

RA patient experience: Delays in diagnosis

Rheumatoid arthritis is difficult to diagnose and patients wait an average of 1-2 years for diagnosis

Rheumatoid arthritis (RA) can be difficult to diagnose in its early stages because the initial signs and symptoms resemble those of other diseases. Compounding this challenge, there is no one test to confirm a diagnosis. Most patients eventually see a rheumatologist who uses a combination of lab tests, imaging, and a physical examination to determine if the symptoms are caused by RA or another condition. While the timing varies widely, the diagnostic process often takes 1-2 years.

How long do patients wait after visiting a doctor for joint pain before receiving an RA diagnosis?¹
n=5278

9%

Of RA patients were diagnosed
within 30 days of symptom onset

42%

Of RA patients were diagnosed
within one year of symptom onset

29%

Of RA patients were diagnosed **more**
than 3 years after symptom onset

Patient stories: Seeking a diagnosis

Example patient experiences illustrate a few of the many possible paths to an RA diagnosis



Sarah, age 43, developed pain and stiffness in her hands and wrists. When it didn't go away after a few days, she got a same-day appointment with her PCP, who referred her to a rheumatologist. At her appointment two weeks later, she was diagnosed with RA, and got advice from a clinician on managing her condition.

Time to diagnosis: <3 weeks



Arthur, age 58, noticed his joints were more painful and swollen than normal. Thinking he just needed to take it easy now that he was getting older, he ignored it. Several months later, his wife convinced him to mention the pain at his annual physical. He was referred to a rheumatologist, but the next available appointment wasn't for 6 weeks.

Time to diagnosis: 8 months



Brooke, age 13, started complaining of a sore ankle and wrists. When she didn't feel better in a few weeks, her parents took her to their pediatrician. Brooke was bounced from specialist to specialist as no one suspected someone her age would suffer from RA. Finally, she was referred to a rheumatologist.

Time to diagnosis: 1.5+ years

1. For a more detailed description of the methodology, see page 4.

Long wait times to see PCPs contribute to diagnosis delays

Patients in pain go to their PCP first

When patients in pain decide to visit a doctor, their first stop is generally a primary care physician's (PCP's) office. Unfortunately, in many areas there is a shortage of PCPs that contributes to long wait times for patient appointments.

PCPs struggle to manage pain patients

PCPs see many patients complaining of pain due to a variety of causes. They must rely on their clinical judgement to decide which patients may have RA (and therefore who should be referred to a rheumatologist) and those who suffer from an unrelated condition.



DATA SPOTLIGHT

Limited primary care supply leads to care delays

29.3 days

Average wait time to see a primary care physician¹

21K-55K

Number of primary care physicians the US will be short from projected demands in 2032



“Rheumatologists get a lot of referrals for people with chronic pain who don’t have inflammatory RA. That slows down the treatment of people with RA who have that critical window of opportunity to slow or even halt the progression of the disease.”

Dr. Shawn Slack, MD, Rheumatology and Arthritis

THE EVERETT CLINIC

Appropriate referrals are critical for making the best use of limited provider time. As referrals to specialists continue to grow, health systems and other provider groups will need to ensure that specialists' time is used as effectively as possible. To support PCPs in this task, they need clear guidelines for when to refer patients to a rheumatologist to be evaluated for RA or other rheumatic conditions.

Referral management critical for efficient use of health care resources

94%

Increase in referrals to specialists from PCPs over a 10-year period

\$8B

U.S. annual spending wasted due to clinician-related inefficiency, including inefficient use of high-cost physicians

1. Based on an analysis of 15 large metropolitan areas.

Source : "2017 Survey of Physician Appointment Wait Times," Merritt Hawkins; "2019 Update, The Complexities of Physician Supply and Demand, Projections from 2017 to 2031," Associate of American Medical Colleges, April, 2019; Barnett ML, et al., "Trends in Physician Referrals, 1999-2009," *Archives of Internal Medicine*, <https://www.ncbi.nlm.nih.gov/pubmed/22271124>; Shrank WH, et al., "Waste in the U.S. Healthcare System: Estimated Costs and Potential for Savings," *Journal of the American Medical Association*, <https://jamanetwork.com/journals/jama/fullarticle/2752664>.

Too few rheumatologists and the shortage will only grow

After referral, patients often struggle to find a rheumatologist and schedule an appointment

Given the lack of definitive diagnostic tests, physicians other than rheumatologists are reluctant to confirm an RA diagnosis. However, patients with suspected RA often face challenges in finding a rheumatologist with appointment availability. Retirement rates for rheumatologists are high, and practicing physicians are often concentrated in metropolitan areas. Access challenges are even more severe for families looking for pediatric rheumatologists.

Existing rheumatology practices often report challenges balancing their existing patient panels with scheduling new patients. Appointments are often filled well in advance by existing patients, leaving few openings for new patients. To address this problem, some have hired patient coordinators to triage referrals, invested in education for PCPs about when to refer, and revised referral forms to smooth patient intake.

As rheumatologists develop a relationship with their patients, they often feel pressure to assume responsibility for all of their patients' health care needs, not just their RA. This pressure comes from two fronts:

- Patients, especially if they have been through a long and stressful diagnostic process, may have lost confidence in their PCP. They may prefer to see a physician who they know recognizes their RA symptoms and understands how to manage them. They also appreciate that their rheumatologist offers longer appointment times to PCP.
- Some PCPs are not confident managing other health needs of RA patients and look to their rheumatologist colleagues for guidance.

Patient access to rheumatology care will likely continue to be a problem in the coming years as patient demand continues to outstrip provider capacity.



DATA SPOTLIGHT

44.8 days

Average wait time for a rheumatology appointment for new patients¹

Quantifying the looming rheumatologist shortage

50%

of rheumatologists anticipated to retire in the next 15 years

< 300

pediatric rheumatologists practicing in the U.S.

102%

excess demand for rheumatology providers relative to supply by 2030

Closing the gap: MetroHealth uses patient coordinators to optimize the referral process



CASE
EXAMPLE

MetroHealth

4-hospital health system • Cleveland, OH

MetroHealth is planning to post a 0.5-1.0 FTE patient care coordinator position to be embedded in their rheumatology practice. They expect this modest investment to lead to a significant improvement in the efficiency of their clinic and in the satisfaction of their rheumatology patients.

Role of the patient coordinator:

- Facilitate referrals from PCPs to the rheumatology practice, including discussing pre-testing to make visits more meaningful and to reduce follow-up visits for issues that do not require in-person conversations
- Screen for urgent referrals and recommend physician review for expedited triage to optimize scheduling
- Contact patients in advance of their appointment to ensure all necessary labs and testing have been completed

1. Based on an analysis of wait time on the athenahealth network.

Source: Hayhurst, C. "The doctor will see you... sometime." Athena Insight. 2017. [Athenahealth.com/insight/doctor-will-see-you-sometime](https://athenahealth.com/insight/doctor-will-see-you-sometime); Volansky, R. "Shrinking Workforce, Increasing Demand Post Imminent Challenges in Rheumatology." Healo. 2018.

Appendix: Data analysis methods

For this analysis, we used a large clinical dataset of both commercially and publicly insured patients. We identified a cohort of patients diagnosed with RA for the first time in 2016. We then filtered this group to include patients for whom we had clinical note data prior to their diagnosis. There were 9,404 patients in the cohort after filtering.

We used natural language processing (NLP) to analyze provider notes from these patient encounters from 2009 through their diagnosis in 2016. For each patient, we identified the earliest visit during which joint pain was recorded. We then calculated the time from that encounter to their first RA diagnosis to estimate the time between RA symptom onset to RA diagnosis.



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