

SURVEY REPORT

CHRONIC PAIN & COVID-19



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MESSAGE FROM THE INTERIM CEO

In the wake of the COVID-19 pandemic, people across the world are facing unprecedented health challenges.

Individuals with chronic pain are particularly vulnerable at this difficult time. This population of patients must cope with the day-to-day realities of managing unrelenting pain *while also* navigating being at higher risk for serious COVID-19 disease.

In order to better understand the challenges the pain community is facing and find ways to help, we conducted a survey of 664 pain warriors about the impact of COVID-19 on their health and medical care. The results, discussed in this report, are eye-opening and, at times, heart-wrenching.

The data suggests ample opportunities for all of us—patient groups, health care providers, insurers, industry stakeholders, and policymakers—to come together to better serve people with pain.



Sincerely,

A handwritten signature in cursive script that reads "Nicole Hemmenway".

Nicole Hemmenway
Interim CEO, U.S. Pain Foundation

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DEMOGRAPHICS

A total of 664 individuals responded over the course of April 1-8, 2020. All 50 states plus Washington, D.C., were represented.

Similar to prior U.S. Pain Foundation surveys, the most common conditions amongst respondents were back pain (69.1%); neuropathy (59.3%); neck pain (53.7%); osteoarthritis (44.5%), fibromyalgia (44.1%), and headache or migraine disease (42.5%). Another disease state of note, given their high-risk status for serious COVID-19 illness, was autoimmune disease (29.9%).

The most common type of insurance was Medicare (46.6%), followed by private insurance through an employer or family member's employer (30.2%), Medicaid (9.7%), and private through a state health exchange (5.1%). Another 8.4% responded "Other": answers included Tricare (military insurance) and/or uninsured. The high rate of Medicare insurance is logical given that many patients with pain may be over 65 and/or be eligible for Medicare because they receive Social Security Disability Insurance.



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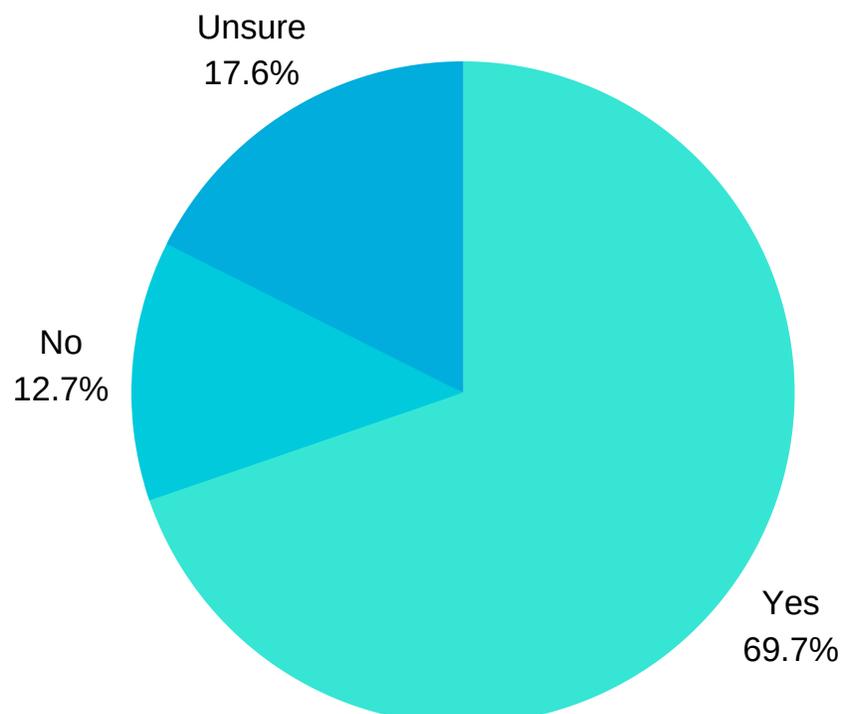
UNDERSTANDING THE HIGH-RISK DESIGNINATION

Experts in pain have indicated that chronic pain (whatever the root cause) may put patients at higher risk for developing serious illness as a result of COVID-19.^{1,2}

Accordingly, a large majority (69.7%) of respondents said they considered themselves to fall into the high-risk category.

12.7% did not consider themselves to be high risk, while 17.6% said they were unsure of whether they were high risk. This level of uncertainty suggests more education is needed about what constitutes high risk, so that patients and providers alike know the proper level of precautions to take.

Q4: Do you consider yourself to fall into a **"high-risk"** category for developing serious illness from COVID-19?



PREVENTING SPREAD

Even though not all respondents considered themselves high-risk, 100% were taking some type of precautions to avoid contracting or spreading COVID-19.

Importantly, 99.2% of respondents were either staying home “as much as possible” or “completely.” The next most common precaution was “washing hands more” (92.8%), followed by “avoiding large crowds” (81.2%).

A total of 60 respondents (9.0%) said they believed they may have come into contact with someone diagnosed with COVID-19, and 10 respondents (1.5%) said they have actually contracted COVID-19. This represents a possible opportunity for further study to understand how COVID-19 specifically impacts people with pain, and what their health outcomes were.



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HEALTH IMPACT

In response to a question on how the COVID-19 crisis had directly affected respondents' health thus far, we anticipated that increased pain would be the most common answer. In fact, the majority said they were experiencing increased stress (86.1%).

This emphasizes the vital importance of emotional support during the course of the pandemic.

That said, increased pain was still a large factor for a majority of respondents at 63.8%. (Upcoming sections will explore the causes of increased pain.) Less than one-tenth—8.8%—said they were unaffected.

63.8% said they were experiencing increased pain as a result of COVID-19.

FINANCIAL IMPACT

A majority (65.6%) said they were not experiencing financial hardship because of COVID-19. Of course, it is not an insignificant portion, roughly one-third, who are experiencing hardship. In fact, 7.6% reported they cannot currently afford their regular medical care.

Compared with national statistics, a relatively small number—3.9%—had been laid off, while 4.7% had had their hours reduced. This smaller number is probably because people with pain, due to physical limitations and disability, are less likely to be in the workforce in the first place.

While respondents' personal jobs were largely unaffected, 21.3% indicated a family member was laid off or had hours reduced.

ACCESS TO TELEHEALTH

At first glance, it was heartening to see a majority of respondents, or 63.1%, had accessed medical care via telehealth as a result of COVID-19.

However, the fact that 36.9% had not accessed telehealth is concerning, given that all respondents live with chronic health conditions and therefore need regular medical care—but should also be limiting contact.

As further evidence of this gap in adequate access to telehealth care, a quarter (25.3%) said they had not been informed of their telehealth options by anyone. In addition, 56.1% said they did not understand their insurer's telehealth coverage policies, and 48.0% said they did not understand their provider's telehealth offerings.

These numbers point to a clear need for more outreach, communication, and education about telehealth.

25.3% of all respondents said they had not been informed by anyone of their telehealth options.



ACCESS TO PAIN CARE VIA TELEHEALTH

The survey asked some specific questions to better understand approaches to telehealth amongst pain providers. 70.0% of respondents said they currently see a pain doctor or go to a pain clinic.

Of that number, 36.0% of respondents said their pain doctor's office or clinic was currently open, while 33.6% said the office or clinic was closed. Interestingly, 30.4% said they were unsure whether it was closed or open.

The majority (48.8%) said the office or clinic was offering telehealth—but that was closely followed by 42.6% of respondents who said they were unsure if telehealth was offered. A small portion, 8.6%, said the clinic or office was not providing services via telehealth.

The most popular telehealth delivery method was videoconference (48.9%), followed by phone calls (40.4%), other methods (7.8%), and email (2.8%). "Other methods" that were written in included specific services like Zoom or WhatsApp, or indicated the patient was unsure as the appointment was scheduled for the future.



36.0% of respondents who see a pain doctor or clinic said the office was still open.

BARRIERS TO CARE

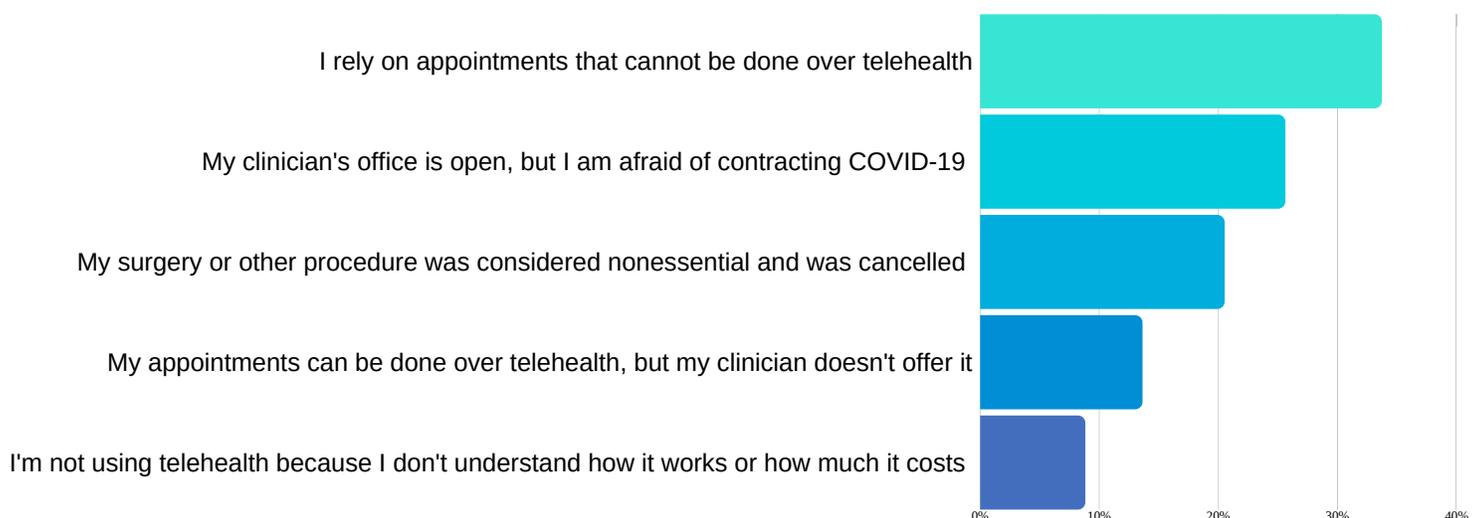
Unsurprisingly, more than three-quarters (77.4%) of all respondents indicated that they are facing barriers to medical care.

The most prevalent barrier was that one-third (33.7%) of respondents rely on appointments that require in-person interaction (such as physical therapy, massage, etc.). Even with increased access to telehealth, these patients' options for medical care may be limited.

Another major barrier was a surgery or other procedure that was considered nonessential being cancelled (20.5%).

Still, for patients who can be served over telehealth, there were a number of issues. 13.6% said their appointment can be done over telehealth, but their clinician doesn't offer it; 8.8% said they aren't using telehealth because they don't understand how it works or the cost; and 4.5% said their clinician offers telehealth, but they don't have the right equipment.

Top six barriers to medical care



BARRIERS TO CARE, CONTINUED

More than a quarter (25.6%) of respondents said that their clinician's office is open, but they are afraid of contracting COVID-19. This finding is somewhat surprising, given that, as of April 8, 95% of this group live in states with stay-at-home orders.³ A possible area for further investigation is whether clinicians are requiring or even encouraging high-risk patients to come in for care that could be delivered via telehealth.

Although in the minority, 4.5% said they felt their clinician was not taking COVID-19 seriously.

All of these findings suggest the need for more guidance for patients and their providers about which medical services are essential and which are not, and what can and should be done over telehealth. They also indicate a need for more outreach to help patients manage their pain at home, whether by providing at-home physical therapy exercises; offering telehealth mental health counseling services; etc. They again underscore the need for clearer, more consistent communication of telehealth options.

We believe that patient groups can help fill these gaps, by offering increased mental health support (online and telephone support groups); education and digital resources on self-management techniques; and so on.

A possible area for further investigation is whether clinicians are **requiring or even encouraging** high-risk patients to come in for care that **could be delivered via telehealth**.

BARRIERS TO MEDICATION

Fortunately, 41.4% of respondents said they had not had issues filling their prescriptions and/or are not currently taking medications. Still, there were a number of alarming trends in this area.

For one, 10.2% of respondents said their clinician refused to fill medications over telehealth. This is problematic given the aforementioned number of states with stay-at-home orders, the high-risk nature of many pain patients, and the fact that the Drug Enforcement Administration is allowing controlled substances to be filled via telehealth.⁴

Insurers are also creating barriers to access. One-quarter of respondents (25.1%) said that despite the special circumstances, their insurer would not cover more than a 30-day supply of their medication, and 17.3% said that their insurer would not fill a medication early. The study did not ask about specific medications; this could be a topic for future exploration.

A similarly discouraging trend is that 10.8% of patients said there is currently a shortage of their medication due to high demand. The study did not ask which medications specifically were in short supply.



10.2% of respondents said their clinician refused to fill medications over telehealth.

ADDRESSING TOP CONCERNS

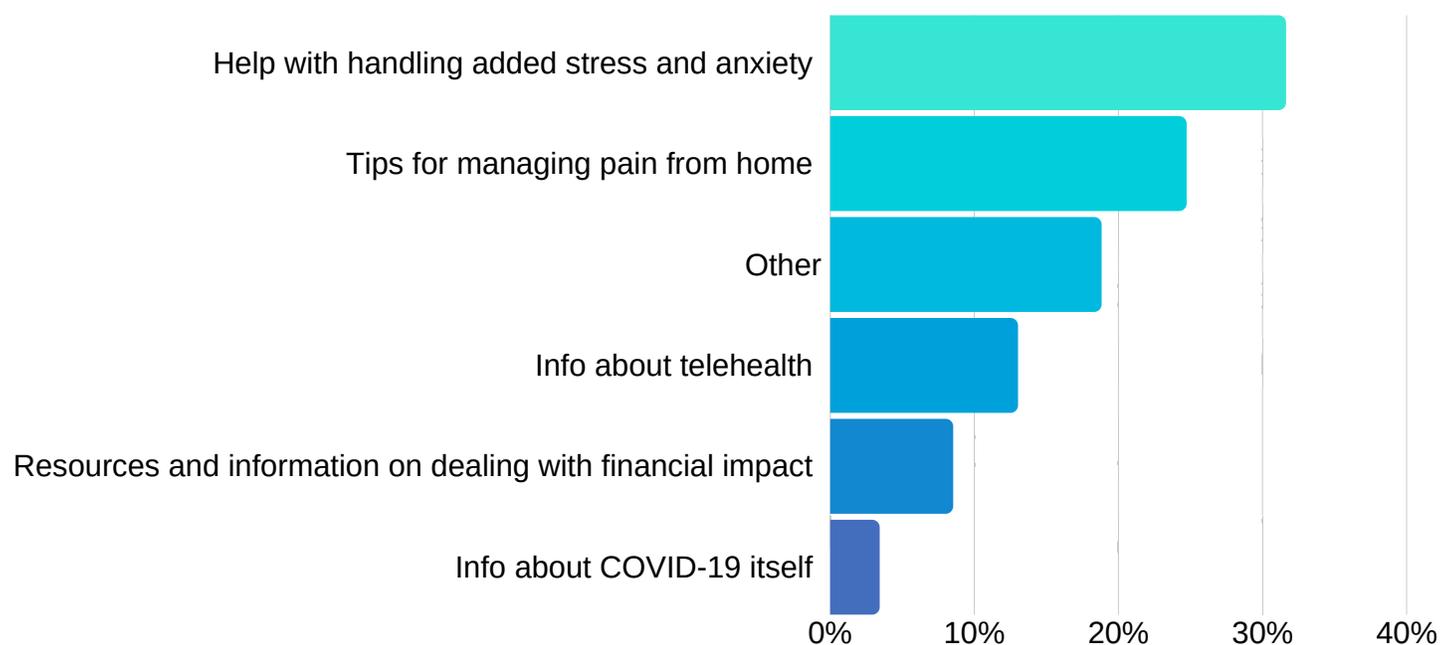
The most common answer to “What is most concerning to you about the COVID-19 crisis?” was contracting COVID-19 (34.1%).

The second top concern was interruptions to regular pain care (25.6%).

When asked what resources would be most helpful at this time, the majority said "help with handling added stress and anxiety" (31.6%), followed by "tips for managing pain from home" (24.7%) and "info about telehealth" (13.0%).

Again, patient advocacy groups are well-suited to provide such resources and should look to address these areas in particular.

Q22: What resources would be most helpful to you right now?



IN THEIR OWN WORDS

"I pretty much feel I have to put my life at risk by forgoing my medical care in order to not put my life more at risk by catching this virus in a hospital or doctor's office."

"Trying to find workarounds, but realizing that I'm going to have to live with increased pain and decreased mobility for the time being."

"I'm already fighting with them [insurance] on so many other medications and devices, I don't really want to add figuring out telehealth to the list."

"I receive regular infusions, and I still have to go to an infusion department with many other patients and workers. I wish I could get it done at home, but my HMO doesn't provide that service."

"I have to physically go to pain management just to pick up my prescription. I feel this is unnecessary and dangerous considering my health issues."

"I am a senior citizen and I am not familiar with smartphones used for telehealth as of this time."

"A surgery I needed was deemed 'not essential,' which ended up causing another issue."

"All of my appointments have been cancelled including psychiatric care with no option of telehealth for these specific appointments."

CONCLUSIONS

During this public health emergency, individuals with chronic conditions that cause pain deserve affordable, timely access to telehealth services. Telehealth services should be clearly communicated and patients should have telehealth options across specialties, including primary care, pain management, and behavioral health. Insurers and providers must also work together with patients to streamline care and limit unnecessary medical appointments and pharmacy visits.

Offering adequate pain management via telehealth is essential for protecting high-risk groups from COVID-19 and reducing spread in the general public. It is also necessary because worsening health and pain levels could increase susceptibility to complications from COVID-19 and/or result in patients seeking treatment via urgent care or emergency rooms, which are already under significant strain.

Even though telehealth is vitally important, it has its limits. Certain treatments or procedures can only occur in person (for example, physical therapy, injections, massage, and so on.) Patient groups can help fill these gaps by offering educational programming on self-management strategies (pacing, stress reduction, sleep hygiene, etc.) and encouraging and empowering patients to maximize their telehealth options. Patient groups are also well-positioned to expand their programming to offer emotional support, stress reduction, and peer-to-peer support groups via online technology given that increased stress produces increased pain, and vice versa.

RECOMMENDATIONS

Here are our specific recommendations in the areas of advocacy and policy, education, and support.

ADVOCACY & POLICY

1. Require public and private insurers to inform beneficiaries of telehealth coverage and out-of-pocket costs within a set time period
2. Require that telehealth visits cost no more out-of-pocket than in-person visits
3. Require insurers to cover 90-day supply of refill medications to limit pharmacy visits
4. Create a process through which high-risk patients can request an exemption from required in-person visits and/or require that providers offer high-risk patients telehealth appointments for treatments or visits that don't require physical assessment

EDUCATION

1. Increase education to patients about telehealth options
2. Develop and deliver web-based training and support programs to help patients learn about coping strategies and self-management for pain

SUPPORT

1. Increase the number of telephone, videoconference, and online support groups with trained leaders
2. Offer stress-reduction webinars for chronic pain specifically

CITATIONS

1. “Out-Patient Pain Management in the Midst of the Covid-19 Public Health Emergency.” Zoom webinar presented April 1, 2020, by David Tauben, MD, Chief of Pain Medicine for University of Washington Medicine. [youtube.com/watch?v=Wf-KcXMZGtE&t](https://www.youtube.com/watch?v=Wf-KcXMZGtE&t)
2. “How Chronic Pain Affects Your Immune System.” Article published on WebMD.com on March 16, 2020, by Peter Abaci, MD, Medical Director of the Bay Area Pain and Wellness Center. blogs.webmd.com/pain-management/20200316/how-chronic-pain-affects-your-immune-system
3. “See Which States and Cities Have Told Residents to Stay at Home.” Article published April 7, 2020, in *The New York Times*. [nytimes.com/interactive/2020/us/coronavirus-stay-at-home-order.html](https://www.nytimes.com/interactive/2020/us/coronavirus-stay-at-home-order.html)
4. “COVID-19 Information Page.” Site on Drug Enforcement Administration website, accessed April 9, 2020. deaddiversion.usdoj.gov/coronavirus.html

PATIENT & PROVIDER RESOURCES

- COVID-19 information center: uspainfoundation.org/covid19
- Dealing with treatment interruptions: uspainfoundation.org/covid19/treatment-interruptions
- Navigating financial hardship: uspainfoundation.org/covid19/financial-hardship
- Coping with emotional stressors: uspainfoundation.org/covid19/emotional-stressors

ACKNOWLEDGMENTS

U.S. Pain Foundation thanks its Corporate Council for their unrestricted support, which enables timely projects like this survey. We also thank the *National Pain Report* for helping publicize the survey.

The Lilly logo is written in a red, cursive script font.The AMGEN logo is in a bold, blue, sans-serif font.The CENTREXION logo features the word "CENTREXION" in a grey, sans-serif font, with a blue sunburst icon replacing the letter "O".The Johnson & Johnson logo is in a red, cursive script font.The PRIMUS PHARMACEUTICALS logo features a stylized "P" icon in red and yellow above the word "PRIMUS" in a blue, serif font, with "PHARMACEUTICALS" in a smaller, blue, sans-serif font below it.The THRIVE TAPE logo is on a black background with a yellow border. It features the words "THRIVE" and "TAPE" in white, bold, sans-serif font, with a lightning bolt icon between them. Below "THRIVE" is the tagline "LIVE LIFE AND PUSH BOUNDARIES" and below "TAPE" is "FAR INFRARED KINESIOLOGY TAPE".

For more information about U.S. Pain Foundation,
visit uspainfoundation.org.

