

2019 Edition

# A Mandate for Action

A First Look at the  
Arthritis Foundation's  
Live Yes! INSIGHTS  
Findings



"I measure my pain by the things that I can no longer do. When my son was first born, my arthritis flared so badly, I was a five on the pain scale every day. That pain meant that I could not hold my newborn son." – Stacy C.



# The Eye-Opening Realities of Arthritis

To Our Invested Community,

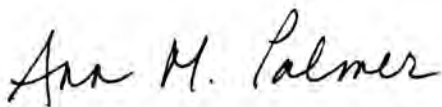
What we have always known is this: More than 54 million people have arthritis in America, making it the number one cause of disability. And that number is rising with conservative estimates showing an increase to 78.4 million by 2040. The toll of this disease is summed up with more than \$304 billion annually from total medical costs and earning losses as of 2013.

While these statistics give us plenty to be alarmed about, they tell us very little about the lives of those 54 million. People with arthritis deserve more; they deserve to be heard, understood and acknowledged by legislators, product designers, care providers and their families. As the largest organization dedicated to changing the lives of people with arthritis, it is our mandate to do that work.

In 2018, we began cataloging the real-world, real-time reporting from arthritis patients, collecting details about pain intensity, sleep, mental health concerns and experience of care. In the inaugural year of this ongoing, cross-sectional analysis, we received 18,000 assessments, making the INSIGHTS program the largest collection of data in our 70-year history and one of the largest in the world.

What we uncovered is this: 100% of patients reported pain – the kind of pain that causes constant fatigue, significantly disrupts sleep and cannot be ignored. Two-thirds of respondents said they found it difficult to participate in family activities and felt depressed and/or fearful and anxious. Many reported their needs are unmet by health care professionals, especially among lower-income patients and minorities. While results came from across the country, and no group or community is immune, the challenges vary widely from one area to another. But what's clear as a whole: Arthritis patients are living a life of less, instead of pushing to reclaim the life they deserve.

The human toll is astronomical. The pain, hardship, isolation and marginalization of people with arthritis can no longer be ignored. This first look will not be our last, and we will continue and expand this study. However, this report does allow us to share with local and national leaders the true impact of living with arthritis. It gives us data points to measure our progress in improving lives. We will use this data to inform our agenda nationally and invite local communities to do the same.



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

# Live Yes!

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## INSIGHTS

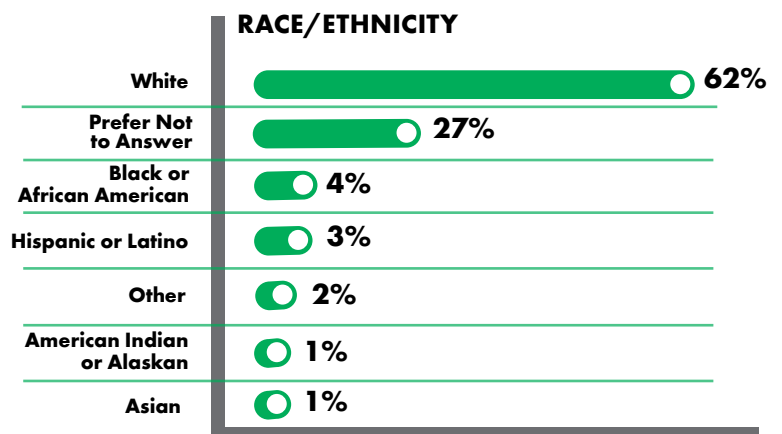
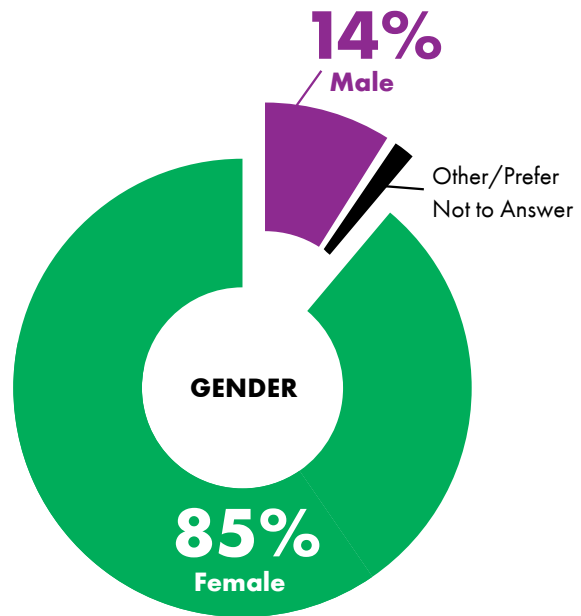
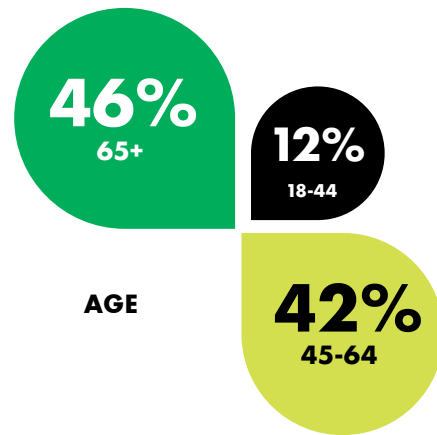
### A first-of-its-kind approach to understanding patient perceptions

The Arthritis Foundation, working closely with leading scientists and measurement experts, used a unique and ambitious patient-validated approach to determining the data points that would be most meaningful.

This report reflects the more than 18,000 Live Yes! INSIGHTS adult assessments collected through October 2019. This study, from across the country, provides an inaugural baseline of patient-reported outcomes and represents the **largest** effort of data collection in the Arthritis Foundation's history.

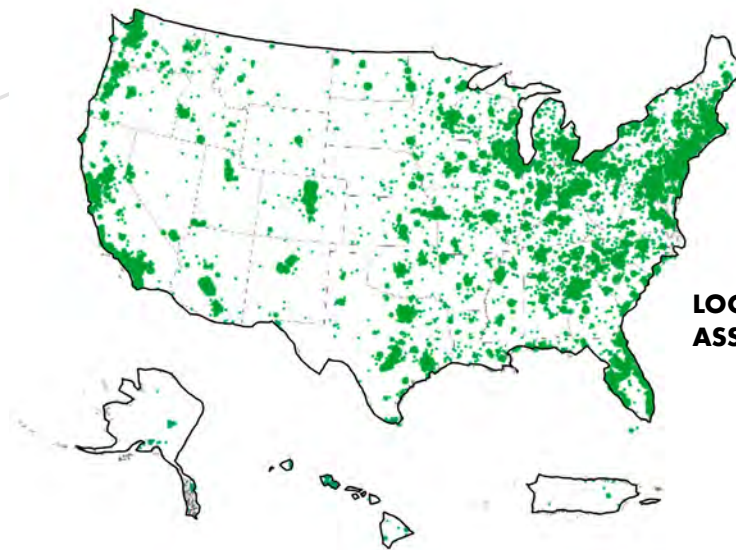
Input from more than 100 patients, health care providers and measurement experts was carefully vetted and tested over a year long process. The result is a research tool that uniquely puts relevant and meaningful data into the hands of national and community decision makers.

## Demographics



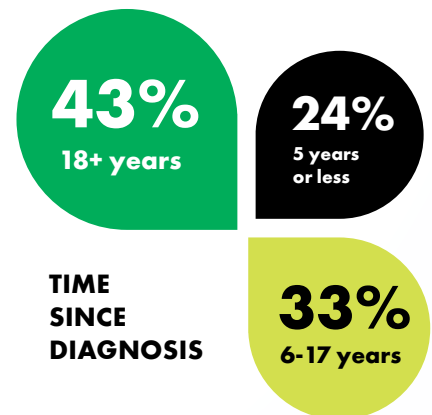
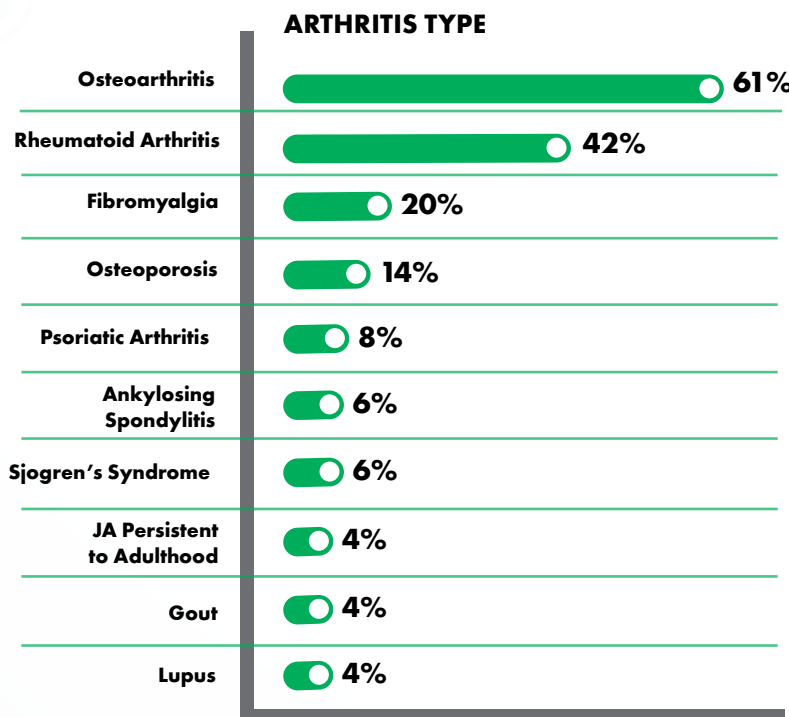
## Participation from all 50 states.

Assessments empowering people, no matter where they live, to lend their voice



LOCATION OF ASSESSMENTS

Results represent a wide variety of arthritis types and length of time with arthritis.



What We Know Is True for Arthritis Patients:

# Impaired Physical Function. Chronic Sleeplessness. Constant Fatigue.

**PAIN CAN'T BE IGNORED. IT IS  
AN INTENSE AND CONSTANT PRESENCE.**



**100%** of patient responders  
**REPORTED PAIN** over the last  
seven days — **with an  
average pain score of  
5 on a 10-point scale.**

## What a “5” on the Pain Scale Means

Moderately strong pain. It can't be ignored for more than a few minutes, but with effort you still can manage to work or participate in some social activities.\*

**92%**  
of patients reported  
that pain interfered  
with their day-to-  
day activities.

“Before my knee replacements, I was barely walking. I needed a walker and sometimes a wheelchair at only 27 years old. I was active my whole life, and all of the sudden I couldn't put one foot in front of the other or get out of bed without my walker.” — LaTosha D.

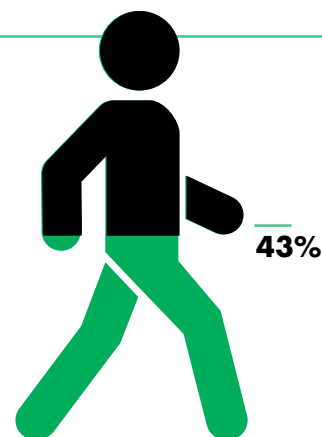
\* Richards KL. The Pain Scale Chart: What it Really Means. ProHealth. Updated May 18, 2019. Retrieved from <https://www.prohealth.com/library/what-the-pain-scale-really-means-34982>

## PAIN LIMITS ABILITY TO WALK.

Almost half of our community cannot walk easily.

**43%** reported that they could not walk at all or had major difficulty walking

for at least 15 minutes during the past seven days.



**Osteoarthritis** patients are more impacted at **51%**.

People in **West Virginia** are impacted even more at **58%**.

**African Americans** are impacted more than any other race at **54%**.

## PAIN CORRUPTS PATIENTS' SLEEP AND UNLEASHES FATIGUE.

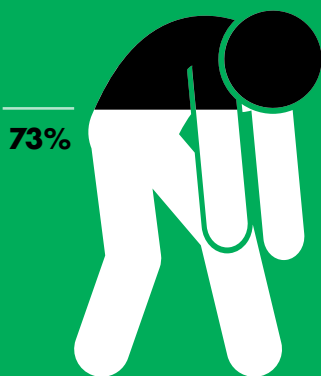


LESS THAN

**1/3**

slept well

in the past seven days.



**73%** reported feeling **fatigued** over the past seven days.

**Lupus** patients are more impacted at **88%**.

People in **Oklahoma and Maine** are impacted even more at **83%**.

**Hispanics** are impacted more than any other race at **78%**.

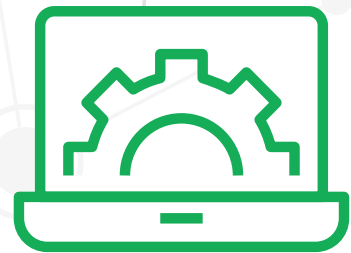
What We Know Is True for Arthritis Patients:

# Reduced Work Abilities. Decreased Family Connectivity. Increased Depression.

## PATIENTS HAVE TROUBLE WORKING.



reported having trouble  
doing all usual work.  
(including work at home)



**Psoriatic Arthritis**  
patients are more  
impacted at **79%**.

People in  
**Mississippi**  
are impacted even  
more at **84%**.

**American  
Indian or  
Alaska Native**  
are impacted more than  
any other race at **81%**.

“When I had to stop working, my life collapsed. It was as if everything that I was, everything that I had ever hoped to be, everything that meant the most to me was taken away. I found my entire identity in my work; I loved it. And when it was taken away by my arthritis, it was as if someone had beaten me up.” – Rick P.



## PATIENTS MISS OUT ON FAMILY ACTIVITIES.



**67%**

reported having trouble doing all the family activities they want to do.

**Ankylosing Spondylitis**

patients are more impacted at **81%**.

People in **Alabama** are impacted even more at **80%**.

**African Americans** are impacted more than any other race at **73%**.

“We have to plan our family vacations around my arthritis. I am unable to walk across a sandy beach. It’s heartbreaking to miss out on those moments with my children because ‘Dad can’t do it.’” – Travis S.

## NOT LIVING THE LIFE THEY WANT IS TAKING AN EMOTIONAL TOLL.

**2/3**

said they felt depressed

during the past seven days.



**2/3**

said they felt anxiety or fear

during the past seven days.

While INSIGHTS data reveals the domains most affected by arthritis, understanding the factors that drive these domains is a next step. More deeply understanding the reasons for the social and emotional tolls of arthritis will point to additional ways to treat not just the joint, but also the many other issues imposed by arthritis.

What We Know Is True for Arthritis Patients:

# Unmet Needs. Disparities in Care. Health Care Shortcomings.

**There is a significant gap in care. Patients with lower incomes report not getting the help they needed at alarming rates compared to those patients with higher incomes.**

INSIGHTS data also reveals that people with severe conditions often have more partnership with the health care system. Unfortunately, people with less severe conditions often feel removed from the decision-making process. This health care gap represents a critical area of unmet need among patients.

“Access can become an impossibility if you are living paycheck to paycheck. You are on shaking ground all the time. You are forced to make tough choices every day to manage your care. I know many families who are forced to choose between buying groceries for their family or medication for themselves.” – Raquel M.

**93%** of patients reported that it is extremely important to have the ability to talk to a professional to answer their questions.

**YET ONLY**

**69%** surveyed were satisfied with their experience.

**93%** of patients reported that it is extremely important to get the help they need at their health care professional's appointment

**YET ONLY**

**57%** surveyed reported they got the help they needed.



**Satisfied with Experience with Health Care provider**

**Got the Help Needed from Health Care Provider**

# A Mandate for Action



## **A bold, innovative research agenda is critical.**

The findings clearly illustrate that today's treatments – even after significant advancements in recent years – are far from perfect. The physical impacts are profound, but so too are the social and emotional costs. A new focus on bold, innovative research paradigms that address the real human burden of arthritis is essential, but underfunded. The Arthritis Foundation must act immediately to pioneer new fields of study guided by the needs of the patient community.



## **Our health care system must take arthritis seriously.**

The INSIGHTS data places numbers on the otherwise invisible consequences of arthritis. Today, arthritis is recognized as one of the chief drivers of health care costs, but less understood are the indirect financial and personal costs as arthritis limits people's ability to work and live the life they want. We cannot solve the nation's health care problems without solving arthritis. Too often, people with arthritis feel marginalized or overlooked by today's health care system, or encounter unacceptable delays in accessing care. The Arthritis Foundation is leading a movement to break through the barriers and innovate care in order to bring systemwide change to arthritis.

“I have always been someone who works nonstop. A lot of my family and friends who saw my nonstop life would assume that I was A-OK. They weren't seeing my six-hour infusions. They weren't seeing the daily pain and stiffness, the brain fog and fatigue. When I need support, it means I have to convince my community that there really is something wrong. And that takes so much out of you, especially when you're struggling with your symptoms.” - Shannan O.

The findings from this study are compelling and paint a picture of gaps that must be addressed. Arthritis continues to take a profound and oftentimes devastating toll, resulting in lost decades of life lived and abandoned dreams. The data illustrates, for the first time, that no community or group is immune. Across all states and all segments of society, there is a gap between what patients need to live well and what is available to help them do so. Now is the time for action. The patients who participated in this study have taken the first step by joining the Arthritis Foundation to change the course of arthritis. Their perspectives demand the focused attention of many: researchers, the health care system, product developers, regulators, lawmakers and the patients themselves.

## Change is needed now!



### **Patients must lead their care.**

Our data reveals that the health care system does not devote full attention to patient needs early in their diagnosis. To overcome this, people with arthritis must be their own advocates. Patient must take a leading role in managing arthritis by seeking experiences outside the health care system, including the support of their peers. The Arthritis Foundation is arming our constituents with the skills, savviness and unwavering determination to get the kind of care every single person deserves. Indeed, data suggests that the next blockbuster drug may be the patients themselves.



### **Patients must challenge our society and industries to do better.**

Our data tells us that patients are not getting what they need from the health care system ... and from our society at large. They struggle daily with products that shine a light on their limitations: clothing that is impossible to button, household products that require a loved one to open, lifestyle and household goods made for someone else's life. It is unacceptable that product manufacturers are not addressing the very real challenges faced by one in four Americans. The Arthritis Foundation is ready to challenge the "business as usual" approach and re-level the playing field so people with arthritis can live the life they deserve.



### **We must reject the one-size-fits-all approach and customize care to our communities.**

By examining patient experience at the ZIP code level, the INSIGHTS data demonstrates that no group or community is immune from the devastating impact of arthritis and that the challenges are very different from one community to another. By sharing data specific to individual communities, the Arthritis Foundation will lead a charge with local providers, businesses and patients to recognize and adapt to the unique needs in cities and towns nationwide.

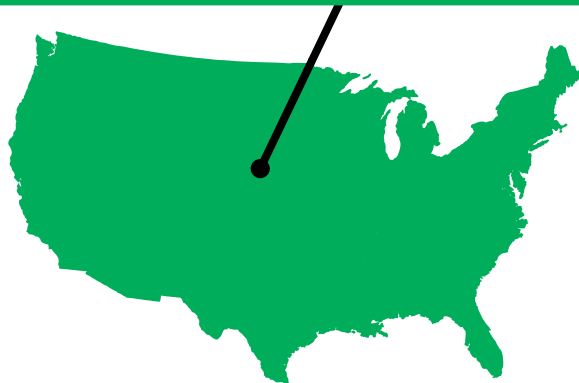
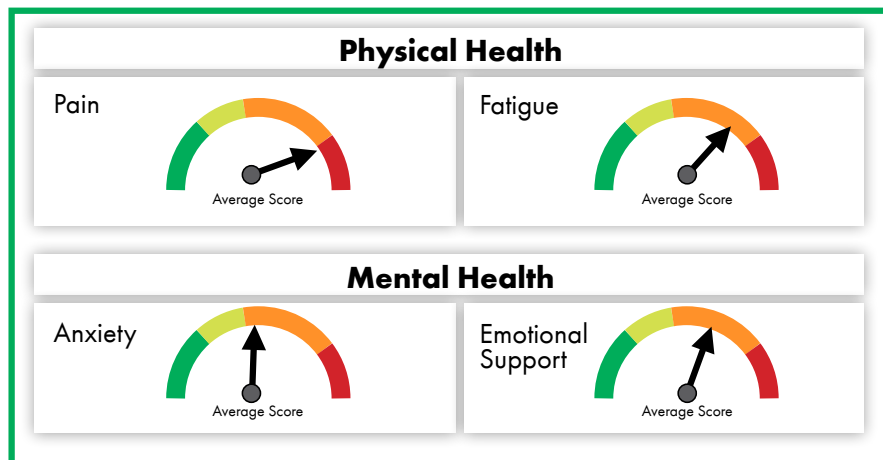
## Addressing Data Locally in Real-Time

Before distributing our assessment to tens of thousands of patients, the Arthritis Foundation dedicated an entire year to gather robust input from more than 100 patients and scientists to help develop this study. Our assessment went on to measure how people with arthritis really feel physically and emotionally, as well as what their health care experience is like. However, it is not a one and done effort.

In addition to reporting results on an annual basis, the Arthritis Foundation is the only organization with a 50-state strategy for translating data into advocacy, research and community programs that change lives. Ongoing, aggregate patient-reported outcomes are monitored in real-time through a robust dashboard (pictured below).

**Not only are results monitored at a national level, but the 70 local Arthritis Foundation markets across the country are making positive changes in their communities through tailored programs based on localized data.**

### MONITORING LOCALIZED DATA IN REAL-TIME FROM THE LIVE YES! INSIGHTS DASHBOARD



## Thank you!

The Arthritis Foundation is so grateful for the patients who contributed to this study. Through the Live Yes! Arthritis Network, the Arthritis Foundation urges patients to continue taking the assessment on an ongoing basis. Together, our collective voice, along with policy makers, scientists, and community leaders can help shape the future together.

Powered by YOU, we invite you to participate at:  
[arthritis.org/INSIGHTS](https://arthritis.org/INSIGHTS)

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### Sources & Acknowledgments

#### Acknowledgments

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

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



“I feel like since I have limited energy and mobility, my family and friends don’t have time for me. The invitations no longer arrive. People invite others on vacation while I stay home.” – Sharon B.

