



MAY 2021 INSIGHTS REPORT

# How It Hurts

Annual Findings on the  
Impact of Arthritis Pain

# Taking Control of Arthritis Pain

**More than 54 million adults in the U.S. have been doctor-diagnosed with arthritis.** So have nearly 300,000 children. It's the nation's number one cause of disability. Many millions more battle arthritis symptoms but haven't been officially diagnosed.

To change the trajectory of arthritis and the impact of chronic pain, we must take action grounded in real-life experiences and challenges. That's why the Arthritis Foundation launched Live Yes! INSIGHTS in 2018, an ongoing initiative to collect much needed data from patients. It's one of the largest patient-reported outcomes (PRO) studies in the United States and the most extensive patient-centered effort we've led in over 70 years.

With input from scientists at Dartmouth College, the Arthritis Foundation developed Live Yes! INSIGHTS through a robust and patient-centered approach to select scientific assessment tools that were meaningful to patients. The innovative selection process directly incorporated input from 110 patients, health care providers and measurement experts. This resulted in a research tool that best reflects the life of a person living with arthritis and serves as the basis for this study. Further, this tool provides validated benchmarking data to assess impact versus a non-arthritis population. This data is showcased throughout this report to illustrate the true impact of arthritis on the lives of those living with daily pain.

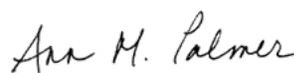
From the first wave of responses to our survey, one thing was loud and clear: Pain — the kind of pain that can't be ignored — is the major challenge

people with arthritis face. Input collected since our Mandate for Action report in early 2020 echoes that finding. We also know that pain is not just a number on a pain scale; we can see how pain impacts every aspect of life and overall well-being. To help mitigate this, the Arthritis Foundation has made pain our major focus. Learn more in this report about our efforts to address pain.

Tens of thousands of arthritis patients have participated in our INSIGHTS study, including many who have connected with the Arthritis Foundation for the first time. Numerous participants have gone on to engage in our webinars, podcasts, online forums, support groups and local programs in their own communities. In turn, people living with arthritis are helping us see more clearly their own experiences.

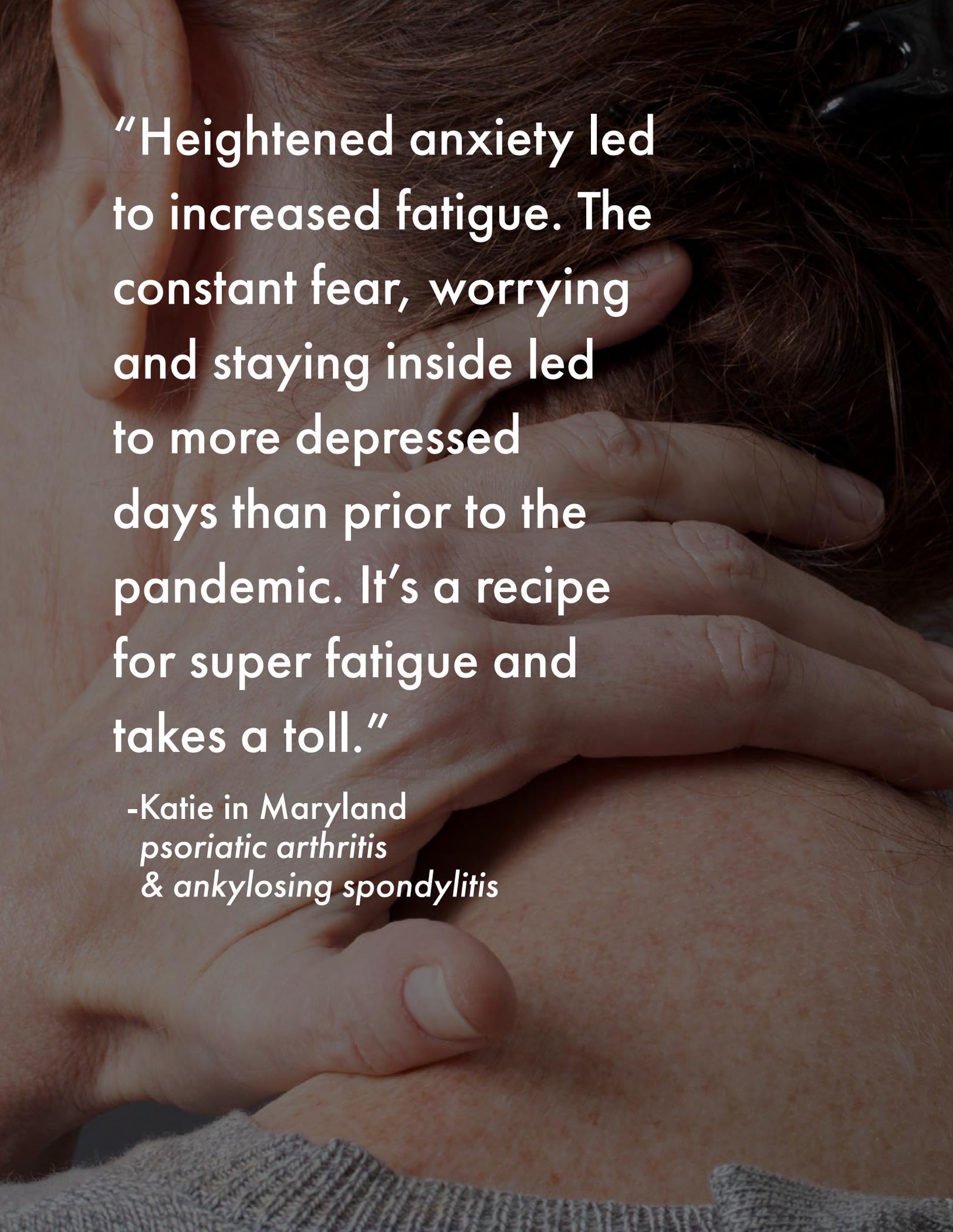
On behalf of the Arthritis Foundation, I am grateful to everyone who is contributing to this next phase of changing the future of arthritis. While the Arthritis Foundation is leading the way in this study, we are taking action alongside many others, from patients and providers to policymakers and other partners. Together, we're gaining traction to have greater power over arthritis pain.

This is our fight to win together.



**Ann M. Palmer**  
President & CEO  
Arthritis Foundation





“Heightened anxiety led to increased fatigue. The constant fear, worrying and staying inside led to more depressed days than prior to the pandemic. It’s a recipe for super fatigue and takes a toll.”

-Katie in Maryland  
*psoriatic arthritis*  
& *ankylosing spondylitis*

## What is Live Yes! INSIGHTS?

With input from scientists at Dartmouth College, the Arthritis Foundation developed Live Yes! INSIGHTS through a robust and patient-centered approach to select scientific assessment tools that were meaningful to patients. The innovative selection process directly incorporated input from 110 patients, health care providers and measurement experts. This resulted in a research tool that best reflects the life of a person living with arthritis and serves as the basis for this study.

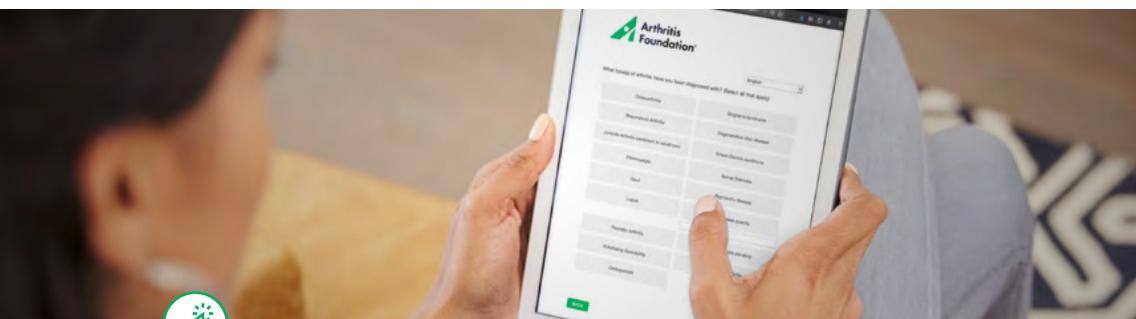
Further, this tool provides validated benchmarking data to assess impact versus a non-arthritis population. This data is showcased throughout this report to illustrate the true impact of arthritis on the lives of those living with daily pain.

Commissioned in 2018, the Live Yes! INSIGHTS study is one of the largest patient-reported outcomes (PRO) collections of data from adults living with arthritis in the U.S.

This ongoing study is the largest one the Arthritis Foundation has ever conducted among patients and caregivers. So far, we've captured results from almost 40,000 surveys of adult arthritis patients (as of the end of 2020).

We've also introduced a second arm of the INSIGHTS study specifically for parents of children with arthritis and other rheumatic conditions.

Our Mandate for Action report in early 2020 highlighted adult findings and next steps. This latest update helps us further refine our plans to better serve people with arthritis, particularly addressing the challenges around pain.



Learn more about the study and help spread the word at [arthritis.org/insights](https://arthritis.org/insights).

Live Yes!  
INSIGHTS



## This Report

This How It Hurts report updates you on what we've learned since our initial Mandate for Action report in 2020, which covered responses received through October 2019.

This accrued data of almost 40,000 responses sheds even more light on patient experiences and how life became even more painful and difficult due to COVID-19.

We're sharing the updated results in this report with our valued and essential partners to help find solutions.



"I'm exhausted from the isolation and disruptive sleep routine during the pandemic, with one day flowing into the next with no social events. Single and living alone has been terrifying."

-Pamela in Tennessee  
*osteoarthritis & fibromyalgia*

## Focus Areas

To help us understand the impact arthritis has on every facet of an arthritis patient's life, we focused on the following areas.



### Physical Health

- Function
- Fatigue
- Sleep
- Interference
- Intensity



### Emotional & Social Health

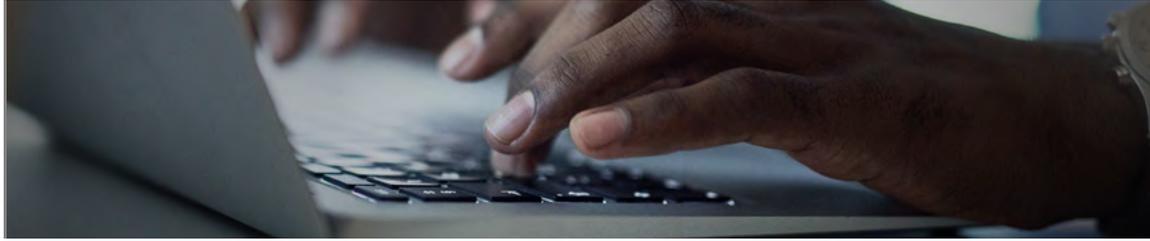
- Anxiety
- Socializing with others
- Emotional support
- Depression



### Experience of Care

- Interactions with health care providers
- Being involved in decisions





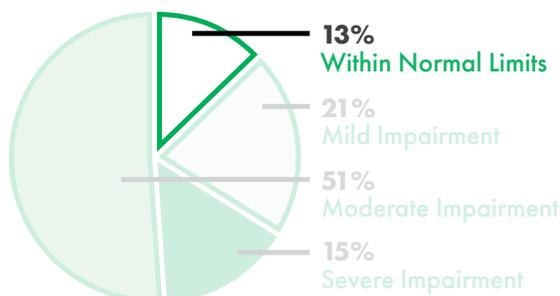
## How We Conducted the Study

The INSIGHTS assessment is deployed using an online survey platform through Qualtrics®. Participants across the country are invited to share their data using a combination of direct email marketing, social media, website promotions and person-to-person outreach.

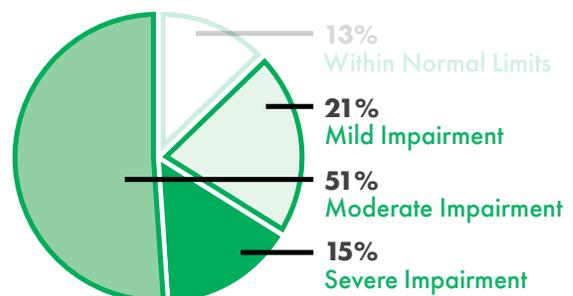
This program incorporated measures included in the PROMIS-29, PROMIS Emotional Support Short Form v2.0 and the Health Care Empowerment Questionnaire. The value of including these measures is that it provides a benchmark for comparison to assess the impact of arthritis on those living with pain every day.

## Interpreting the Charts

The use of validated measurements provides a comparison to benchmarks of the general population. When the score for a given measure is within the benchmarked range of the general population, the score is considered “within normal limits.” In this example, the white pie slice represents the proportion of arthritis patients taking the survey who experience an interruption in their daily lives similarly to those without arthritis.



The three green slices represent the proportion of arthritis patients taking the survey who experience a more significant interruption in their daily lives due to arthritis. What you will see on the following pages is how the majority of arthritis patients who participated in this study are being impacted negatively by their arthritis throughout all aspects of their lives.





## Pain Is Extremely Prevalent

Chronic arthritis pain can't be ignored. It is an intense and constant presence that impairs physical function, disturbs sleep and causes debilitating fatigue. Compounding the pain and disability are the hardships, isolation and marginalization people with arthritis often encounter. Since our last report, scores have worsened, indicating what an even more challenging year it was for arthritis patients.



**5.4**

Average Pain Score on a 10-point scale



**66%**

report a pain level of 5 or higher, indicating moderately strong pain approaching distress.

Those reporting **moderate arthritis impairment or symptoms** are not doing as well as people in the general population. Numbers in this range (5 to 7) are a cause for concern, requiring appropriate resources and support.

Patients with **severe impairment or symptoms** are not doing nearly as well as the general population. Numbers in this range (8 to 10) are alarming, and appropriate resources and support are urgently needed.



**100%**

of survey respondents reported pain over the past 7 days.



**15%**

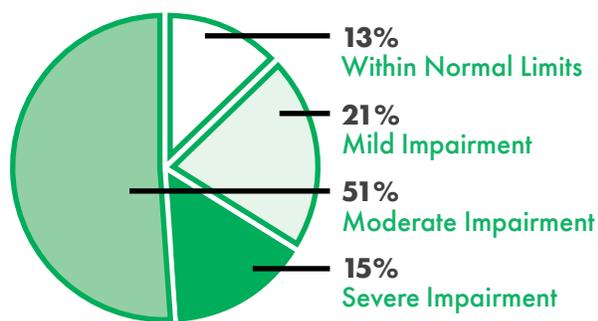
felt pain at 8 or higher, described as intense, excruciating or unbearable.

## Pain Interferes With Our Daily Lives

Those living with arthritis face many challenges due to the pain they are experiencing. Pain prevents them from participating in normal activities and interferes with their ability to do the everyday things they need to do, both at home and at work. Likewise, arthritis-related pain interferes in social aspects of people's lives, keeping them from doing all the activities they want to do with families and friends.

### Daily Life and Activities

Almost 90% of arthritis patients surveyed have pain that interferes with their daily lives and activities.



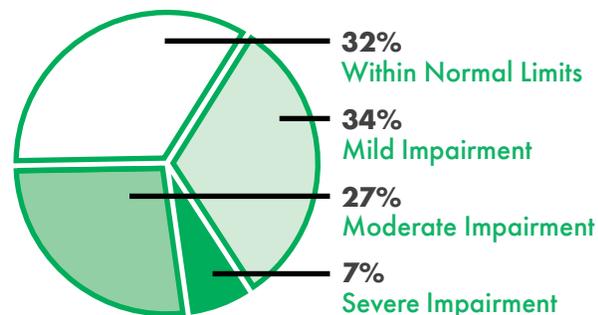
**75%**

reported that pain interfered somewhat, quite a bit or very much with their day-to-day activities.

- 66% reported that pain interfered somewhat, quite a bit or very much with their ability to participate in social activities.

### Social Participation

Two-thirds of people with arthritis report a disruption in their ability to participate in social activities.



**74%**

reported they had difficulty doing activities with family.

- 76% reported they had difficulty doing activities with friends.

Pain is experienced differently among all who live with arthritis. Some experience pain that is similar to those who are not diagnosed with arthritis; their level of pain is “within normal limits” based on validated benchmarks. However, most arthritis patients experience pain that causes significant impairment to their quality of life.



"My arthritis pain, basically in both my hands, got worse as the days and weeks went by, but I do not blame the pandemic. It was the disease progressing as time went by since I was 16 years old; that's 67 years ago."

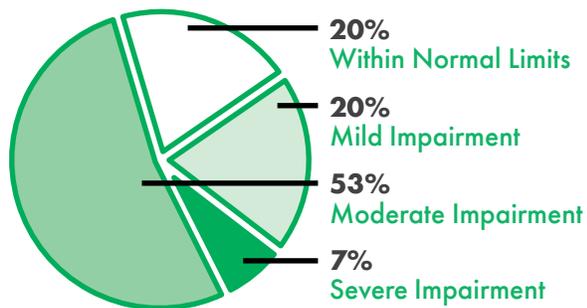
-Valmoore in New Hampshire  
*osteoarthritis, rheumatoid arthritis  
& fibromyalgia*

## Pain Limits Our Abilities

Arthritis pain is linked to moderate to severe impairment of physical functioning, including daily living activities, such as doing chores, walking or going up and down stairs. People with arthritis often report difficulty with tasks like bathing and dressing, vacuuming, doing yard work, running errands and shopping. Many have to give up cherished hobbies and other things they love to do.

### Physical Function

4 out of 5 arthritis patients experience more difficulties in their ability to function physically than the general population.



**62%**

reported they either could not go, or had difficulty going, up and down stairs at a normal pace.



**49%**

reported they could not walk at least 15 minutes or had difficulty doing so.



Live Yes! With Arthritis podcasts offer pain management tips and other helpful information. [arthritis.org/podcast](https://www.arthritis.org/podcast)

WITH ARTHRITIS PODCAST



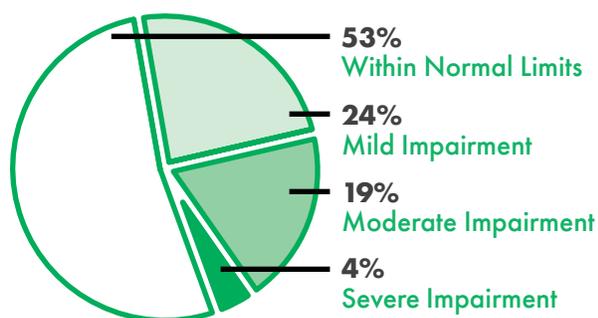


## Pain Interrupts Our Well-being

Arthritis pain is linked to other factors that affect the well-being of patients, including sleep deprivation and chronic fatigue. Pain stops people from getting a good night's sleep. It's often hard to fall asleep and pain wakes them up during the night. Poor sleep quality from pain easily leads to chronic fatigue, which makes it hard to get started on things because they feel run down and exhausted.

### Sleep

Nearly half of arthritis patients have worse sleep than the general population.



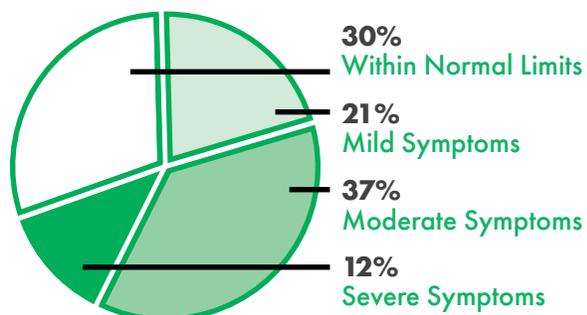
**49%**

reported they had difficulty falling asleep.

- 35% said sleep quality was poor.
- 20% said sleep was not refreshing.

### Fatigue

More than two-thirds of arthritis patients experience higher levels of fatigue than the general population.



**50%**

reported feeling moderate to severe fatigue, including tiredness and overwhelming exhaustion.

- 40% reported having trouble starting things because they are tired.
- 56% reported feeling quite a bit or very much fatigued.

**“My sleep quality has been uneven over the past year. I have difficulty falling asleep. I also feel out of sorts much of the time because I feel trapped at home.”**

**-Jonathan in Washington  
*osteoarthritis*  
& *axial spondyloarthritis***



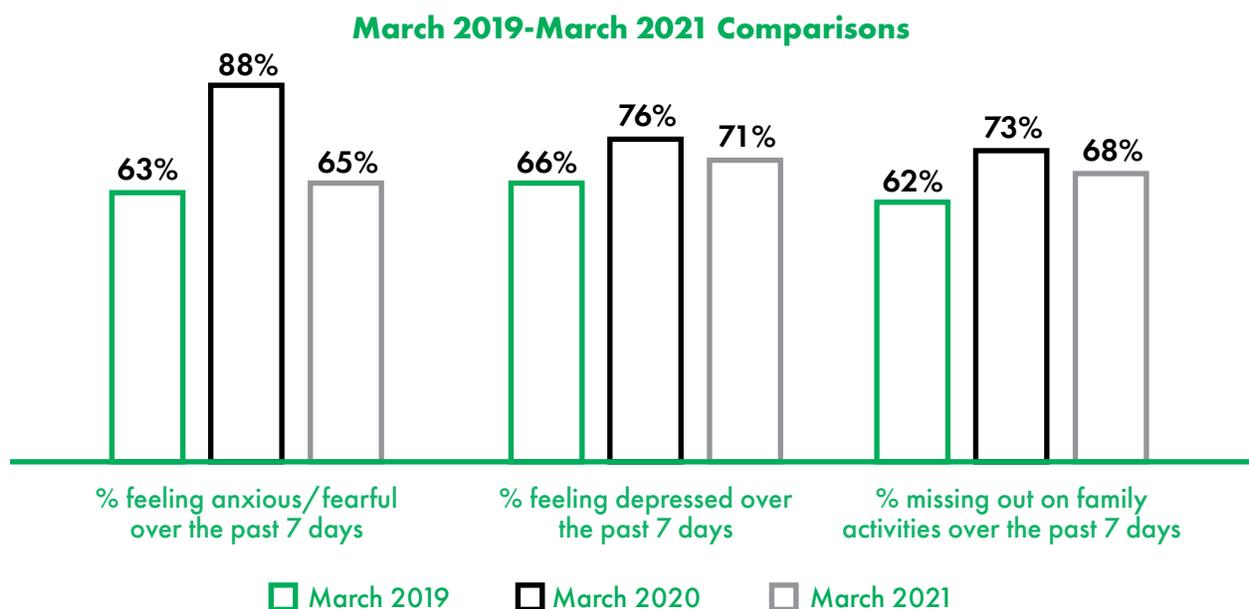


## Arthritis & COVID

In 2020, the COVID-19 virus affected people with arthritis profoundly. Some found the pandemic lock-down to be beneficial, but most did not. Worried about their immunity already being compromised, many arthritis patients were on edge throughout the year as their social and emotional well-being were dramatically impacted.

On the upside, COVID brought more attention to what immunocompromised patients deal with every day. It was also amazing how fast the medical community developed effective COVID vaccines and got them authorized by the FDA. So far, three-fourths of INSIGHTS respondents have gotten or plan to get vaccinated against COVID.

As seen here, there was a marked increase in how INSIGHTS survey participants felt about their situation from the year before. March 2021 data suggests that, while not returning to pre-COVID levels, fewer arthritis patients are experiencing feelings of anxiety and depression. Likewise, fewer report their inability to participate in family activities, suggesting that more patients are able to get back to spending time with their families.



## Unequal Outcomes

Pain disproportionately impacts some patients, causing less ability to do regular work, home and leisure activities.



**83%**

of patients with a household income of \$15,000 or less experienced moderate to severe impacts on their daily lives.



**77%**

of patients with a high school education or less experience moderate to severe impacts on their daily lives.



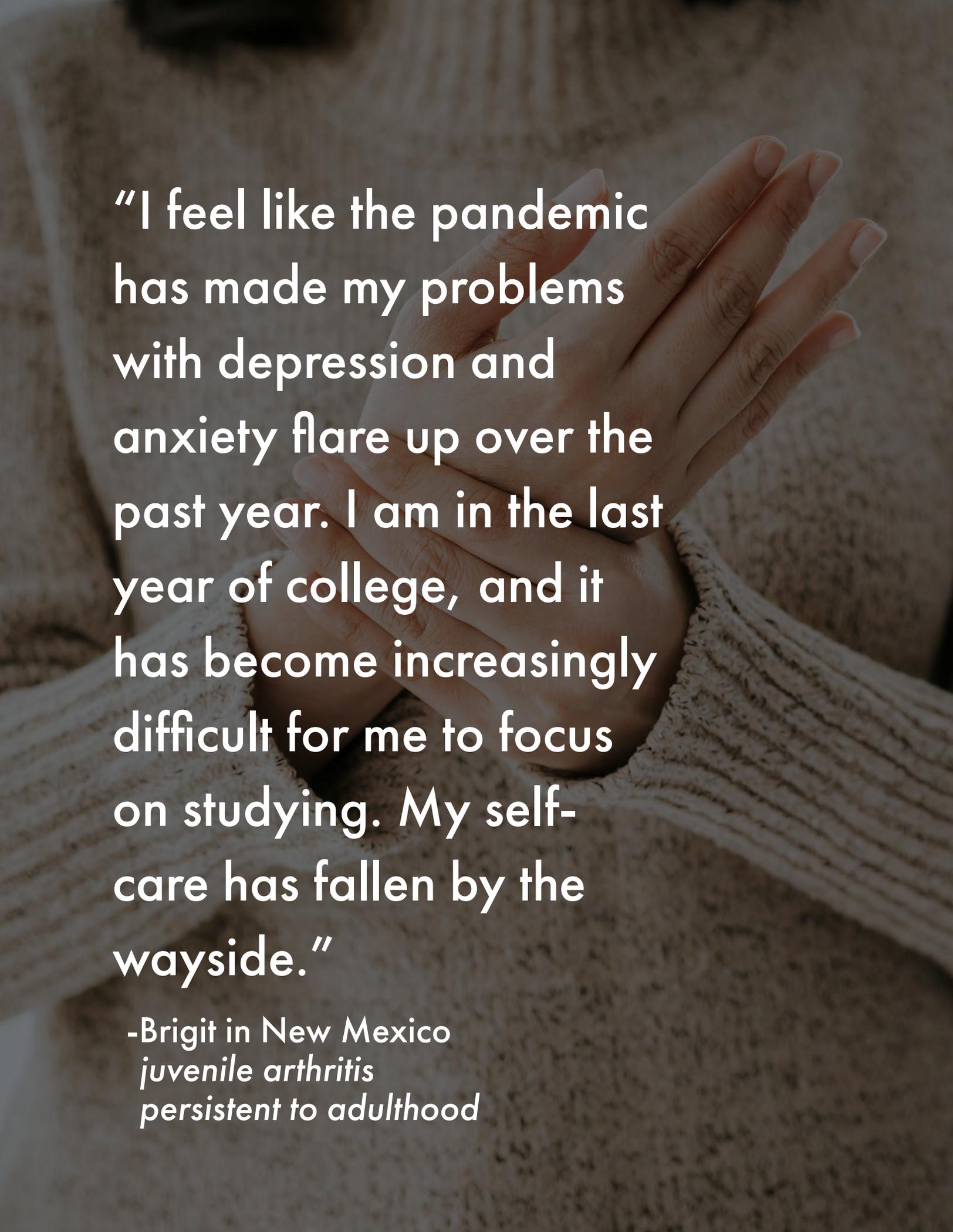
**75%**

of patients with both osteoarthritis and inflammatory arthritis are particularly challenged to do the work, home and leisure activities they want to do.



Learn more about arthritis pain management and related topics in our series of webinars. [arthritis.org/webinars](https://arthritis.org/webinars)





"I feel like the pandemic has made my problems with depression and anxiety flare up over the past year. I am in the last year of college, and it has become increasingly difficult for me to focus on studying. My self-care has fallen by the wayside."

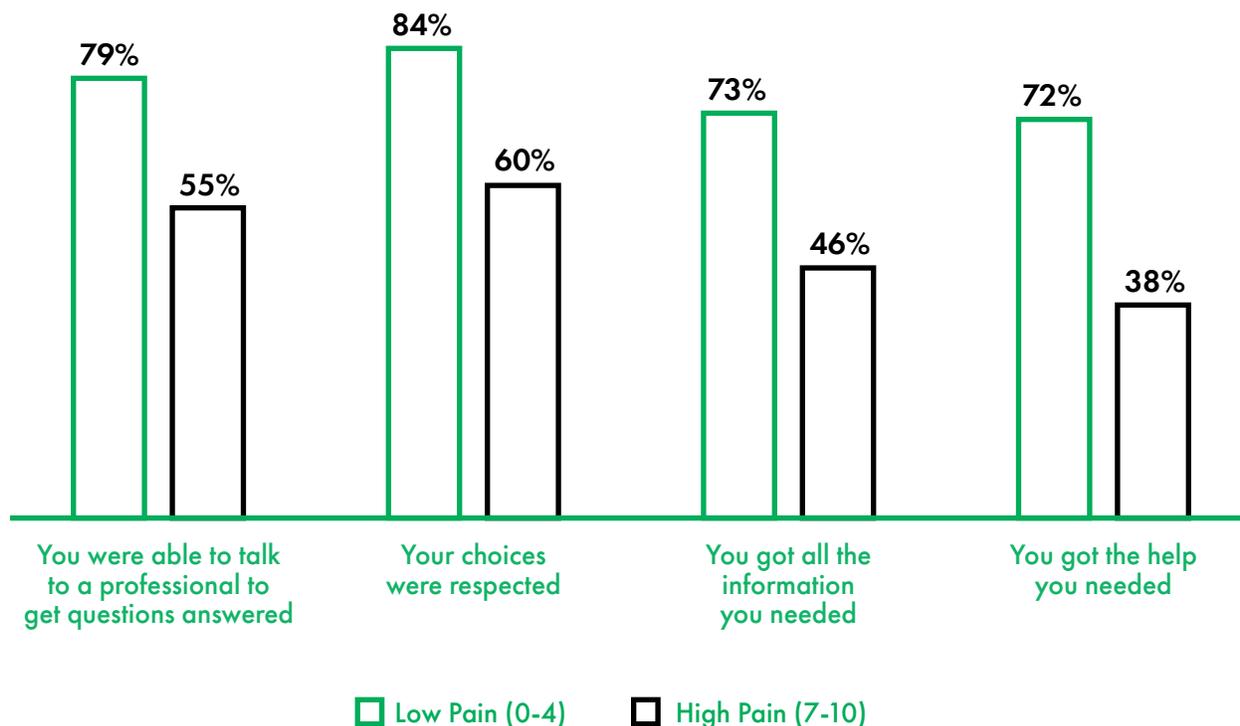
-Brigit in New Mexico  
*juvenile arthritis  
persistent to adulthood*



## Inequality in the Care Experience

People who live with high physical and emotional pain seem to be less likely to feel empowered, perhaps because of the complexity of their diagnosis, or possibly due to their income, education, gender, ethnicity or other factors. The latest data are being examined to find solutions.

### Interactions With an HCP



# Marginalized Population Segments

While arthritis can impact anyone, regardless of age, gender, race or socioeconomic status, research indicates that several population groups are disproportionately affected by arthritis-related limitations: African American/Black individuals, Hispanic/Latinx American individuals, Asian American individuals, low-income individuals and those living in rural areas.

Arthritis may diminish their ability to work and participate in daily living, an issue compounded by systemic barriers to accessing diagnosis, treatment and support.

These populations also disproportionately battle other chronic conditions, such as diabetes, heart disease and anxiety, which can further exacerbate arthritis symptoms.

Language is another common barrier for these patients.

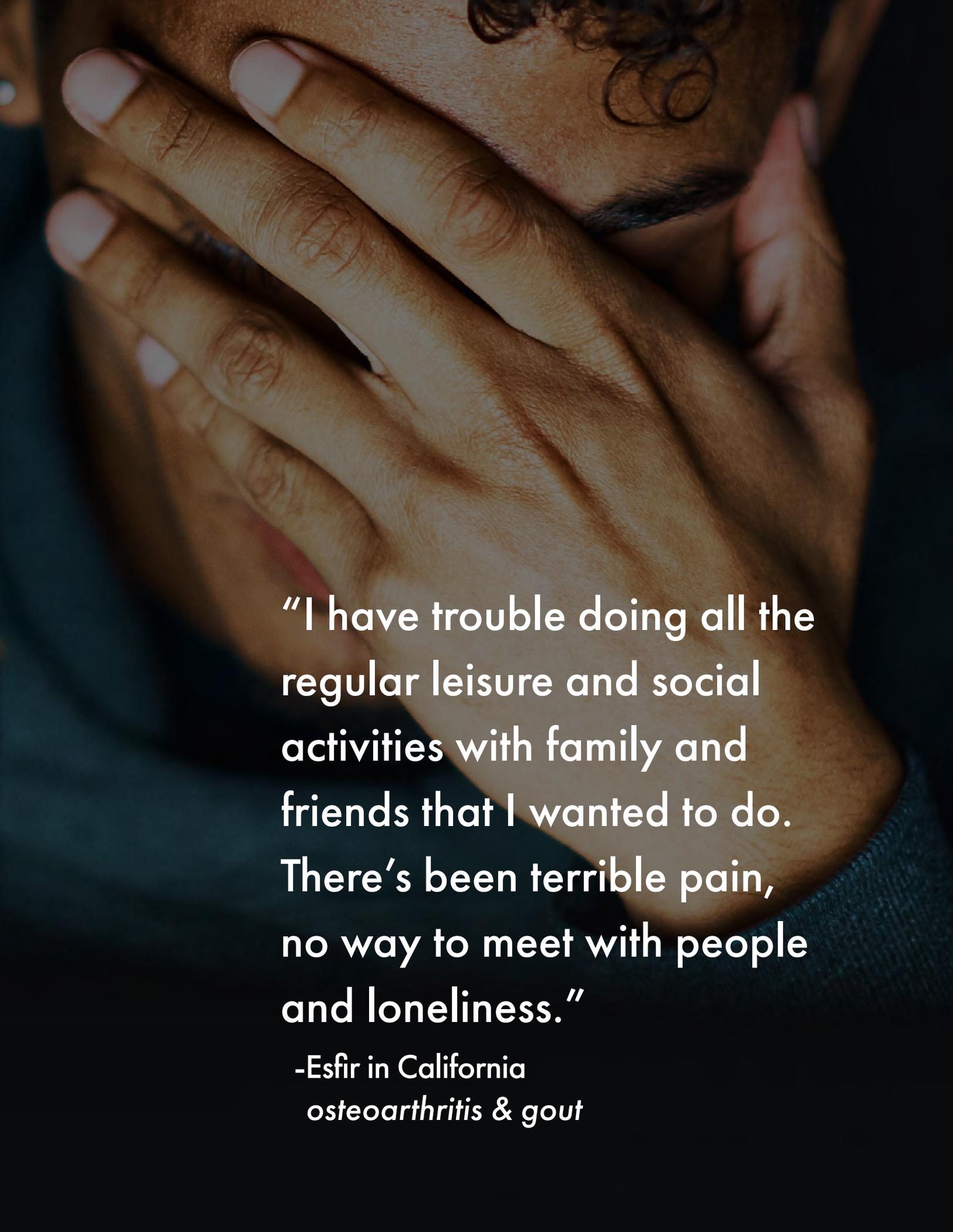
Population Segment	% Population With Doctor-Diagnosed Arthritis <sup>1</sup>
African American/Black	12.4%
Hispanic/Latinx American	11.3%
Asian American	3.1%
Low-income American <sup>2</sup>	8.5%
Rural area American <sup>3</sup>	15.8%

Despite these disparities, the experiences of patients in underrepresented populations who live with arthritis are going largely untold in today’s landscape of research, treatment and policy.

Our goal is to have the representation of each listed group in the Live Yes! INSIGHTS study be as close as possible to the CDC/U.S. Census data on those with doctor-diagnosed arthritis. The significant underrepresentation of these populations in our data collection effort must be addressed in order to figure out solutions to the burdens they face.

The Arthritis Foundation is committed to ensuring that more historically underserved arthritis patients participate in the INSIGHTS study.

<sup>1</sup>CDC Vital Statistics: Selected results from TABLE 1. National Health Interview Survey (US), 2013–2015  
<sup>2</sup>Household income of <\$25,000 per year  
<sup>3</sup>Rural areas as defined by U.S. Census data



“I have trouble doing all the regular leisure and social activities with family and friends that I wanted to do. There’s been terrible pain, no way to meet with people and loneliness.”

-Esfir in California  
*osteoarthritis & gout*

## Pain Intensity and Pain Interference Are Correlated

The majority of patients (57%) report a level of pain that makes daily living a real challenge. If they have a lot of pain, they also have a lot of pain interference.



Consider joining our Online Community forums or a Connect Group to meet others battling arthritis pain. Sign up at [arthritis.org/LiveYes](https://www.arthritis.org/LiveYes).

Live Yes!

## What's Next?

We heard the message about pain loud and clear. And that's why we've made responding to arthritis pain with better pain management solutions our top priority. We also know that juvenile and adult arthritis aren't the same, which is why we launched the Live Yes! JA INSIGHTS program to gather data from parents of children ages 5 to 17 with arthritis and related diseases.

Moving forward, helping patients overcome the challenges of chronic pain will be our driving force. It's the reason for everything we do.



### Science

We follow the science and search for a cure.



### Advocacy

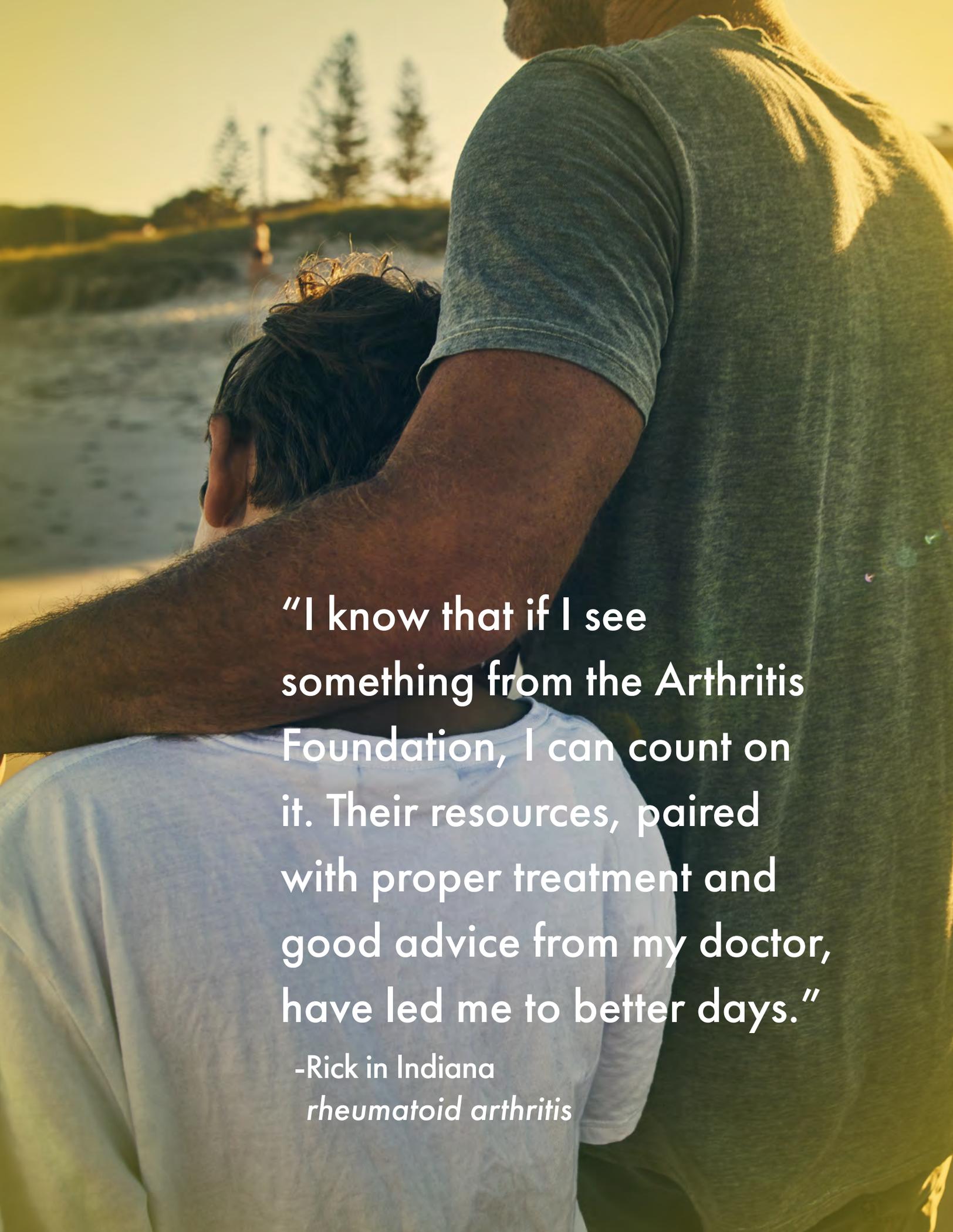
We advocate for access to quality care.



### Programs

We work to educate and connect the arthritis community.





"I know that if I see something from the Arthritis Foundation, I can count on it. Their resources, paired with proper treatment and good advice from my doctor, have led me to better days."

-Rick in Indiana  
*rheumatoid arthritis*

# We're in this fight together, and with your help, we can win.



## Making Millions of Lives Better

In 2021, as part of our response to addressing pain, we're launching a three-year initiative to positively impact the lives of millions of people with arthritis. We know that's just a start.

This work will lay the foundation for better research, increased funding and stronger connections within the arthritis community. Soon, you'll see components of this initiative come to life and start to make a difference:

**Pain awareness campaign** aiming to bring the issues of the arthritis community to the forefront, illustrating the importance of our INSIGHTS study, the research we fund and the resources we provide

**New app** that will give people with arthritis more power over their pain, providing hope and solutions with:

- Expert Educational Content
- Goal & Activity Tracker
- Community Connections & Support

**Stepped-up efforts** to make our INSIGHTS study more inclusive through greater outreach to underserved and underrepresented communities

Together these pieces will give us the traction we need to make more advances in:

**Patient Education & Support:** We're working to deliver new resources that our diverse community tells us they want and need most.

**Scientific Research:** We're working with researchers to further investigate chronic pain and find better therapies and a cure.

**Advocacy:** We're working to raise awareness of the tremendous toll arthritis takes and to enact policies and laws that will make living with the disease better.

A close-up, over-the-shoulder view of a person with dark hair wearing a white VR headset. A hand is visible near the right lens of the headset. The background is a soft, out-of-focus yellow and blue.

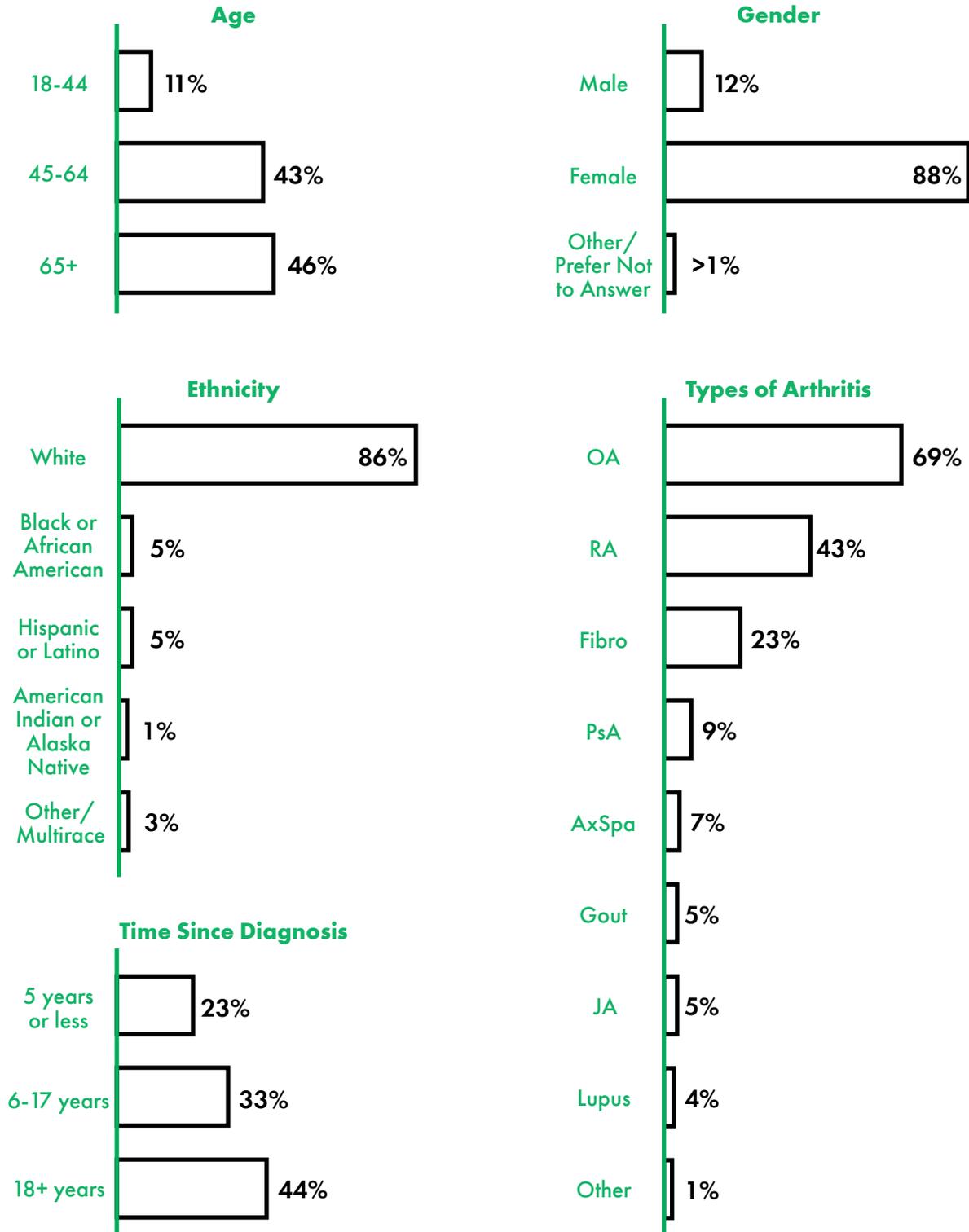
**“Until a cure is found,  
we have this amazing  
Arthritis Foundation that  
goes to great lengths to  
help us live our best life.  
We are not alone in this  
lifelong journey!”**

*-Stacy in Georgia  
rheumatoid arthritis*

# APPENDIX

## Demographics of Live Yes! INSIGHTS Participants

March 2018 through December 2020





# Live Yes!

---

# INSIGHTS

## Take the Survey

The **Live Yes! INSIGHTS** study is ongoing and cumulative. Arthritis patients, including more of those in underrepresented segments of society, are encouraged to participate — and then continue weighing in at regular intervals so data is kept constantly updated.

This is a great opportunity for people with chronic arthritis pain to rise above their limitations — to help themselves and the entire arthritis community. While there may be things they can't do, sharing their experiences is something they **CAN DO** to improve lives today and change the future of arthritis.

[Learn More](#)



# Live Yes!

---

## INSIGHTS

### **Acknowledgments**

- The Dartmouth Institute Center for Program Design and Evaluation
- Arthritis Foundation Patient Leadership Council
- 110 patients, health care professionals and measurement experts who helped select the measures
- Patients who took the survey

**The Arthritis Foundation is grateful to the following companies for their support of the Live Yes! INSIGHTS assessment tool:**

abbvie

 Bristol Myers Squibb™

**Genentech**  
A Member of the Roche Group

janssen  PHARMACEUTICAL COMPANIES OF  
*Johnson & Johnson*