expansion (e.g., Alabama, Texas), and inadequate integrative services outside major metro areas.

Even in states like Colorado and Oregon that reported strong health systems or expanded insurance, pain-specific services are often limited, unevenly distributed, or entirely absent— especially beyond urban centers. General health care access ≠ chronic pain care access.

Another resounding message from respondents: Insurance coverage does not guarantee access to chronic pain care. Many insured individuals still faced months-long waits, had no nearby options, or couldn't find providers offering multidisciplinary treatment.

These gaps are not just a rural problem, nor one that insurance reform alone can solve. They represent a widespread, systemic failure that cuts across geography, income, and infrastructure, leaving patients without the specialized support they need.



GENERAL HEALTH CARE ACCESS ≠ CHRONIC PAIN CARE ACCESS.

COVERAGE WITHOUT CARE: THE HEALTH INSURANCE PARADOX

Even when services are available nearby, and even when individuals have health insurance, many still face significant access challenges. The following data from our survey reveal the disconnect between **coverage on paper** and **care in reality**.

Survey respondents reported a wide range of insurance types:

• Medicare: 52%

• Private or employer-sponsored: 40%

• Medicaid: 18%

• Marketplace plans (healthcare.gov): 7%

VA or military: 3%Uninsured: 2%

Despite this broad coverage, significant barriers to pain care were reported across every insurance category—demonstrating that insurance status alone is a poor predictor of whether someone will receive effective or appropriate treatment.

For individuals living with chronic pain, insurance often serves as a gatekeeper rather than a gateway—limiting not only what treatments are covered but also which options are affordable, accessible, and timely.

Across all insurance types, cost emerged as one of the most frequently cited barriers to care, with **50%** listing it as a factor (and **26%** also citing high copays). Cost posed an access hurdle for respondents at the following levels based on their insurance coverage category:

- **53%** of respondents with private or employer-sponsored insurance
- 46% of those with public insurance (e.g., Medicare or Medicaid)

These findings challenge the assumption that private insurance invariably offers superior access. In reality, the broad fluctuations in coverage through employer-sponsored plans mean that many participants still face high deductibles, copays, or out-of-pocket costs, and limited coverage for non-drug or alternative therapies.



Disproportionate Impact on Low- and Middle-Income Households

Cost-related barriers were especially acute. Nearly **1 in 4** of respondents with a household income of less than \$50,000 had not seen a medical provider at all for their pain.

Middle-income respondents (with a household income of \$50,000–\$100,000) also faced significant barriers. Often ineligible for public programs yet unable to afford high out-of-pocket expenses, they frequently fell into a "coverage gap." Notably, those in this income bracket with private insurance were more likely to report cost barriers than their publicly insured peers—highlighting shortfalls in employer-based insurance plans.

Even among higher-income respondents (with a household income of more than \$100,000), more than 20% still cited cost as a barrier, underscoring the fact that affordability challenges are structural —not confined to low-income populations.

Bureaucratic Hurdles and Delays

Financial concerns were only part of the picture. Many respondents also encountered **insurance-related administrative barriers** that delayed or denied access to care:

- Prior authorization requirements (46%)
- Step therapy or "fail-first" protocols (26%)
- Annual visit limits (11%)
- Non-medical switching practices (6%)

Another particularly fraught hurdle facing individuals with pain was access to prescription medications—especially opioids. Among respondents who sought opioid prescriptions, 73% encountered at least one barrier. In addition to cost or insurance access issues, other barriers included stigma from providers or pharmacies, providers who refused to prescribe the medications, dosing reductions, and CDC guideline restrictions.

These challenges often left patients without viable alternatives—forced to endure unmanaged pain despite exhausting other treatment options.



Frequency of Care Closely Tracked With Income

Respondents with a household income of over \$100,000 were often more likely to report five or more medical appointments per month, while those with a household income of under \$25,000 often had less-frequent appointments, many seeing a doctor once a month or even less often. This underscores stark disparities in access to comprehensive care.

Yet more care did not always mean better care. Among those with frequent appointments, 21% still felt "not at all understood" by their providers, a similar rate as those seeing the doctor less frequently—highlighting persistent gaps in provider empathy, communication, and trust.

Rather than being shaped by medical need, access to pain care is more often dictated by a complex web of systemic limitations. These include insurance hurdles, cost, restricted provider availability, geographic inequity, and stigma. Until these barriers are addressed, treatment decisions will continue to reflect what the system allows—not what patients genuinely need to manage their pain and restore their lives.

ACCESS TO PAIN CARE IS TOO OFTEN DICTATED BY BUREAUCRACY—NOT MEDICAL NEED.

NAVIGATING A FRAGMENTED SYSTEM: THE REALITIES OF PAIN MANAGEMENT

People living with chronic pain are often forced to piece together their own treatment and coordinate multiple specialists—facing a disjointed maze of inadequate, ineffective, or unavailable care. Many respondents shared that **no single option offers complete or consistent relief**. Multidisciplinary care is key, but a lack of coordination often curtails effective holistic care.

Respondents were asked what treatments or therapies they *have ever tried* for pain. The **most commonly tried** approaches were:

- Medications, both prescription and over-thecounter (89%)
- Restorative therapies, such as physical therapy, massage, or heat or cold (87%)
- **Self-management strategies**, like pacing, movement, or mindfulness (86%)
- Injections, blocks, or infusions (78%)

This tells a clear story: People with chronic pain are actively engaged in their care and routinely combine multiple treatments, often out of necessity.

PEOPLE LIVING WITH CHRONIC PAIN ARE OFTEN FORCED TO PIECE TOGETHER THEIR OWN TREATMENT.



Self-Management Is the Norm, Not the Exception

Among respondents who had ever tried selfmanagement techniques, **88%** said they *currently* use them. These strategies include:

- Activity pacing and modification (81%)
- Movement or exercise (69%)
- Stress reduction (61%)

This high rate of usage highlights how central self-directed strategies have become. Additionally, many turn to these methods in the absence of formal care, reflecting a population managing symptoms with limited external support.

Restorative Therapies Play a Key Role

73% of respondents who have tried **restorative therapies** reported *currently* using them. Some of the most commonly utilized are:

- Heat and cold therapy (76%)
- Physical therapy (50%)
- Exercise programs (40%)

These treatments are frequently used in tandem with medications or self-management. But access is often determined by cost and geography—not clinical appropriateness.

Complementary and Integrative Health: Cost and Access Matter

A total of **55%** of respondents have tried **complementary or integrative health options**, and among those, **41%** are *currently* using them. Examples include **yoga** (52%), **herbal or vitamin products** (51%), and **acupuncture** (35%).

Several trends were noted among lower-income participants:

- 31% of individuals currently using these methods had a household income of less than \$50,000.
- 45% of those who do not use these strategies or skipped this question are in the same income bracket.

Price, availability, provider awareness, and a lack of focus on comprehensive care all suppress uptake —even among those who might benefit.

Mind-Body Approaches Are Desired, But Disjointed

Among the **56%** of respondents who have ever utilized **mind-body or behavioral health approaches**, **78%** are *currently* doing so. These include:

- Meditation and mindfulness (71%)
- Stress reduction (68%)
- Counseling or therapy (51%)



PATIENTS WANT ACCESS TO A BROAD RANGE OF TREATMENTS.

Continued utilization is strong among those accessing these treatments, suggesting a clear patient appetite for nonpharmacologic, whole-person approaches to pain relief. While these techniques are gaining traction, they often exist outside of the traditional medical system, leaving patients to discover and implement them on their own. The growing integration of new chronic pain treatment programs that emphasize the mind-body connection may be an early indicator that this is changing.

Prescription and OTC Medications: Widespread Use, Mixed Results

Medications remain a pillar of pain management, with **89%** of respondents having utilized them at some point.

- 83% of those *currently* use **prescription** medications.
- 68% currently use over-the-counter (OTC) medications like ibuprofen, acetaminophen, or naproxen.

Opioids, muscle relaxants, antidepressants, antiepileptics, and NSAIDs were most frequently cited as helpful—but side effects are common. Many respondents reported constipation, drowsiness, brain fog, opioid-induced constipation, and nausea.

Despite these risks, 21% said no side effect would stop them from trying a medication—highlighting the desperation some feel for the possibility of relief. This is a recurrent finding that has surfaced in previous surveys.

Barriers to Opioid Access: Systemic and Unequal

Of those who sought or received a prescription for opioid medications, **73%** faced barriers. Among that group, respondents reported:

- Stigmatization from providers or pharmacies (61%)
- Dosing reductions (56%)
- CDC guidelines (56%)
- Doctors unwilling to prescribe (55%)
- Pharmacies unwilling to fill prescriptions (42%)

These barriers disproportionately affect low-income patients—45% of those who faced challenges had a household income of under \$50,000. The most-affected states included California, Florida, Texas, Illinois, and Maryland, indicating that both policy and geography shape access.

Cannabis and CBD Are Being Used More—But Not Fully Integrated

Almost half of respondents **(48%)** have tried **medical cannabis, CBD, or both** to manage their pain. Of that group, **48%** are *currently* using one or both. Among those who responded:

- 66% found these methods somewhat or very effective.
- **73%** support integrating cannabis and CBD into formal pain care.
- Just **30%** felt their provider was knowledgeable about these options.

Top motivations for trying medical cannabis or CBD included lack of relief from traditional options, personal research, and recommendations from friends or family—often more than formal medical guidance. Reduced pain intensity was the largest impact at 79%, followed by improved sleep (63%) and reduced anxiety (59%).

Common concerns about using these treatments remain: cost, legal or regulatory issues, safety and side effects, stigma, provider cooperation, acceptance, and lack of research.



Neuromodulation: Noninvasive, Yet Underused

More than half of respondents (54%) have tried external neuromodulation or stimulation devices for pain relief, but only 39% of those who tried them *currently* use them. TENS units were by far the most common (72%), followed by neuromuscular electrical stimulation (14%), infrared light therapy (13%), and vagus nerve stimulation (7%).

While interest in neuromodulation continues to grow, broader adoption may be hindered by barriers including affordability, accessibility, and variability in provider awareness or endorsement. As nonpharmacologic and noninvasive options, these tools warrant greater inclusion in comprehensive pain care.

Interventional Treatments Are Common—But Communication is Lacking

A striking **84%** of those who had tried any **interventional procedure** (such as injections, blocks, infusions, surgical procedures, implanted devices, or neurolysis procedures) had tried more than one type; **68%** had tried more than two; and **53%** had tried more than three. Yet:

- Only 50% received an in-depth conversation with their health care provider about risks and benefits prior to the procedure.
- Just 34% were thoroughly informed about non-interventional alternatives to these procedures.

This suggests that while many people are routed into invasive procedures, there is often a lack of fully informed consent or shared decision-making.

Together, these findings expose a care system that puts the burden of trial and error on patients. People with chronic pain are not passive—they are resourceful individuals trying to navigate a fragmented system, often with incomplete information or a lack of coordinated support.

Despite trying a wide range of therapies—self-management, medications, medical cannabis, procedures, and more—few found consistent or lasting relief. Treatment is often piecemeal, shaped more by barriers than by clinical guidance.

Access remains uneven, shaped by income, geography, education, stigma, and poor or disconnected provider communication.

CLINICAL TRIALS AND THE CHRONIC PAIN COMMUNITY

Despite progress in chronic pain research, a deep disconnect remains between scientific advancement and patient participation. Just 11% of respondents had ever taken part in a clinical trial, and 70% were unaware such studies existed for chronic pain. Yet interest is high: 85% said they would consider joining—if trials were designed with patient needs in mind.

The top barrier? Awareness, cited by 59% of respondents who either have participated in research or are interested in doing so. But other obstacles are present. Many feared stopping current treatments (46%), worried about side effects (42%), or hesitated to risk being in a control group without active treatment (38%). Logistical hurdles—transportation (28%), financial strain (26%), and time constraints (24%)—added further difficulty, especially for those already managing pain and disability. Notably, one in four cited mistrust of the medical or research system, reflecting a long-standing credibility gap in pain care.

Additional concerns included unclear study goals (20%), data privacy (19%), and a lack of study updates or follow-up (13%).

Yet the survey also revealed a clear path forward to improved patient participation in vital research. Respondents overwhelmingly called for:

- Virtual participation (71%)
- Transparent communication (65%)
- Flexible scheduling (63%)
- Travel reimbursement or assistance (60%)
- Peer or emotional support during studies (33%)



Health care providers were the most common link to research opportunities—yet **fewer than 10%** of respondents felt that chronic pain research was meaningfully applied in their care. Meanwhile, **95%** agreed that patients should have a voice in shaping research priorities.

These findings reveal a tremendous untapped opportunity. People with pain are willing and ready to engage in research—but only if it becomes more transparent, inclusive, and aligned with their day-to-day realities. For this community, clinical trials aren't just about generating useful data—they're about being validated, respected, and protected.

Research must be managed in a way that is considerate of patient needs, centered around patient safety, and respectful of the opinions of individuals with lived experience. Making research patient-centered isn't a luxury. It's the only path to meaningful breakthroughs.

THE MISSING PIECE: PATIENT EDUCATION

Patient education is widely recognized as a cornerstone of effective chronic pain management—yet for many, it remains elusive. **Nearly half** of individuals living with chronic pain report that they have either **never received education** from a health care provider about managing their condition (38%) or are **unsure** if they have (11%). Only 51% confirmed receiving any such guidance, underscoring a significant breakdown in communication between patients and providers.

Even among those who did receive education, the quality and impact appear limited. While 42% of respondents found the information helpful, nearly the same proportion expressed indifference, and 16% found it unhelpful. These findings raise serious concerns about both the **relevance** and **delivery** of educational content, especially given its potential to improve outcomes, support selfmanagement, and build therapeutic trust.

Respondents most commonly recalled discussions focused on non-medication approaches such as physical therapy, mindfulness, exercise, nutrition, and lifestyle changes, as well as medications. Yet fewer than half received information on topics like mental health, managing their comorbidities, or understanding their condition and its progression—despite the vital role these areas play in comprehensive pain care.

In response to these gaps, many patients turn to non-clinical sources. A majority—83%—reported seeking pain management information from outside the medical system. Among these, online resources (96%), books and articles (69%), and social media or online communities (61%) were most frequently used. Respondents also cited educational videos, advocacy organizations, and peer support groups. This pattern reflects both a thirst for knowledge and a systemic failure to meet that need within clinical settings.



83% OF PATIENTS SEEK PAIN MANAGEMENT INFORMATION FROM OUTSIDE THE MEDICAL SYSTEM.

BEHIND THE NUMBERS: 2025 NATIONAL SURVEY



ARE STRONGLY
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Importantly, patients are not turning away from health care—they are supplementing it. The top two preferred learning methods, both sought after by 60% of respondents, were in-person discussions with health care providers and online resources, revealing a clear desire for education that blends credibility with accessibility.

Encouragingly, nearly **85% of respondents** expressed interest in a **free educational online pain management program**, highlighting a powerful opportunity to meet patients where they are—through comprehensive, affordable, and trustworthy resources.

Taken together, these findings spotlight a critical yet often-overlooked component of pain care: patient education. Individuals living with chronic pain demonstrate strong motivation to learn, self-manage, and engage with care—but they are frequently left without adequate guidance from the health care system.

To close this gap, patient education must be repositioned as a core clinical service—not an optional add-on. Expanding access to comprehensive, multidisciplinary education, delivered in formats that are trusted, inclusive, and patient-centered, should be a top priority in any modern approach to chronic pain care.

ADVOCACY, REPRESENTATION, AND POLICY REFORM

People living with chronic pain are emerging as a powerful yet underutilized voice in shaping health care policy. Among respondents, there is both a deep understanding of systemic challenges and a strong desire to be part of the solution. Yet their insights, experience, and leadership are rarely invited into the rooms where health policy decisions are made.

Despite facing overwhelming daily challenges, this community demonstrates powerful civic potential. While only **34%** of respondents have participated in any form of advocacy to date, a striking **82%** expressed a desire to become more involved—if opportunities to engage were more accessible, inclusive, and low-barrier. This gap reveals an enormous untapped potential for grassroots advocacy.

For people living with pain, advocacy can be exhausting. Respondents cited barriers such as pain-related fatigue, fear of being dismissed, emotional strain, and uncertainty about how or where to begin. Even within a community already connected to structured advocacy opportunities—like the U.S. Pain Foundation—these barriers remain real and persistent.

Yet many are still finding ways to engage. Peer support networks, online campaigns, storytelling platforms, and training programs offering prewritten letters have all helped lower the threshold for impactful action.

When asked what matters most in pain policy, these leading priorities emerged:

Advocacy Priorities	% of Respondents
Increased pain education for health care providers	51%
Developing new pain medications	35%
Balanced opioid prescribing policies	29%
Reducing insurance barriers	28%



BEHIND THE NUMBERS: 2025 NATIONAL SURVEY

These are not abstract policy goals — they reflect the urgent, lived experience of people whose access to care is being compromised. Two-thirds (66%) of respondents said current pain policies have made it harder for them to access effective treatment. Over 70% believe that opioid regulations are unbalanced and restrictive. And only 10% felt that health care providers truly understand the policy landscape patients are expected to navigate.

Still, the most painful theme to emerge was **exclusion**. A full **84%** of respondents said they do **not** feel adequately represented in policy discussions. **Only 2%** felt that their voices are genuinely heard.

Participants called for a shift to "nothing about us without us" models of engagement—including patient-led advisory boards, accessible testimony opportunities, and co-design of research and clinical programs. Without meaningful inclusion of lived experience, even the best-intentioned policies risk falling short of the needs they aim to serve.

The chronic pain community is ready to lead. But they must be invited in, supported, and truly heard.



THE CHRONIC PAIN
COMMUNITY IS READY
TO LEAD.

WHAT'S NEXT: NINE RECOMMENDATIONS FOR SYSTEMIC CHANGE

This survey exposes the **scale and complexity** of chronic pain in America—and the systemic failures that shape how pain is experienced and treated. But it also illuminates **solutions**. These nine recommendations form a framework for **meaningful**, **people-centered reform**.

- **1. Expand insurance coverage** to include all evidence-based pain care services, and eliminate short-term cost-driven treatment barriers.
- **2.** Make peer support a standard component of care, recognizing its clinical value and embedding it into health systems and reimbursement models.
- **3. Develop multidisciplinary care models** that center on patient needs and incentivize outcomes over volume.
- **4. Integrate mental health** into all pain care, acknowledging that emotional well-being, trauma, and grief are inseparable from physical pain—and addressing them jointly to foster effective coping strategies.
- **5. Remove access barriers** linked to geography, income, and stigma through telehealth, mobile care, and public awareness.
- **6. Improve provider education and timely diagnosis** by mandating training in chronic pain, implicit bias, and empathetic care.
- **7. Empower patients through education**, offering accessible, evidence-based tools to facilitate self-management, shared learning, and long-term engagement in their care.
- **8. Democratize research** by making clinical trials more inclusive: Co-design with patients, offer flexible participation, and expand access through primary care.
- **9. Prioritize lived experience in policymaking**, giving patients leadership roles in shaping care models and systems.

CONCLUSION: A ROADMAP AND A WARNING



This report is more than data. It is a **portrait of our current lived reality**, drawn from thousands of individuals who have endured pain in silence—and are now speaking out together.

Chronic pain is not simply a symptom. It is a condition shaped by systems: health care, insurance, geography, culture, and policy. It is also shaped by stigma, misconceptions, disbelief, fragmentation, and delay.

Yet in the collective responses to this survey, the **resilience**, **clarity**, **and leadership** from those living with pain shines through.

This report is both a warning and a roadmap.

It warns what happens when pain is ignored.

And it points toward what's possible when people with pain are heard.

WHEN PEOPLE WITH
PAIN ARE HEARD
RATHER THAN IGNORED,
POSSIBILITY EMERGES.

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