

# 2019 RHEUMATIC DISEASE PATIENT SURVEY

Access, Affordability &  
Lifestyle Challenges for  
Americans Living with  
**Rheumatic Disease**



AMERICAN COLLEGE  
of RHEUMATOLOGY  
*Empowering Rheumatology Professionals*

# Key Findings

- Nearly 60 percent (57.41%) of individuals living with a rheumatic disease are currently being treated by a rheumatologist or were referred to seek treatment from a rheumatologist. However, **about two-thirds** (63.68%) had to wait more than 30 days after a referral before getting an initial appointment – if they could get one at all.
- Despite recent policy efforts to curb its usage, a significant number of patients are subjected to insurer step therapy requirements. **Almost half** (46.49%) of respondents receiving treatment for a rheumatic disease reported that they were required to undergo step therapy in the past year.
- Affordability remains a top concern for individuals living with a rheumatic disease. **Nearly 60 percent** (57.13%) of patients receiving treatment for a rheumatic disease said they had difficulty affording their medication(s) or treatment(s) in the past year.
- **One-quarter** (25.1%) of patients reported annual out-of-pocket spending greater than \$1,000 while about six percent (6.24%) of patients reported out-of-pocket spending greater than \$5,000 per year.
- **Almost two-thirds** of patients (63.81%) said that rheumatic disease limited their ability to perform simple tasks like eating, getting dressed, cooking, or running errands, and younger patients appeared to have more difficulty with these tasks.

**60%**

Reported  
difficulty affording  
treatment

**1/2**

Were forced to  
undergo step  
therapy

**2/3**

Reported activity  
and lifestyle  
limitations due  
to their disease

# About This Survey

*In conjunction with Rheumatic Disease Awareness Month 2019, the American College of Rheumatology and its Simple Tasks public awareness campaign conducted a national survey to gain insights into the unique access and affordability challenges faced by rheumatology patients. The survey asked participants about their ability to access rheumatology care, afford their medications and treatments, and perform daily tasks. This executive summary takes a look at the survey results.*

## Rheumatic Disease in America

Rheumatic diseases are autoimmune, inflammatory, and degenerative conditions that affect a person's joints, muscles, bones, and organs. There are more than 100 rheumatic diseases and conditions, including commonly known conditions such as osteoarthritis, rheumatoid arthritis, lupus, and gout. Lesser known conditions include Sjögren's syndrome, scleroderma, vasculitis, spondylarthritis, and polymyalgia rheumatica.

### DATA & METHODOLOGY

*The Rheumatic Disease Patient Survey was conducted by the American College of Rheumatology using the online polling tool SurveyMonkey Audience. The survey was conducted June 28-29, 2019, among a nationally representative sample of 1,517 adults with a rheumatic disease ages 18 and older living in the United States. The margin of error for this survey was approximately 3 percent. For results based on other subgroups, the margin of error may be higher.*

An estimated 54 million U.S. adults currently live with a rheumatic disease, according to the Centers for Disease Control and Prevention (CDC).<sup>1</sup> While significant progress has been made in diagnosing and treating rheumatic diseases, numerous challenges remain for the nearly one-quarter of American adults who live with these diseases every day.

Last year, the American College of Rheumatology (ACR) and its Simple Tasks® public awareness campaign identified these challenges in the *2018 Rheumatic Disease Report Card: Raising the Grade on Rheumatology Care in America*, which graded each of the 50 states and the District of Columbia on the factors associated with an individual's ability to live well with a rheumatic disease.

This survey aims to provide additional context to this discussion by asking patients directly how their disease impacts daily life.

These findings were released in September 2019 during the 4th Annual Rheumatic Disease Awareness Month.

---

<sup>1</sup> Barbour KE, Helmick CG, Boring M, Brady TJ. Vital Signs: Prevalence of Doctor-Diagnosed Arthritis and Arthritis-Attributable Activity Limitation – United States, 2013–2015. *Morb Mortal Wkly Rep.* March 2017; 66:246–253.

# Access

Access to rheumatology care is critical for patients to adequately manage their rheumatic disease. Unfortunately, ongoing policy challenges – including a severe national rheumatology workforce shortage, lack of insurance coverage, and insurers’ use of restrictive step therapy practices – make it difficult for many patients to access care.

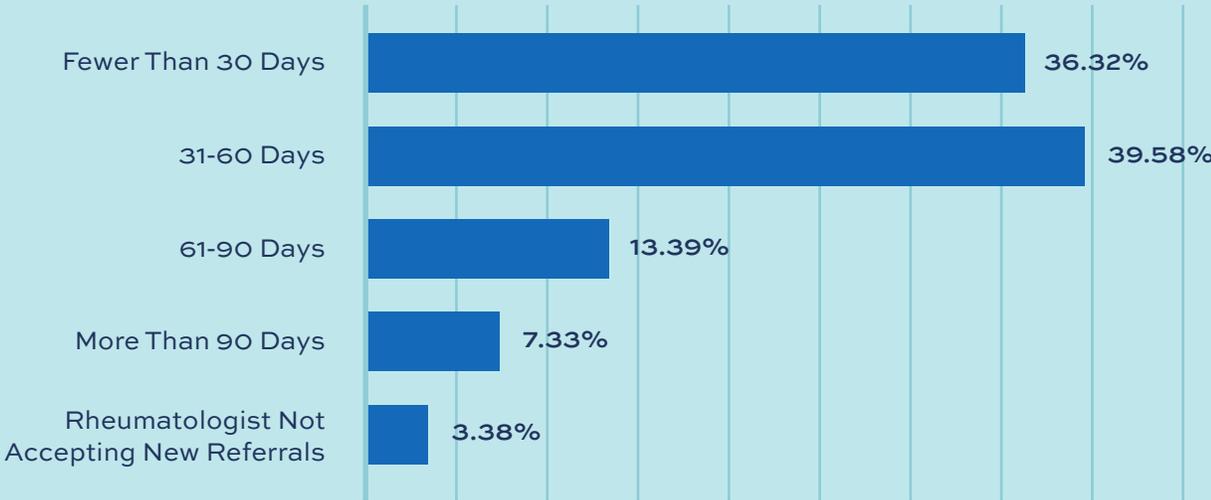
## WAIT TIMES

Nearly 60 percent (57.41%) of respondents with rheumatic diseases said they were currently being treated by a rheumatologist or had been referred to seek treatment from a rheumatologist. However, it appears younger patients are much more likely to

receive treatment from a rheumatologist than older patients, as only 30 percent (30.21%) of respondents over the age of 60 are currently being treated or have been referred to seek treatment for their rheumatic disease.

The vast majority of patients who were referred to seek treatment were eventually able to make an appointment with a rheumatologist. However almost two-thirds (63.68%) had to wait more than 30 days after a referral before getting an initial appointment, and nearly 40 percent (39.58%) had to wait between 31-60 days to get an initial appointment. Only 3.38 percent of patients were told that the rheumatology practice they were referred to was not accepting new referrals at the time.

### DAYS BETWEEN REFERRAL AND INITIAL RHEUMATOLOGY APPOINTMENT



# STEP THERAPY

This survey's findings also suggest that step therapy impacts a significant number of patients with rheumatic disease. Step therapy, sometimes known as "fail first," is a practice used by insurers that requires patients to try therapies preferred by the insurance company before the insurer will cover the therapy a patient's doctor has prescribed - even when doctors are not confident the insurer-preferred option will be effective.

Almost half (46.49%) of patients receiving treatment for a rheumatic disease reported that they have been required to undergo step therapy in the past year. Approximately 40 percent (39.27%) have not had to undergo step therapy while approximately 14 percent (14.24%) didn't know whether or not their insurance company required this process.

A person's geographical place of residence also appears to determine the likelihood he/she will be subjected to step therapy. For example, patients in the east south-central region (Kentucky, Tennessee,

Mississippi, and Alabama) (60.34%) and the mid-Atlantic region (New York, New Jersey, Pennsylvania) (53.17%) were more likely to undergo step therapy practices. By comparison, 42 percent (41.94%) of patients living in the New England region (Massachusetts, Connecticut, Rhode Island, Vermont, New Hampshire, and Maine) had to undergo step therapy.

In addition, approximately half of men (50.52%) who receive treatment for their rheumatic disease reported that they were required to undergo step therapy within the past year. This includes 59 percent (59.41%) of men aged 18-29 years. Regardless of gender, step therapy disproportionately affects younger patients with rheumatic disease. Fifty-seven percent (56.80%) of patients aged 18-29 years who received treatment for a rheumatic disease were required to undergo step therapy in the past year while this was required of only 20 percent of patients over the age of 60.

## PERCENTAGE OF PATIENTS RECEIVING TREATMENT WHO WERE SUBJECTED TO STEP THERAPY



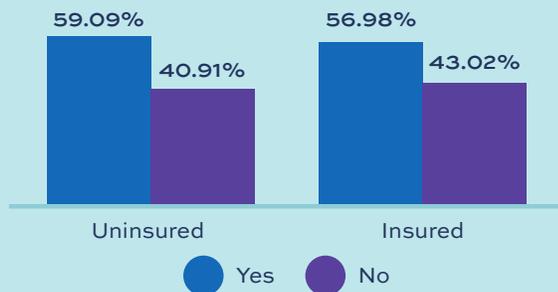
# Affordability

The survey findings suggest affordability is a top concern for individuals with rheumatic disease. The high price of prescription drugs and insurer practices that require patients to pay a significant portion of specialty drug costs out-of-pocket continue to make it difficult for many to afford their treatments.

Nearly 60 percent (57.13%) of patients who take prescription medications or receive treatment for a rheumatic disease said they had difficulty affording their medication(s) or treatment(s) in the past year. Affordability concerns persisted even among patients with insurance coverage.

*While 90 percent (90.16%) of patients surveyed had health insurance coverage, almost 57 percent (56.98%) of insured patients still reported difficulty affording treatment.*

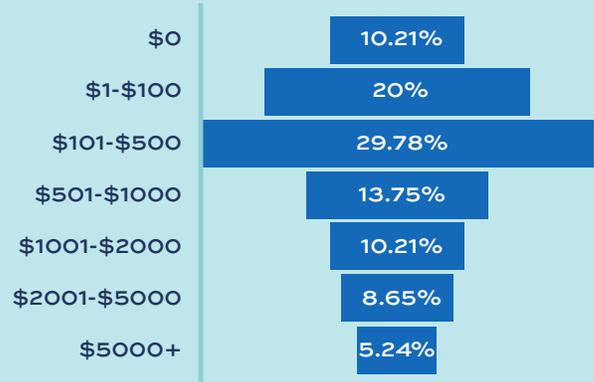
## IN THE PAST YEAR, HAVE YOU HAD DIFFICULTY AFFORDING YOUR MEDICATIONS OR TREATMENTS?



Treatment affordability was especially a concern among older patients. More than two-thirds (67.78%) of patients over 60 with a rheumatic disease had difficulty affording their treatment, while only a little more than a third (38.17%) of patients aged 18-29 years did. Even starker, nearly 90 percent (88.57%) of men over 60 years old have had difficulty affording their medication(s) or treatment(s) for their rheumatic disease.

Furthermore, many individuals with rheumatic disease struggle with high out-of-pocket costs. A quarter (25.1%) of patients reported out-of-pocket spending greater than \$1,000, while about 6 percent (6.24%) of respondents reported out-of-pocket costs greater than \$5,000 per year. The median annual out-of-pocket spending among all patients was \$475.

## ANNUAL OUT-OF-POCKET COSTS FOR PATIENTS RECEIVING TREATMENT FOR RHEUMATIC DISEASE • ALL PATIENTS



High out-of-pocket costs remain a problem even for patients who have health insurance. Among insured patients, about 23 percent (23.76%) of patients were still paying more than \$1,000 out-of-pocket for prescription medications.

## ANNUAL OUT-OF-POCKET COSTS FOR PATIENTS RECEIVING TREATMENT FOR RHEUMATIC DISEASE • INSURED PATIENTS



# Lifestyle/Activity

Individuals living with a rheumatic disease often face difficulties in performing daily tasks. If not properly treated, these limitations can become more severe and can lead to permanent disability.

Almost two-thirds of respondents (63.81%) said that their rheumatic disease limited their ability to perform simple tasks like eating, getting dressed, cooking, or running errands. Younger patients appear to experience more activity limitations than

older patients, which may indicate that the younger patients in this sample are living with a more severe or debilitating rheumatic disease. Approximately 70 percent of patients aged 18-29 years (70.80%) and 30-44 years (69.10%) reported that their disease limited their ability to perform these tasks. Meanwhile, 61 percent (61.75%) of patients aged 45-60 and 43 percent (43.23%) of patients aged 60 and over had difficulty performing these simple tasks.

## Conclusion

The survey makes clear that Americans with rheumatic disease—irrespective of gender, age, or income—are struggling to access affordable care to improve their quality of life. By providing additional context to the *Rheumatic Disease Report Card*, this survey contributes new insights into the unique access, affordability, and lifestyle challenges faced by these individuals.

The challenges presented in this survey may be alleviated with appropriate legislative and regulatory reforms. It will be critical for patients, clinicians, and policymakers to work together to improve access to rheumatology care, make it easier for patients to afford their prescribed treatments, and help patients with rheumatic diseases live longer, healthier and more fulfilling lives.



AMERICAN COLLEGE  
*of* RHEUMATOLOGY  
*Empowering Rheumatology Professionals*

The American College of Rheumatology (ACR) is the nation's leading medical association for the rheumatology community and represents more than 7,700 U.S. rheumatologists and rheumatology health professionals. As an ethically driven, professional membership organization, the ACR is committed to improving healthcare for Americans living with rheumatic diseases and advocates for policies and reforms that will ensure safe, effective, affordable and accessible rheumatology care.



The American College of Rheumatology's (ACR) Simple Tasks campaign aims to raise awareness about rheumatic diseases and their impact, highlight the healthcare policy issues that affect patients' ability to access high-quality care, and provide education and resources to rheumatology patients to help them live well with rheumatic disease. For more information, visit [www.simpletasks.org](http://www.simpletasks.org).

2200 LAKE BOULEVARD NE  
ATLANTA, GA 30319  
PHONE: (404) 633-3777

R H E U M A T O L O G Y . O R G