### UNDERSTANDING BARRIERS TO MULTIDISCIPLINARY PAIN CARE



#### MESSAGE FROM THE CEO

Clinical experts agree that a multidisciplinary, individualized approach is best practice in pain management.<sup>1</sup> Even state and federal officials have begun to weigh in on the topic, writing policies and laws that emphasize the importance of access to a wide array of therapies.

But does our health care system—from insurance policies to clinician recommendations—actually support a comprehensive approach to pain?

To better understand the real-life barriers patients face in accessing pain care, the U.S. Pain Foundation recently conducted a 57-question survey in collaboration with Sunbeam<sup>®</sup>. The results were strikingly clear: our pain care practices and policies do not align with our principles. Although patients want and need a diverse range of treatment options, they often have difficulty accessing them due to obstacles ranging from cost to mobility issues.

Our hope is that this survey report can serve as a starting point to addressing and reducing these barriers. Given the enormous burden of pain on our health care system and finances, it is the wise thing to do. But we must not forget that beyond its quantifiable impact, pain also represents enormous suffering and an untold loss of human potential.

Reducing barriers to treatment is, in fact, a moral imperative.

Sincerely,



Nicole Herm

Nicole Hemmenway CEO, U.S. Pain Foundation

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### KEY TAKEAWAYS

THE REALITY ON THE GROUND IS THAT MOST PAIN PATIENTS ARE NOT GETTING ACCESS TO MULTIDISCIPLINARY AND INTEGRATIVE PAIN CARE, THE CARE THAT IS WIDELY VIEWED AS BEST PRACTICE.

- Of patients seen at pain clinics or centers, more than threequarters said that the clinic or center only offers pain doctors, not multidisciplinary specialists, like psychologists, nutritionists, physical therapists, or sleep specialists (76.5%).
- Providers typically most emphasized medications (38.4%) and interventional procedures (26.2%), while patients wish they most emphasized complementary and integrative health (39%), restorative therapies (36.6%), and medications (35.5%).

COST IS THE BIGGEST BARRIER TO ACCESSING TREATMENTS, INCLUDING THOSE THERAPIES THAT LACK COVERAGE AND SOME THERAPIES THAT ARE COVERED, BUT HAVE UNAFFORDABLE COPAYS OR LIMITS ON THE NUMBER OF VISITS COVERED BY PAYERS.

- More than three-quarters of respondents indicated cost prevented them from accessing one or more treatment options (76.5%). Cost was most commonly a barrier to massage (52.8%), acupuncture (39%), physical therapy (29.4%), chiropractic care (27%), exercise programs (26.8%), and medical cannabis (24.4%).
- Of those with insurance, more than half said high copays prevented them from accessing treatment (51.9%).
  High copays were most commonly a barrier to physical therapy (26%), massage (24.4%), chiropractic care (21%), acupuncture (21%), and counseling/talk therapy (16.4%).

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TELEHEALTH HAS IMPROVED ACCESS TO CARE FOR LARGE NUMBERS OF PAIN PATIENTS. THE HASTENING OF COVERAGE PARITY FOR TELEHEALTH SERVICES BROUGHT ABOUT BY THE PANDEMIC HAS BEEN A HUGE SILVER LINING FOR PAIN PATIENTS.

- Slightly more than half (50.7%) said mobility issues—primarily difficulty driving—have prevented them from accessing treatment.
- An overwhelming majority of respondents (89.9%) said they would like telehealth to continue beyond COVID-19.

#### THE TOP THERAPY MOST OFTEN USED TO MANAGE PAIN IS HEAT AND COLD THERAPY. THIS IS A HIGHLY EFFECTIVE BUT UNDERAPPRECIATED RESOURCE.

- When asked what they currently use to manage pain, 65.7% of respondents chose heat and cold therapy.
- When asked what selfmanagement strategies are "somewhat effective" or "effective," a large majority (77.3%) chose heat and cold therapy.
- 67.8% use heat at least once a week, and 44.9% use cold at least once a week.

#### PAIN PATIENTS MOST WANT ACCESS TO MASSAGE THERAPY BUT CONFRONT BARRIERS TO THIS MODALITY.

- When asked which providers they would like to see or see more of, but cannot because of barriers like cost, massage therapists was the top choice of respondents (48.4%), followed by pain physicians (32.9%), and acupuncturists (29%).
- A majority (52.8%) of respondents said cost prevented them from accessing massage therapy.

#### BEHAVIORAL HEALTH AND PAIN MUST BE FURTHER ADDRESSED.

- 26.4% of respondents wished mind-body and behavioral health therapies were emphasized more by their providers.
- 20.7% of respondents living in rural areas were unable to access support groups due to their geographic location.
- 19.8% of patients wished they could see, or see more of, a psychologist, psychiatrist, or other mental health professional, but can't because of barriers like cost.

#### DEMOGRAPHICS

Between August 4 and 13, 2020, a total of 1,581 individuals responded from across all 50 states and Washington, D.C. To qualify for the survey, respondents had to answer "yes" to living with chronic pain, which is defined as pain that persists for six months or more.

The most common age range was 55-64 years (35.1%), followed closely by 45-54 years (26.2%). The age groups 65-74 (15.2%) and 35-44 (14.9%) were similar portions.

By far, the large majority of respondents were female (81.7%). Women are more likely to report pain than men, but this does not account for such a high number.<sup>2</sup> Of interest for future research could be whether men are less likely to connect with patient organizations, and if so, why.

Survey authors chose to allow respondents to select multiple races to better reflect individuals who are mixed race. Most respondents identified as white (85.2%), while 4.4% chose "Prefer not to answer." A total of 10.5% indicated they were either people of color (5.4%) or mixed race (5.1%). The breakdown of people of color, by race, is as follows: Black or African-American (3.9%), American Indian or Alaskan Native (3.6%), Hispanic or Latino (3.1%), Asian (0.9%), and Native Hawaiian or Other Pacific Islander (0.1%). (These numbers combined equal more than 10.5% because respondents could select multiple races.) This data suggests a significant need to conduct more outreach to diverse patient communities, who are disproportionately underrepresented in this survey.

A small number, 4.1%, indicated that they were active members of the military or veterans.

The majority of respondents indicated having private insurance through their employer or a family member's employer (31.6%), followed by Medicare and private insurance (27.8%); Medicare alone (20%); Medicaid (12.3%); and insurance through the Affordable Care Act (4.4%). A total of 4% report having no insurance.

Interestingly, Blue Cross Blue Shield was the leading private insurer for respondents at 44.9%; the next highest selection was "other" (20.3%), United Health at 12%, and Aetna 11.3%.

<sup>2</sup> https://www.iasp-pain.org/GlobalYear/PaininWomen#:~:text=Female%20Pain%20Issues&text=Chronic%20pain%20affects%20a%20higher,longer%20lasting%20pain%20 than%20men

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## PAIN SEVERITY & CAUSES

Most respondents report living with musculoskeletal conditions (80.9%) or neurological conditions (69.7%); followed by rheumatological conditions (52.8%); gastrointestinal conditions (26.8%); gynecological or urological conditions (13.7%); endocrinological conditions (13.3%); infectious diseases (3.1%); oncological conditions (2.9%); and hematological conditions (1.3%).

Nearly three-quarters of respondents (74.1%) have been living with their pain for at least 10 years, with one-third living with it for more than 20 years (33.8%).

Overall, respondents' answers indicate that the large majority experience high-impact pain with corresponding levels of disability, which is congruent with past U.S. Pain Foundation surveys.

When asked about average daily pain level on a scale of 0 to 10, with 10 being the highest pain, the average response was 6.7. More than half (58.4%) rated their pain as a level 7 or above. A total of 82.1% said that they consider themselves to be disabled, while about half of respondents said they currently receive Social Security Disability Insurance (49.6%).

To better understand the level of disability, the survey asked respondents to describe their ability to work, go to school, or act as a caretaker. More than half indicated they could not do those items at all (57.1%), while 17.4% said they could do them occasionally, 13.1% said part-time, and 12.5% said full-time.

When asked, "Has pain restricted your ability to engage in any of the following?" and presented with a list of topics (such as work, household chores, hobbies, exercise), only 0.5% said that they were unaffected. The most commonly checked activities were exercise, household chores, and sleeping (roughly 90% or more).



<image>

### TYPES OF PAIN PROVIDERS

The types of providers respondents indicated they currently see were primary care physicians (65.1%), pain specialists (57.2%), neurologists (31.7%), psychologists (29.7%), physical or occupational therapists (22.3%), and rheumatologists (22.3%). That a significant portion see psychologists is noteworthy, as it underscores the impact of severe chronic pain on mental health.

Just over half of respondents reported that a pain specialist is primarily responsible for managing their pain (53.9%) with the next most common answer being primary care physician, at 30.5%.

When asked "Which providers would you like to see or see more of, but haven't because of limited resources, whether cost, insurance barriers, travel time, etc." the most common responses were massage therapist (48.4%); pain specialists (32.9%); acupuncturists (29%); naturopaths, homeopaths, or functional medicine specialists (25.7%); physical or occupational therapists (25.6%); sleep specialists (21.3%); nutritionists (21%); and psychologists, psychiatrists, or other mental health professionals (19.8%). All other specialists were chosen less than 18% of the time.

Massage therapy is clearly a sought-after but inaccessible treatment option for many. In addition, it is striking to see that nearly one-third are not able to see pain specialists as much as they would like to.



Of patients seen at pain clinics or centers, more than threequarters said that the clinic or center only offers pain doctors, not multidisciplinary specialists.







#### PROVIDERS & MULTIDISCIPLINARY CARE

More than half of patients (54.1%) report being seen at a pain clinic or center. Of patients seen at pain clinics or centers, more than three-quarters said that the clinic or center only offers pain doctors, not multidisciplinary specialists like psychologists, nutritionists, physical therapists, sleep specialists, etc. (76.5%). This represents a significant area for improvement as far as advancing multidisciplinary pain care as a best practice.

When asked what types of treatment respondents felt their providers emphasized most, roughly one-third (38.4%) answered prescribed medications, followed by injections and blocks (26.2%), and over-the-counter medications (5.9%). According to respondents, other categories were only emphasized between only 1% and 4% of the time: self-management strategies (3.6%); restorative therapies (3.4%); mind-body and behavioral health approaches (2.8%); complementary and integrative therapies (2.7%); neuromodulation or electrical stimulation devices (1.6%); and surgical interventions (1.3%). A total of 14.2% said their providers "emphasize all categories equally."

The following question, "Which categories of pain management do you wish were emphasized more by your providers?" revealed a preference for a much broader range of therapies than are typically offered or covered by payers. The most common answers were complementary and integrative therapies (39%); restorative therapies (36.6%); prescribed medications (35.5%); mind-body and behavioral health approaches (26.4%); self-management strategies (24%); neuromodulation or electrical stimulation devices (22.5%); injections and blocks (15.7%); surgical interventions (12.1%); and over-the-counter medications (3.3%).

Roughly one-fifth, or 19.8%, said "There is no category I wish was emphasized more."

While the tendency for providers to recommend medications and injections and blocks may be representative of the severity of respondents' pain—and of insurance coverage policies, as will be discussed later on this report—this data reveals a large gap between current pain care practice and what is widely considered to be best practice: a multidisciplinary, integrative approach to care. At a minimum, even if a broader range of services are not available at a practice location, clinicians could establish a network of a broad range of experienced therapists to refer patients to.

### TREATMENTS CURRENTLY USED

The most in-depth section of the survey focused on barriers to specific treatments.

To obtain baseline information about treatments used, respondents were first asked how they currently manage their pain. The answers can be found in the table at right. (Note that this same list of treatments was generally repeated as answer options for all questions on barriers, unless not applicable. In the proceeding sections of this report, only the most common options are typically mentioned expressly.) A small minority responded with "I don't use any of these treatment options" (2.2%).

Each of these statistics is interesting in its own right, but there are a few worth calling out in particular. Heat and cold therapy was surprising as the most common selection, but suggests the importance of convenient, affordable, at-home options for relief. We were also struck by the relatively large number who use natural products; it would be helpful to know what types of products are being used (one might guess that CBD is a common choice, despite that products are not well-regulated).

It is concerning to see that fairly low percentages are receiving some type of mental health support (whether through support groups, counseling/talk therapy, or psychiatric care, etc.). Given the severity of pain and disability experienced, we would anticipate the associated emotional impact would be quite significant. We were also surprised to see low usage of relatively well-known therapies, such as acupuncture, other electrical or neurostimulation therapies (PENS, PEMF, PNFS, IFC), and occupational therapy.





### THE COST OF CARE

Respondents were asked whether cost had prevented them from accessing specific treatment options. This question was asked irrespective of insurance, given that many therapies are not commonly covered (such as massage, acupuncture, etc.).

More than three-quarters indicated cost was a factor in preventing them from accessing one or more treatment options (76.5%).

Interestingly, massage therapy was, by far, the most common response, at 52.8%. Acupuncture came next (39%), followed by physical therapy (29.4%), chiropractic care (27%), exercise programs (26.8%), and medical cannabis (24.4%). Options between approximately 15% and 20% included: Reiki/healing touch (20.1%); herbal or vitamin supplements (19%); counseling/talk therapy (17.7%); natural products (oils, creams) (17.6%); and biofeedback or neurofeedback (17.3%).

All other treatment options were selected by fewer than 15% of respondents.

#### **INSURANCE BARRIERS**

The next two questions, about insurance costs and barriers, were shown only to respondents who indicated they have health insurance (1,470 individuals or 95%).

Respondents in this subset were asked to indicate which treatment options their insurer does not cover. The most common answers fell in the categories of complementary and restorative therapies. In descending order, the top answers were: massage therapy (65%); herbal or vitamin supplements (64.3%); natural products (oils/ creams) (64.1%); Reiki/healing touch (62.7%); art, music or dance therapy (61.4%); acupuncture (59.6%); exercise programs (yoga, Pilates, cardio) (59%); mindfulness or stress reduction programs (40.4%); medical foods (39.9%); heat/cold therapy (38.1%); biofeedback or neurofeedback (37.3%); chiropractic care (31.9%); and specialty or compounded medications (26.9%). All other treatment options were selected by fewer than 25% of respondents.

Inversely, the most commonly covered options were epidural injections (94.6%); nerve blocks (94.3%); prescription medications - nonopioids (93.5%); trigger point injections (93.1%); neurolysis or nerve ablation (93.1%); and prescription medications - opioids (92.4%).

This data is extremely important because, while experts increasingly emphasize multidisciplinary treatment,<sup>3</sup> insurance coverage does not reflect that. Instead, it primarily covers medications and interventional procedures.

It is understandable that coverage might be limited for choices that lack a robust evidence base—such as herbal or vitamin supplements; natural products; Reiki/healing touch; or art, music, and dance therapy. But for those therapies that are supported by a growing evidence-base, like acupuncture, massage therapy, exercise programs, and mindfulness or stress reduction programs, insurance coverage is undeniably behind the curve of best practices in pain care.

Next, respondents with insurance were asked whether high copays specifically prevented them from accessing certain treatment options; more than half indicated yes (51.9%). The most common answers, in descending order, were: physical therapy (26%); massage therapy (24.4%); chiropractic care (21%); acupuncture (21%); counseling/talk therapy (16.4%); and psychiatric care (15.2%). All other treatment options were selected by less than 15% of respondents.

Based on these trends, it is possible to extrapolate that the most unaffordable therapies are those that require multiple visits over an extended period of time. While the per-visit copay for treatments like PT and counseling may seem reasonable, in aggregate, they present a significant financial barrier.

It is worth noting that the two categories where copays are common obstacles are 1) restorative therapies and 2) mind-body and behavioral health approaches. These categories are consistently emphasized by experts as essential components of effective pain management;<sup>4</sup> but according to these results, insurance policies do not support that belief.

Respondents with insurance were then asked whether, aside from costs, requirements or limits (prior authorization, annual visit limits) prevented them from accessing certain treatments. The most common answers, in descending order, were: physical therapy (33%); massage therapy (30.9%); chiropractic care (25.6%); acupuncture (25.6%); and prescribed medications – opioids (20%). All other treatment options were selected by 17% or fewer respondents.

It is unsurprising that restorative therapies comprise the majority of answers here, given that they typically have maximum annual visits an unfortunate obstacle for people living with a chronic condition that could last for years or a lifetime—and may require regular appointments over long periods of time.

Approximately one-third (34.6%) answered no, "insurance requirements or limits have not prevented me from accessing these options."

<sup>3</sup> https://www.hhs.gov/ash/advisory-committees/pain/reports/index.html <sup>4</sup> https://www.hhs.gov/ash/advisory-committees/pain/reports/index.html



While experts increasingly emphasize multidisciplinary treatment, insurance coverage does not reflect that.

### SIDE EFFECTS AND RISKS

The next question asked whether "concerns about side effects and risks" had prevented respondents from trying any of the following options. Respondents reported being most weary of side effects and risks associated with interventional procedures. The most common responses were spinal cord stimulators (22.6%); neurolysis or nerve ablation (20%); epidural injections (19.7%); nerve blocks (19.1%); chiropractic care (18.1%); Botox injections (17.9%); medical cannabis (17.7%); and other injections or procedures (15.4%).

All other treatment options were selected by fewer than 15% of respondents.

Of note as well is that only 13.5% suggested they were concerned about opioid medications, relatively equal to concerns about nonopioid medications (11.5%).

Overall, a significant portion (43.8%) said concerns about side effects and risks have not prevented them from trying the treatment options listed.





## INFORMATION ABOUT OPTIONS

The survey also asked respondents whether a lack of information about treatment options had prevented them from trying or accessing them. The theory was that some less common treatments might not be well-explained to patients, whether by providers or other information sources.

However, three-quarters of respondents (75.8%) said a lack of information had not prevented them from accessing treatment.

The treatments that respondents most commonly indicated they lacked information about were: biofeedback or neurofeedback (10.4%); virtual reality programs (10.2%); other electrical or neurostimulation therapies (PENS, PEMF, PNFS, IFC) (9.9%); Reiki/ healing touch (9.8%); acupuncture (8.8%); and medical cannabis (8.4%). All other treatment options were selected by 8% or fewer respondents.

While the percentages are fairly small, they do clarify areas where more patient education could be helpful.

## PHYSICAL ACCESS

The next several questions focused on whether respondents have easy physical access to specific therapies (and/or the providers who offer them).

Approximately one-third of respondents responded "yes" when asked if they live in a rural area (33.4% or 516 total individuals). "Rural" was not defined specifically, which creates some grey area in this sample.

This subset of respondents were asked which treatment options they were unable to access due to their geographic location. The most common answers were: support groups (20.7%); acupuncture (20%); Reiki/healing touch (19.6%); exercise programs (18.2%); art, music or dance therapy (18.2%); massage therapy (16.5%); mindfulness or stress reduction programs (15.9%); and biofeedback or neurofeedback (15.7%). All other treatment options were selected by approximately 14% or fewer respondents.

It is very interesting that support groups were the most frequent answer, which suggests an opportunity for increased virtual support offerings during the pandemic and in-person groups in the future. On a positive note, more than half (57.4%) said that living in a rural area had not prevented them from accessing the treatments listed.

While geographic location is one barrier in terms of physical access, mobility issues—such as difficulty driving or being upright—are another problem entirely. Nearly half of all respondents said that mobility issues have prevented them from accessing treatment (50.7%).

The most common mobility issue was, by far, difficulty driving (70.6%), followed by difficulty with certain activities/positions (ex. stretching at PT, holding still for an injection) (59.4%); difficulty being upright (40.2%); and the office or clinic not being handicapped accessible (5.4%). Nearly one-third selected "Other" mobility issues.

Given these physical access challenges, stakeholders should look to increase the availability of telehealth and/or non-emergency medical transportation programs.





#### COVID-19 & PAIN CARE

U.S. Pain Foundation conducted an in-depth survey on COVID-19 and chronic pain in the spring of 2020 (results can be viewed at <u>uspainfoundation.org/covid19</u>). But given that the crisis is ongoing, key questions about the pandemic's impact on the pain community were revisited.

Respondents were nearly evenly split when asked whether the COVID-19 pandemic had led to increases in their pain. Slightly more said no (53.6%) than yes (46.4%). (In U.S. Pain's earlier survey, 63.8% said the pandemic had led to increases in their pain.)

When asked whether COVID-19 pandemic had decreased their ability to access pain care, slightly more (53.1%) said yes.

The survey also asked how COVID-19 had specifically impacted them. The most common answers, in descending order, were: "Stress about COVID-19 has increased my pain" (62.2%); "The locations/offices/clinics where I normally receive care are closed" (49.8%); "I am concerned about contracting COVID-19, and am not seeking out my normal care" (43.6%); "Financial constraints reduced my ability to afford normal care" (25.7%); and "I contracted COVID-19" (3.1%). Respondents were also asked whether, beyond the pandemic, they would like to see providers continue to offer telehealth. Unsurprisingly—especially given difficulties with physically accessing appointments, as previously discussed—the large majority (89.9%) said yes.



An overwhelming majority of respondents (89.9%) want access to telehealth beyond the pandemic.

### SELF-MANAGEMENT STRATEGIES

In light of the pandemic, the penultimate section of the survey examined the use and efficacy of self-management or at-home strategies for pain relief. Respondents were asked about whether they had tried certain options in this category, and if they had, whether they were effective.

The most commonly used self-management therapies were heat and cold therapy and over-the-counter medications. The therapies reported most often as "effective" or "somewhat effective" were heat and cold therapy (77.3%); exercise, stretching, or strengthening programs (59.2%); pacing or activity restriction/ modification (57.6%); assistive devices (braces, canes, wheelchairs) (56.2%); stress reduction or mindfulness practices (48.4%); diet and nutrition changes (46.6%); over-the-counter medications (41.5%); sleep habits or "hygiene" (41.2%); and portable devices like acupuncture mats or TENS units (40.4%). Interestingly, overthe-counter medications were most frequently rated as ineffective (53.4%), followed by sleep habits (40.6%).

We were also interested to see whether providers discuss selfmanagement or at-home strategies with patients. Fortunately, only a small number of individuals (12.7%) said these types of options were not discussed with them whatsoever. Respondents most commonly reported providers discussing exercise, stretching, and strengthening programs (66.1%); heat and cold therapy (62.7%); over-the-counter medications (48.6%); diet and nutrition changes (45.4%); portable pain relief devices (acupuncture mats, traction units, massage tools, TENS units) (44.7%); stress reduction or mindfulness practices (43.3%); and assistive devices (braces, canes, wheelchairs) (41.4%). All other categories were selected by less than 38% of respondents.

Based on what is most effective but least discussed, providers should consider increasing their emphasis on 1) pacing or activity restriction/modification and 2) assistive devices (braces, canes, wheelchairs).





#### HEAT & COLD THERAPY

The final subject examined by the survey was heat and cold therapy. A significant majority (83.2%) said they use heat or cold therapy to manage pain. The proceeding questions were shown only to those who answered "yes."

Roughly half (52.6%) said they found heat more effective, while 18.7% preferred cold. Nearly one-third (28.7%) said they were about equal. A majority of respondents indicated they primarily use heat and cold (62.5% and 50.6%, respectively) "while having pain, as a way to manage or reduce it." Some individuals used it both as a preventative and while having pain (47.3%). Interestingly, nearly onethird responded that they do not use cold at all (29.3%). For heat therapy, that portion was only 6.1%.

As far as types of heat and cold therapies, the following therapies were most commonly rated either "somewhat effective" or "effective": heating pads – electric (71.3%); hot baths/showers (58%); ice packs (55%); hot tubs (40.9%); and heating pads – not electric (38%). Compared to other options given, cooling sprays/creams and heating patches (wearable/adhesive) were most often rated as ineffective (27.6% and 18.2%, respectively). Most respondents had not tried ice baths (78.3%), cryotherapy (73.8%), or saunas (64.7%) to manage their pain.

# CONCLUSION & RECOMMENDATIONS

By and large, the study clearly underscores the enormous gap between best practices in pain management and the pain care that is currently affordable and accessible to patients. More must be done to reduce these barriers to care—particularly, incentivizing the creation of multidisciplinary pain centers, improving insurance coverage for a wider range of therapies, and educating providers on the importance of an individualized, multidisciplinary, integrative approach to pain management.

Here are our specific recommendations:

#### ADVOCACY AND POLICY CHANGE

- Incentivize the creation of truly multidisciplinary pain care centers through value-based payment models or improved reimbursement.
- Disseminate and train clinicians (particularly primary care providers) on the best practices called for in the HHS Pain Management Best Practices Task Force Report: individualized, multidisciplinary, integrative care with access to a broad range of therapeutic options.
- Improve insurance coverage of multidisciplinary therapies, particularly massage therapy, acupuncture, physical therapy, chiropractic care, exercise programs, and counseling/talk therapy.
  - Specifically, copays for therapies that require multiple visits over a long period should be reduced, and annual visit limits eliminated or at the very least, increased.
- Given mobility issues, ensure telehealth remains an option for appointments even after the COVID-19 pandemic ends.
  - Consider other solutions to mobility issues faced by people with pain, such as increasing availability of statefunded, non-emergency medical transportation (NEMT) or partnering with private rideshare NEMT programs.
  - Sensitize pain practices to the importance of asking patients if anything can be done to make their visit more comfortable, such as a place to lie down while waiting for their doctor or other healthcare provider, or a way to avoid waiting in line, etc.
- Continue to invest in basic research that will lead to novel, safe, effective treatment options for pain, as well as clinical research to build an evidence-base for a broader range of non-pharmaceutical options.

#### EDUCATION

- Provide more patient education on the value of multidisciplinary care, particularly in finding the right combination of therapies for management of each individual's pain.
- Provide education on what patients say are the most effective selfmanagement strategies: heat and cold therapy, various types of exercise and strengthening, and pacing.
- Provide education on treatment options where patients indicated they lacked information including those self-management strategies that they wished they knew more about. These include biofeedback or neurofeedback; virtual reality programs; other electrical or neurostimulation therapies (PENS, PEMF, PNFS, IFC); acupuncture; Reiki/healing touch; medical cannabis; portable devices; exercise; diet; and stress reduction and mindfulness.
- Increase communications about options and resources available to help patients better access care, including insurance coverage options, tips for saving on health costs (FSA/HSA programs, etc.); telehealth offerings; and non-emergency medical transportation.

#### SUPPORT

- Educate providers on behavioral health as an integral part of multidisciplinary pain care, and reduce copays for visits with behavioral health care providers.
- Increase the availability of both virtual and in-person support groups. In particular, ensure virtual group offerings are available to those in rural areas.
- Continue to incorporate educational components into support group offerings, especially on the many topics that respondents have surfaced in this survey.

Note: To encourage participation, 250 heating pads were raffled off to respondents who completed the survey. While the survey instructions stated that the raffle was random and respondents' answers would not influence their chances of winning, it is difficult to be certain that it did not, in some way, affect responses related to heat and cold therapy.

#### ACKNOWLEDGMENTS

The U.S. Pain Foundation thanks its 2020 Pain Awareness Month sponsor, Sunbeam<sup>®</sup>, for its collaboration on this important initiative.



#### WE ALSO WOULD LIKE TO THANK SEVERAL GROUPS AND ORGANIZATIONS FOR HELPING PUBLICIZE THE SURVEY, INCLUDING:

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Alliance for Balanced Pain Management

Alliance for Gout Awareness

American Academy for Pain Medicine

American Porphyria Foundation

Association of Migraine Disorders

CHAMP (Coalition for Headache And Migraine Patients)

Clusterbusters

For Grace

Healthy Women

International Foundation for Autoimmune and Autoinflammatory Arthritis

Interstitial Cystitis Association

Lupus and Allied Diseases Association

National Headache Foundation

Osteoarthritis Action Alliance

Sick Cells

Society for Pediatric Pain Medicine



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