

2020 RHEUMATIC DISEASE PATIENT SURVEY

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

ABOUT THIS SURVEY

In conjunction with Rheumatic Disease Awareness Month 2020, the American College of Rheumatology and its Simple Tasks™ public awareness campaign conducted a national survey of individuals living with rheumatic disease to gain a better understanding of the quality of life issues associated with these diseases. This survey builds on the ACR's 2019 National Patient Survey and provides new insights into how these issues have changed over time.

This survey was conducted between June 5-8, 2020 using the online polling tool Survey Monkey Audience among a national representative sample of 1,109 U.S. adults ages 18 and older. The margin of error for this survey was approximately 3%. For results based on other subgroups, the margin of error may be higher.

WHAT IS A RHEUMATIC DISEASE?

Rheumatic diseases are autoimmune, inflammatory, and degenerative diseases that affect a person's joints, muscles, bones, and organs. There are more than 100 rheumatic diseases and conditions, including more commonly known diseases like osteoarthritis, rheumatoid arthritis, lupus, and gout. An estimated 54 million U.S. adults currently live with a rheumatic disease – including an estimated 300,000 children. Rheumatic diseases can be debilitating and, if not properly treated, life threatening.

KEY FINDINGS

- > From 2019 to 2020, there was a **52% decline** in the percentage of respondents who said they were currently being treated by a rheumatology provider.
- > **About 66%** of patients reported having a telehealth appointment with their rheumatologist within the past year, with COVID-19 reported as the most common reason.
- > Out-of-pocket costs **more than doubled** from 2019. The median annual out-of-pocket treatment cost in 2020 was \$1,000 – up from \$475 last year.
- > **Almost half** (46.17%) of patients reported that their insurer subjected them to step therapy requirements. About another half (47.94%) reported that their provider needed to obtain prior authorization before getting a prescription.
- > **Approximately 83%** (82.97%) of people living with a rheumatic disease reported at least one activity limitation as a result of their disease, including ability to exercise, work, and perform physical activities.
- > **A majority** (68.7%) of respondents reported their disease sometimes feels invisible because they don't "look sick" to most people.

52%

Decline in patients currently seeing a rheumatologist between 2019-2020

66%

Had a rheumatology appointment via telehealth

2X

Increase in out-of-pocket costs between 2019-2020

1/2

Were subjected to step therapy & prior authorization requirements

83%

Reported activity & lifestyle limitations due to their disease

68%

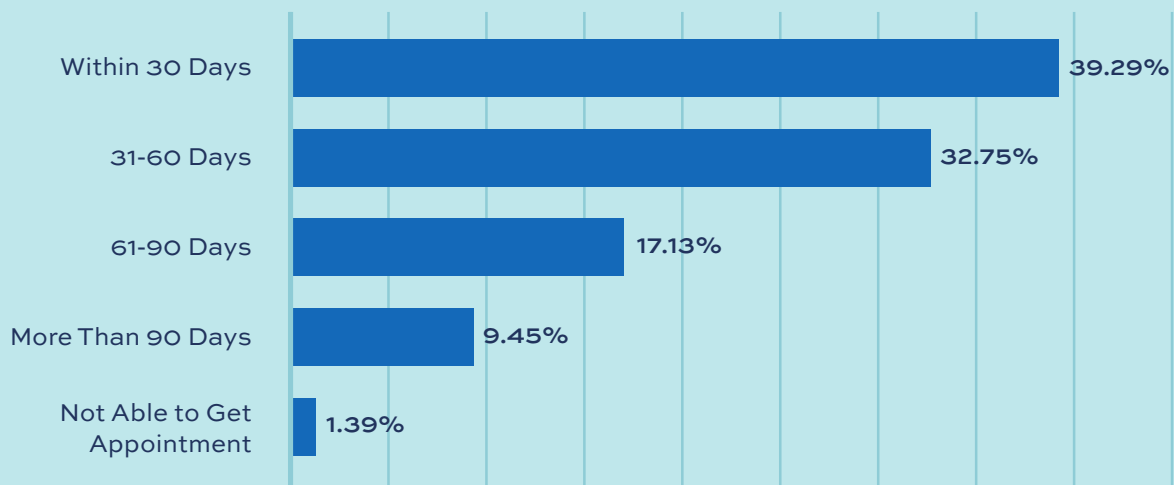
Said their disease felt invisible because they don't always "look sick"

TREATMENT & WAIT TIMES

From 2019 to 2020, there was a 52% decline in the percentage of respondents who said they were currently being treated by a rheumatology provider. In 2020, roughly one-third (33.53%) said they were currently being treated, while about 38% (38.23%) said they used to be treated by a rheumatologist or rheumatology provider. In 2019, about 60% (57.41%) of respondents said they were currently being treated by a rheumatologist.

There was also an increase in reported wait times to see a rheumatologist from 2019. In our 2020 survey, about 17% (17.13%) of respondents had to wait between 61-90 days to get a first appointment with a rheumatologist following referral, compared to only 13% (13.39%) in 2019. These results could be attributed to factors such as the COVID-19 pandemic, an increase in the number of individuals without health insurance, and the growing nationwide shortage of rheumatology health professionals.

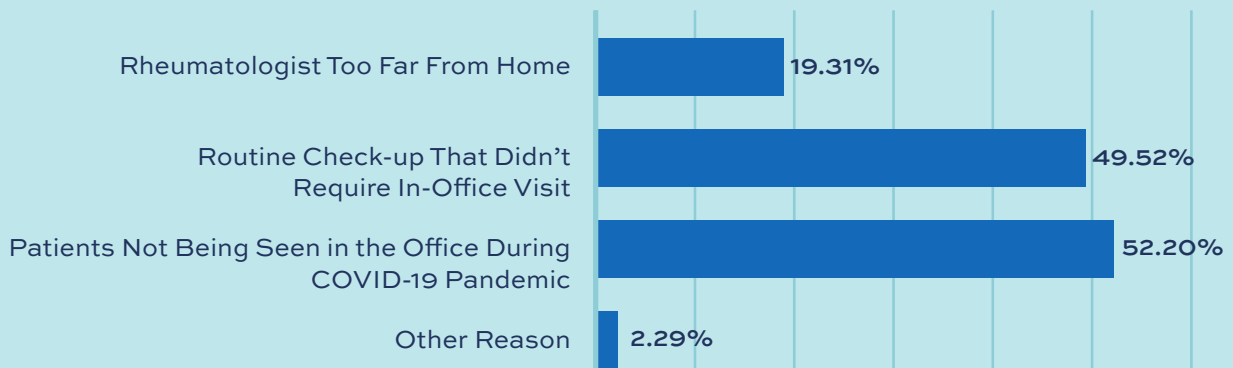
DAYS BETWEEN REFERRAL AND INITIAL RHEUMATOLOGY APPOINTMENT



TELEHEALTH

About 66% of respondents who have been treated by a rheumatology provider reported having an appointment via telehealth within the past year. These results suggest that telehealth has played a significant role in the treatment and management of rheumatic diseases.

REASONS FOR USING TELEHEALTH



PRESCRIPTION MEDICATION: ACCESS & AFFORDABILITY

Approximately 61% (61.30%) of respondents reported currently taking prescription medication or receiving other treatment, such as physical or occupational therapy, for their rheumatic disease.

Respondents were asked to report their annual out-of-pocket costs for rheumatic disease treatment. The median annual out-of-pocket spending on treatment for rheumatic disease was \$1,000 per year in our 2020 survey. This is **more than double** the median number in 2019 – \$475. Further, these results show that a significant number of patients are spending more than \$2,000 per year out of pocket on treatment.

\$1,000

Median annual out-of-pocket cost

48%

Of providers needed to obtain prior authorization

47%

Of patients were subjected to step therapy

PRIOR AUTHORIZATION

About 48% (47.94%) of patients receiving treatment for their rheumatic disease reported that their provider needed to obtain prior authorization for their prescription in the past year.

STEP THERAPY

About 47% (46.17%) of patients receiving treatment for their rheumatic disease reported that they were required to undergo step therapy, a process where patients are required to try therapies preferred by their insurance company before they can receive the therapy their doctor originally prescribed – even when doctors are not confident the insurer-preferred option will be effective.

MEDICATION SHORTAGES

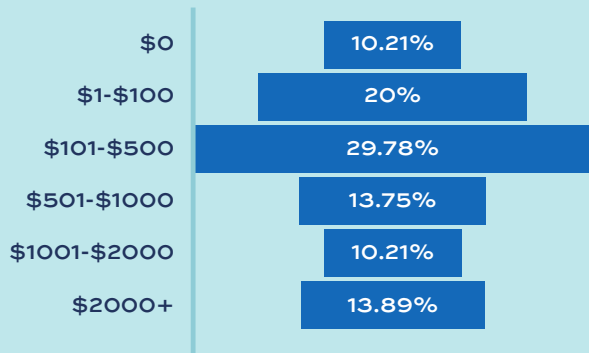
About half (49.20%) of respondents receiving a prescription medication for their rheumatic disease reported that they had difficulty filling their prescription because the medicine they needed was not in stock. The most common out-of-stock medications were:

- > **hydroxychloroquine**
(Plaquenil, Quineprox)
- > **methotrexate**
(Otrexup, Rasuvo, Rheumatrex, Trexall, Xatmep)
- > **gabapentin**
(Gralise, Horizant, Neurontin, Gabarone)
- > **acetaminophen**
(Tylenol, Actamin, and others)
- > **ibuprofen**
(Advil, Motrin, and others)

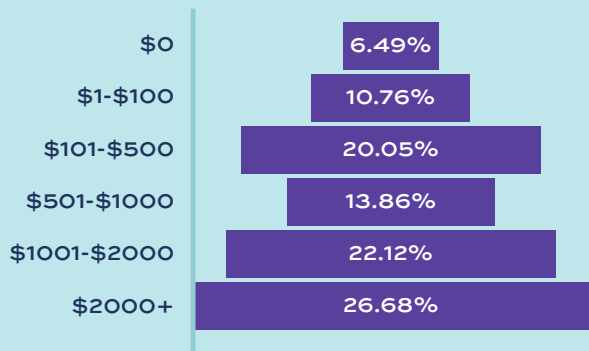
BIOSIMILARS

About 35% of patients reported that they were prescribed a biosimilar medication to treat their rheumatic disease. However, the survey also showed that about 29% (28.91%) were not sure whether they had been prescribed a biosimilar drug, suggesting a possible lack of patient education about biosimilars and how they compare to bio-originators.

OUT-OF-POCKET COSTS IN 2019

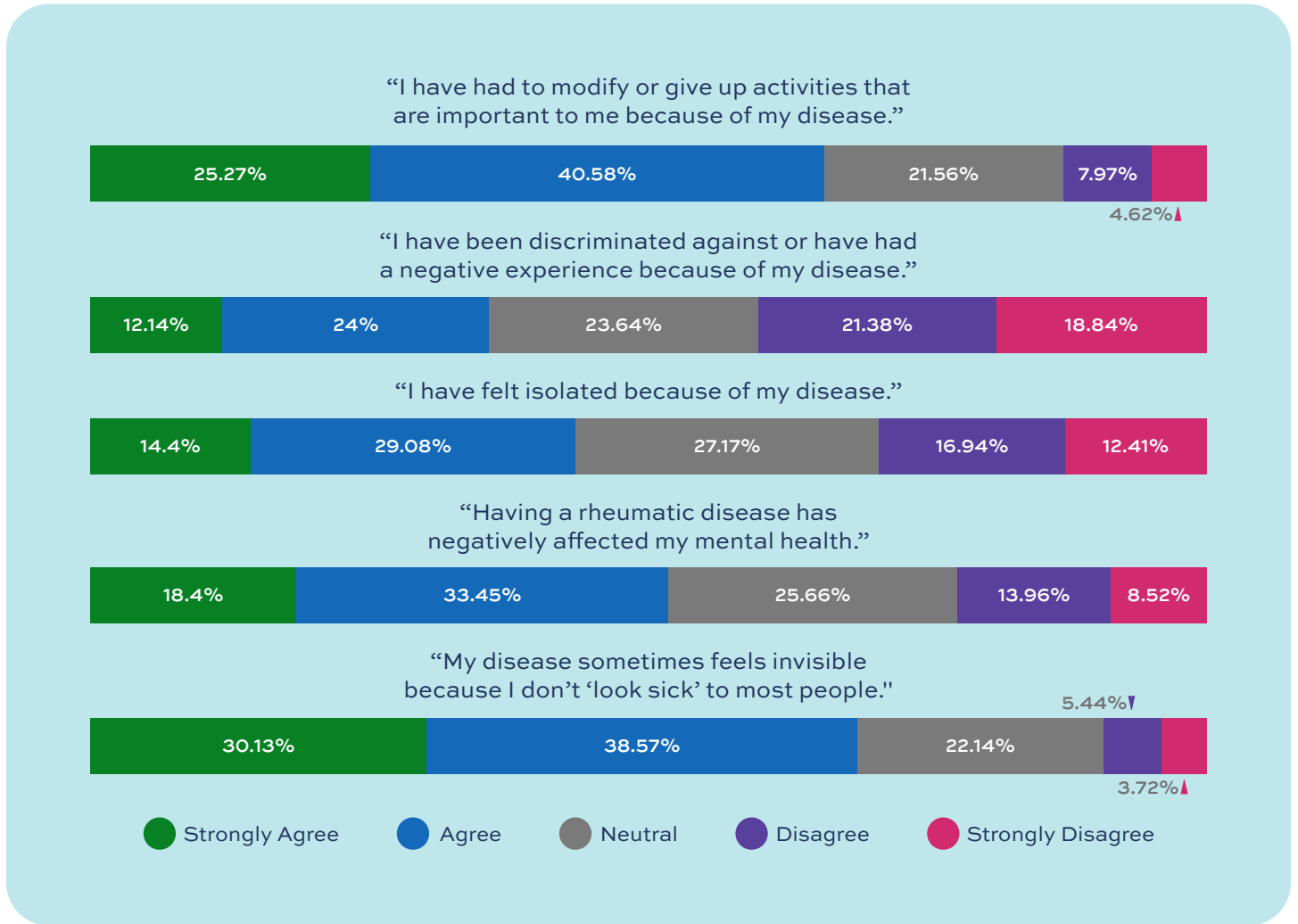


OUT-OF-POCKET COSTS IN 2020



PERCEPTIONS OF RHEUMATIC DISEASE

In order to gauge how patients perceived their disease and how it has affected their daily lives, respondents were asked how strongly they agreed or disagreed with a series of statements about living with a rheumatic disease. A majority of respondents agreed that their disease has forced them to modify or give up certain activities, has negatively affected their mental health, and has made them feel as if their disease is invisible because they don't "look sick" to most people. Responses to each question are broken down further below:



ACTIVITY LIMITATIONS

The vast majority of individuals (82.97%) living with a rheumatic disease reported at least one activity limitation as a result of their disease. The most commonly reported activity limitations were the ability to:

- > **Exercise or perform physical activities** (51.36%)
- > **Work** (43.93%).
- > **Perform simple tasks like eating, getting dressed, cooking, or running errands** (29.26%)
- > **Continue a hobby** (26%)
- > **Care for a child or loved one** (19.84%)

CONCLUSION

The survey findings show that Americans living with a rheumatic disease face significant challenges in their daily lives – including treatment access and affordability issues, lifestyles and activity limitations, and negative effects on mental and emotional health. It is critical for patients, clinicians, and policymakers to work together to improve rheumatology care so that those living with these diseases can live longer, healthier, and more fulfilling lives.