Utilization Management, Insurance Barriers Survey & Focus Group Findings
2024

Arthritis Foundation®

arthritis.org/advocacy

People living with arthritis rely on nearly every aspect of the health care system — from access to specialists and prescription drugs to medical research. This report presents findings from online surveys and focus groups of arthritis patients, both affiliated and not affiliated with the Arthritis Foundation, to gain a deeper understanding of the impact of Utilization Management (UM) protocols, especially step therapy and prior authorization.

Utilization management (UM) refers to techniques used by health insurance companies and other health care benefits purchasers to control health care costs. These techniques include strategies like prior authorization and step therapy, which assess the medical necessity and appropriate use of a product or service before the insurer approves coverage and payment.

Prior authorization, also known as preauthorization or precertification, is a requirement by health insurance companies to gain approval from the insurer before rendering the service or treatment. The process intends to verify that the prescribed care is medically necessary and cost effective, according to the insurer's criteria. Step therapy, or "fail first protocols," requires patients to try insurer-preferred medications before those initially prescribed by their doctors. These and other UM practices can significantly impact timely access to proper patient care and treatment adherence, leading to irreversible disease progression and worsened health outcomes.

In this project, we sought to gain more granular insights into how often patients experience these practices, at what point during their treatment journey they occur, how long it takes to complete a step therapy or prior authorization requirement, and outcomes.

Overall, the report highlights the significant burden that step therapy and prior authorization processes place on patients living with arthritis, affecting their health outcomes and quality of life. Our findings underscore the need for policy changes to improve medication access and reduce the administrative burden faced by patients.

Surveys Overview

Two online surveys were conducted in July/August 2023, targeting a diverse group of patients living with arthritis. The first sample of 809 included participants from the Arthritis Foundation's Patient Voice Panel and Arthritis Foundation Advocates. The second survey included 750 arthritis patients who were not affiliated with the Arthritis Foundation.

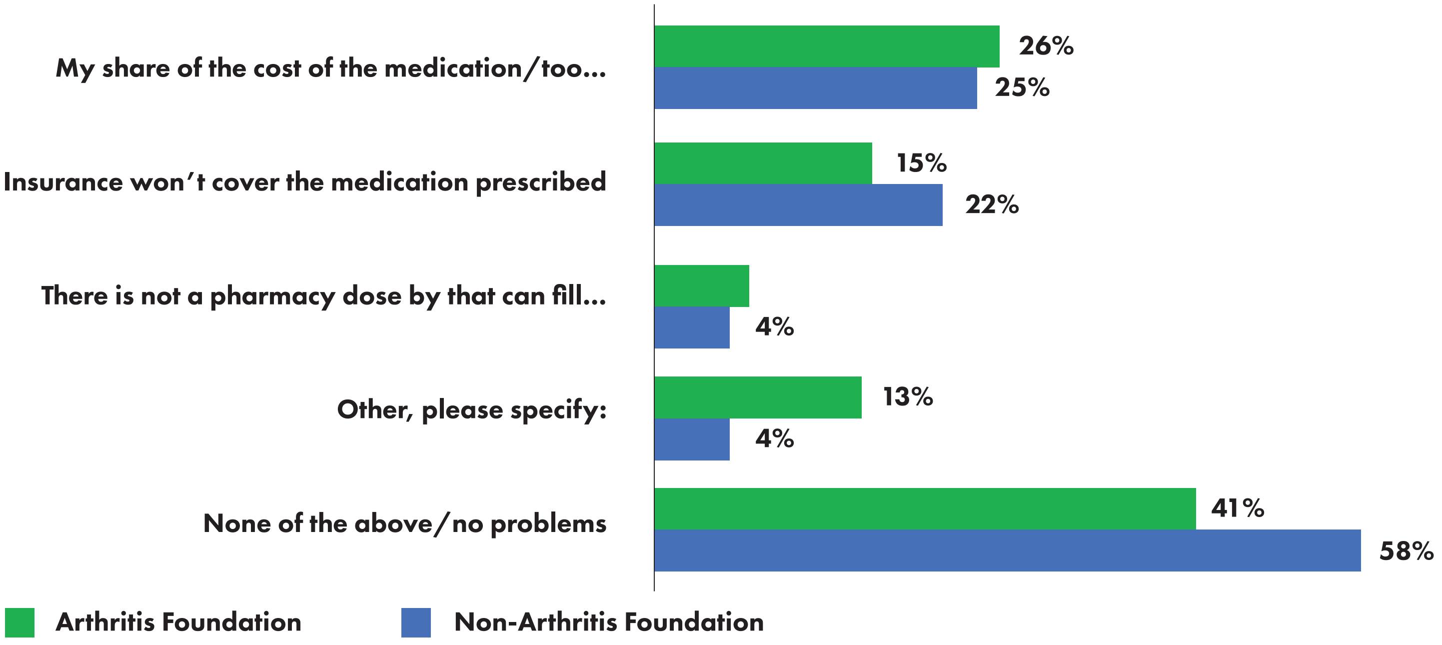
Arthritis patients face numerous, significant barriers to care, from understanding their health insurance plan to challenges in accessing prescribed medications. In particular, step therapy and prior authorization requirements are hindering access to medications for both groups of patients, particularly regarding out-of-pocket costs and coverage details.

Delays in obtaining medications led to many significant negative consequences, physically, socially and emotionally, including new or worse joint damage and increases in stress, anxiety and depression. Patients also reported an inability to participate in normal activities of daily living, including missing work or family activities.

Step Therapy Key Findings

- **Patients reported having the greatest difficulty getting clear answers about how much they would have to pay out of pocket and what their insurance would cover.**
- 59% of patients reported problems getting doctor-prescribed medications, primarily due to insurance coverage and medication costs.

PROBLEMS GETTING MEDICATION

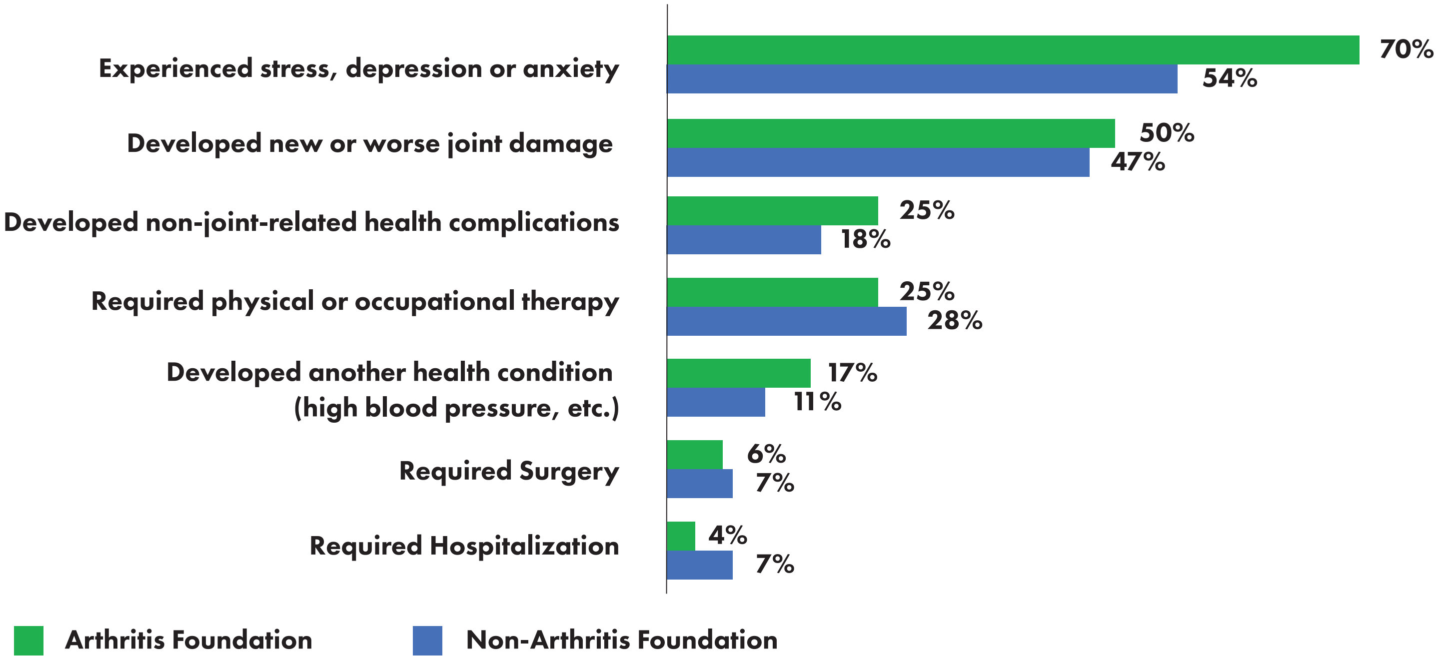


- 70% of those affiliated with theArthritis Foundation and 63% of those not affiliated underwent step therapy multiple times, with 12% having to go through step therapy five or more times for their arthritis medications in the past five years.

Health Impacts as a Result of Step Therapy

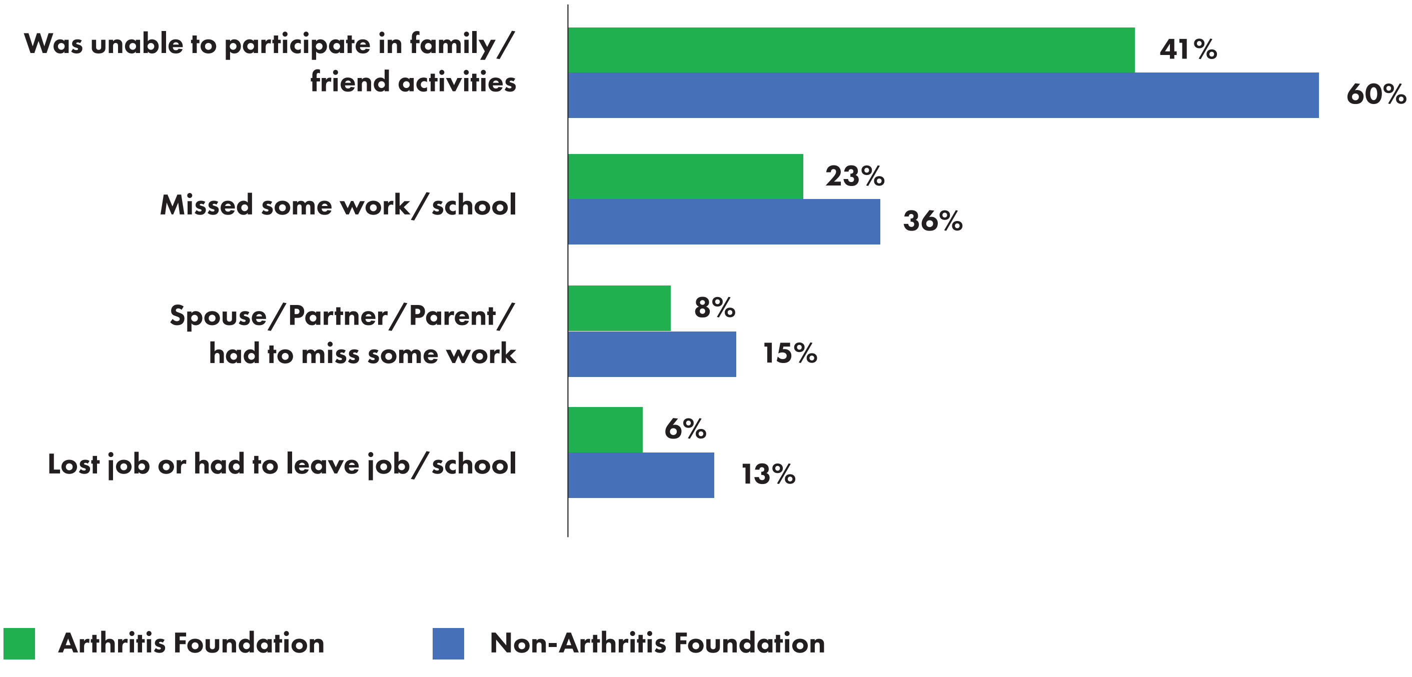
- **70% of patients affiliated with the Arthritis Foundation experienced stress, depression or anxiety.**

HEALTH IMPACTS AS A RESULT OF STEP THERAPY



- Half of all patients developed new or worse joint damage, and over 25% required physical and/or occupational therapy as a result.
- **More than half of all patients indicated their arthritis was at least somewhat well-managed before going through insurance-mandated step therapy protocols.**
- 41% of affiliated patients and 60% of those not affiliated were unable to participate in activities with family or friends.
  - **Over a quarter of all respondents missed work or school,** and nearly 15% indicated their spouse, partner or parent missed school to help take care of them due to step therapy.
  - 6% of affiliated patients and 13% of those unaffiliated lost their job or had to leave school/job as a result of step therapy.
- More than half of all patients requested an appeal to waive step therapy, but only about a third of these requests were granted.
  - Over 50% of patients waited five or more days for a response to their appeal request.
  - The top reason cited for requesting an exemption was having already tried and failed the drug that the insurer was requiring. The second most common reason was that the patient was stable on the medication. The third most common reason was that the drug was not clinically advised due to other medications the patient was taking.
  - More than a third of both groups of patients were required to step through three or more medications before receiving the drug initially prescribed.

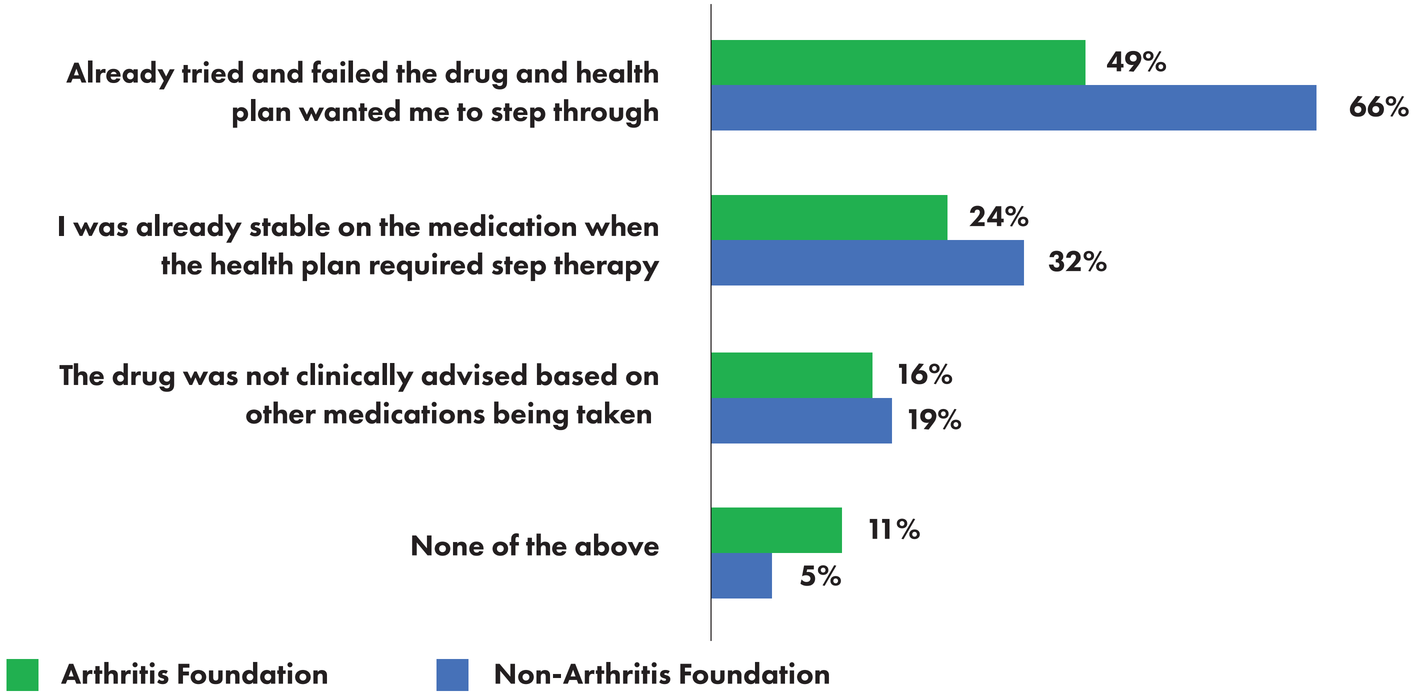
OTHER IMPACTS AS A RESULT OF STEP THERAPY



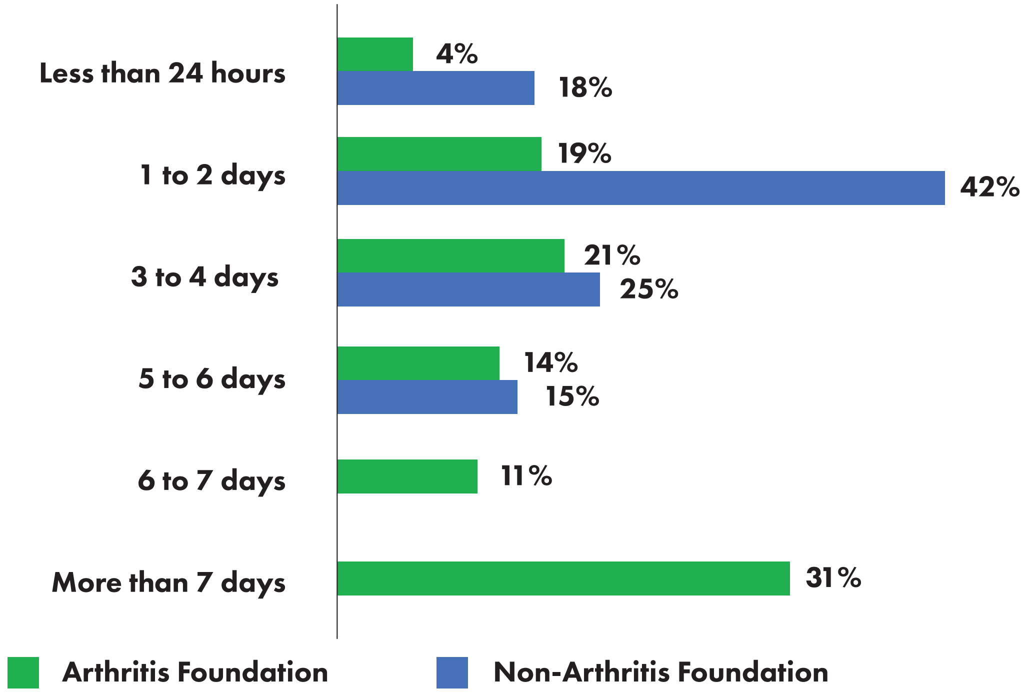
Prior Authorization Key Findings

- Patients indicated that step therapy and prior authorization were most often required when a medication was first prescribed. The most common reason was that it was required by their health plan.
- **37% of Arthritis Foundation-affiliated patients reported having to go through prior authorization every plan year for at least the previous five years.**
  - While most patients waited one or two days for a response to their appeal, over 31% of patients reported having to wait over seven business days for any response from their insurer.

REASON FOR REQUESTING AN EXCEPTION



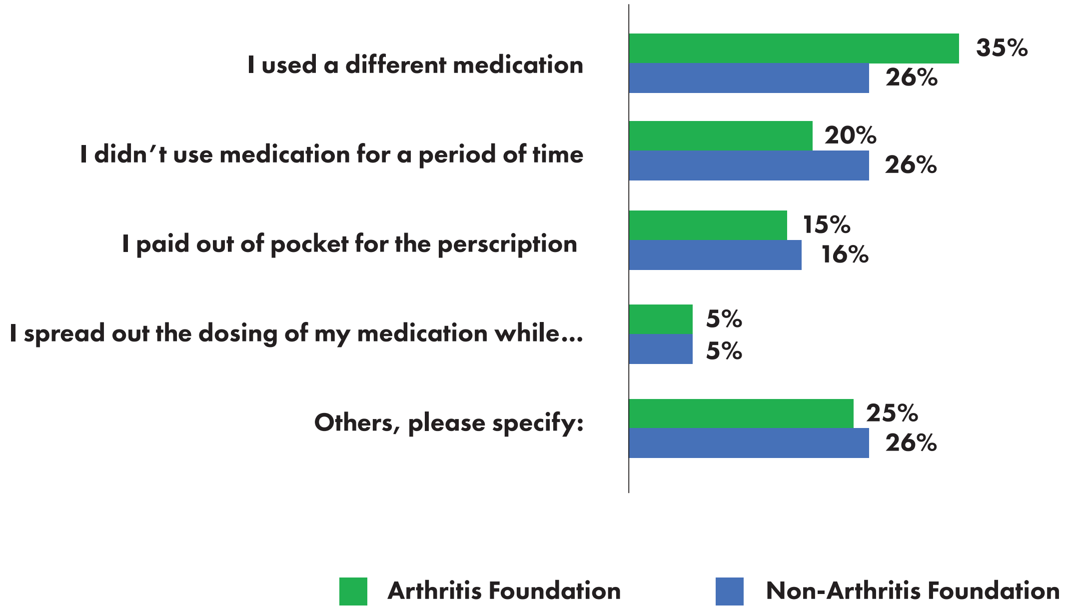
TIME WAITED FOR A RESPONSE



- **Arthritis Foundation-affiliated patients were significantly more likely to appeal a prior authorization decision** (71% vs. 46%).
  - o Of those who appealed, more affiliated patients had their appeal granted than unaffiliated patients (28% vs. 21%)

- **As a result of an unsuccessful prior authorization appeal, most patients had to switch to another medication.** Nearly a quarter did not use any medication for a period of time. About 15% paid out of pocket for their prescription, while others spread out the dosing of their medication while waiting for an appeal decision.

RESULT WHEN THE APPEAL WAS UNSUCCESSFUL



Survey Demographics: Arthritis Foundation-affiliated % (not affiliated %)

Arthritis Type

56% (33%) Rheumatoid Arthritis

56% (58%) Osteoarthritis

28% (16%) Fibromyalgia

27% (26%) Degenerative Disc Disease

20% (15%) Osteoporosis

16% (10%) Psoriatic Arthritis

14% (3%) Juvenile Arthritis

9% (5%) Ankylosing Spondylitis

5% (7%) Gout

Age

65-74: 30% (26%)

55-64: 25% (21%)

45-54: 16% (15%)

75-84: 15% (7%)

35-44: 6% (21%)

25-34: 4% (8%)

18-24: 2% (0%)

85+: 2% (0%)

Primary Health Insurance

Employer or spouse's employer: 32% (24%)

Medicare: 28% (15%)

Medicare Advantage: 24% (26%)

State Exchange/ Marketplace: 4% (7%)

Medicaid: 4% (22%)

Tricare/VA Plan: 2% (2%)

Focus Groups Key Findings

Three focus groups (one in person, two virtual) were conducted to explore the impact of UM protocols on patients living with arthritis and their treatment journeys. Key findings highlight substantial barriers to medication access, inefficiencies in communication and variability in successfully navigating insurance processes.

1. Insurance Barriers to Accessing Medication

All but one participant experienced one or more insurance barriers to medication, such as step therapy, prior authorization, denials, appeals, etc. They expressed similar issues and concerns, including frustration with the amount of time it took to manage the issue or wait for resolution. Most importantly, they experienced worsening joint symptoms and developed permanent joint or other damage while waiting. Even those who have been stable on a therapy for a period of time have been required to re-authorize or get re-approval, sometimes on a routine basis and sometimes randomly.

There was a broad sense of exhaustion among participants about the "fight." Many described fighting insurance barriers as a part- or full-time job. There was a slight difference in experiences among them in how they have navigated this; some were very supported by providers and provider offices and even described the provider handling it for them. Others expressed a more personal burden, needing to do it themselves to make sure they had access to what they needed.

2. Communication Approaches, Needs and Wants

Although participants varied in their preferred methods of communication, the group in general leaned toward digital methods (portal, email and text). More than anything, they just wanted communication to be accessible and transparent. Many had a sense of being walled off from what the insurance company was doing, both by those navigating the barriers themselves and those getting support from the provider. They also conveyed that efficient communication was important; the phone was particularly time-consuming, and waiting for responses was also frustrating. The worst offender was regular (snail) mail, with participants sharing stories about receiving letters after an issue had already been resolved.

3. Changes or Unique Needs Across Patients' Lifespans

Participants' reports varied about whether these processes have gotten easier or harder over time. Some cited specific times when navigating was more difficult, like the transition from pediatric to adult care, or during and after significant medical events, like childbirth or menopause. Others referenced processes in their providers' offices that influenced the way medication and other issues are handled, such as the addition of office staff to manage insurance denials and approvals. Despite this extra staff assistance, many patients were still frustrated by the process — especially being shut out and unable to know where their medications were "in the process."

4. Ideas for Improving the "Process"

Many expressed frustrations about the opacity of the processes. They want to be self-sufficient and drive the process. And if not, at least to be aware of where in the process they are. Many participants shared aspects of how clunky and unclear the process is.

They also shared a desire for more concrete processes that are universal across plan type and geographic location. Interestingly, two people specifically called for a clear definition of "fail" in fail-first policies, including the amount of time required for the failure. Someone suggested an "Uber"-type approach that visually indicates where the therapy is in the process of being approved and available.

The idea of the provider playing a key role was raised by a few people. They shared examples like having the provider supply detailed notes from clinical visits and be involved in efforts to access medication, as well as hopes for greater engagement with the provider to better understand how to navigate the insurance process (i.e., having the steps written down and explained).

5. Additional Themes

The nature/type of insurance was not discussed among the second group of participants in the same way as in the first, but distinctions between types of insurance did surface. Notably, we found that barriers occur even with "good" insurance (i.e., large group plans). There were also several references to the role of pharmacy benefits managers, all of which were negative.

Issues beyond medication management also came up and with similar concerns, such as delays in care, delays in symptom relief and sometimes irreversible damage resulting from such delays. These barriers include needing specific referrals for care by specialists and access to diagnostic or therapeutic services, such as MRI imaging or physical therapy. And participants voiced the same frustration about having to "fight," expending time and energy, and needing to push through the barriers to get results, either individually or through providers.

Conclusion

Patients possess valuable insights that can help streamline and improve health insurance processes, making them more efficient and user-friendly. Exploring partnerships with health plans to understand the reasons behind current cumbersome UM practices and co-design better systems could be beneficial. Additionally, quantifying the health impacts of these practices on patients is crucial, particularly the effects of treatment delays and overall cost-effectiveness of current practices. Understanding the long-term and indirect effects, including the stress and potential health consequences that patients face while seeking to access their medications, is essential to improving the overall health care system. Our findings underscore the urgent need for step therapy reform to improve patients' timely access to effective treatments to better manage their arthritis.