



OCTOBER 2017

RHEUMATOID ARTHRITIS: ACCESS, POLICY AND ADVOCACY GOALS

The European Alliance for Patient Access brings together physicians and patient advocates from across the globe to advocate for policies that protect patients' access to advanced medicine. Their unique insights can guide policymakers to make informed decisions about value, safety, cost and, ultimately, patient access. This policy brief organises feedback from international meetings of EAFPA and its partners with the goal of facilitating international dialogue and advancing direct advocacy efforts on patient access to treatment for rheumatoid arthritis.

INTRODUCTION

Rheumatoid arthritis (RA) is a painful autoimmune disease that creates inflammation and progressive deterioration of the joints. The body's mistaken immune response causes it to attack its own tissues.

Women are three times more likely to develop RA than men,¹ and there are significant geographical differences. The annual incidence rate of RA for adults ranges from 22 cases per 100,000 in the United Kingdom to 35 per 100,000 in Finland.² More than 23 million people have RA worldwide, including over 6 million in Europe.³

HEALTH CARE CHALLENGES

Though RA is widespread, proper and timely diagnosis and treatment remain a common challenge.

Many individuals with RA do not recognise early symptoms and often confuse them with simple musculoskeletal pain from overexertion or as a sign of getting older. This may also be the case with general doctors or internists. There is also a stigma among the public about going to the doctor “without good reason” or “just” for arthritis. Therefore, it can go undiagnosed and untreated for years.

Thus, early detection and proper diagnosis are essential areas for improvement. Yet general practitioners often do not recognise early signs of RA, causing delays in referrals and leading to significantly sub-optimal outcomes. In addition, patients can be slow to refer themselves and miss the window of opportunity during the first 12 weeks after onset of symptoms, when intervention can make a positive, long-lasting impact.⁴

There is also a stigma among the public about going to the doctor **“without good reason” or “just”** for arthritis. Therefore, it can go undiagnosed and untreated for years.

Patients more often seek out a primary care physician believing they need treatment for an injury or other condition—and there are, in fact, numerous conditions that need to be ruled out before an accurate diagnosis of RA can be made. It is important that clinicians examine family history. But once again, generations of individuals can underreport RA and be embarrassed to share their problem with a family member, so this information can be incomplete or unreliable. Scrutinising a patient's own medical history, performing a thorough physical exam, and conducting blood tests and imaging tests can all be critical steps.

Even with a proper diagnosis, patients may not get a **timely and appropriate referral.**

Even with a proper diagnosis, patients may not get a timely and appropriate referral. Primary care physicians often see their roles as a “gatekeepers” and may be disincentivised to refer patients to a specialist. Yet primary care physicians don't have the training or resources that a rheumatologist has, so they may take multiple visits over weeks or months to finally refer a patient. This is complicated by the fact that there are rheumatologist shortages across Europe, so too many patients are inappropriately referred to orthopaedists instead.

POLICY RECOMMENDATIONS

The challenges faced by patients with rheumatoid arthritis suggest several key areas where policy improvements are needed.



Physician Education

The most important intervention has to happen on the front lines. Primary care physicians need a better understanding of RA, and this can and should occur in multiple environments. Study requirements on rheumatic diseases for medical students should be increased beyond the required six hours of training. There have been workshops for general practitioners, with rheumatologist involvement, to help raise awareness of rheumatic diseases; such activities should also be more prevalent and better funded.

Nurses should also be trained in rheumatology and be empowered to care for patients with RA independent of physician supervision. In countries where the specialist rheumatology nurse has been established, such as the United Kingdom, the Netherlands and Germany, patient care has experienced great improvements.



Patient Empowerment

Patients should be encouraged to serve as active participants in their own treatment journey, and this begins with patient education—even prior to diagnosis. Improving public awareness and supporting patients to discuss RA with their doctors may lower treatment costs significantly in the long run, and can improve outcomes. These discussions should become regular and ongoing. Patients might convey any changes or worsening in their symptoms, as well as details about which everyday activities exacerbate symptoms. Those who receive treatment can communicate how the therapy is impacting them. Beyond the details of their experience, however, patients should communicate their goals for treatment, working with their physician to reach a common definition of remission. Patients should be empowered to make informed choices about diagnosis and treatment in conjunction with their treating physician.

It is also important that patients' empowerment extends beyond the clinic. Patients should be better prepared to self-manage their RA by being provided with resources, such as validated patient information and referral to relevant patient associations, that allow them to live independently for the substantial part of their lives when they are not directly utilising clinical support.

Additionally, due to poor awareness amongst patients and lack of prioritisation from physicians, pharmacovigilance—the monitoring of adverse events experienced as a result of medical therapies—is underpowered. More robust monitoring and reporting would not only aid patients' own courses of treatment, but also compel pharmaceutical and biotechnology companies to analyse the real-world outcomes, report them to the European Medicine Agency, and adjust their recommended uses and product labelling if necessary.



Patient-Reported Outcomes

By increasing awareness and fostering prompt action as described above, we can also strengthen our overall societal management of the consequences of RA. If patients are better informed, they are likely to be more aware and conscious of their individual experiences. Those experiences should be welcomed and analysed by thoughtful policymakers. While clinical research plays a critical role in advancing medicine, patient-reported outcomes offer an equally valuable glimpse of how patients respond to advanced medicine in real-world settings. Physicians, policymakers and payers who shape access policies must be equipped to receive and respond to information from the general RA population.



Payer Participation

Policy improvements must involve payers as well. In addition to representing the interests of individual patients, a more proactive case for removing barriers to access should be made to improve the efficiency and effectiveness of programmes at the national level. Payers must work toward incorporating the patient perspective to help shape better public policy throughout Europe.



Shared Decision-Making

These recommendations add up to one overarching principle: Physician objectives and patient needs must be aligned. Common goals are particularly important for treating to target, which is a widely-used, goal-focused approach to moving rheumatoid arthritis patients toward remission or reduced disease activity.⁵ The physician-patient relationship is the crux of quality care; no decision, be it an initial choice of medication or the choice to switch that medication, should be made without the patient being appropriately informed and having the opportunity to discuss this with his or her physician.

CALL TO ACTION: COORDINATED ADVOCACY

As the patient advocacy community looks to expand access for those living with RA, there must be collaboration towards broad-scale improvements that incorporate these five principles:

- » Primary care physicians who are better educated about RA
- » Patients who are empowered to recognise, report and help to manage their symptoms
- » Policy that takes into account the needs and wishes of individual patients
- » Payer involvement in questions of patient-centered treatment
- » Shared decision making between patients and their physicians.

These principles in action can help women and men living with RA throughout Europe to have more timely, appropriate and effective access to treatment.

REFERENCES

1. Arthritis.org [Internet]. Atlanta: Arthritis Foundation; c2017. What is Arthritis? [cited 2017 Sept 5]; [about 1 screen]. Available from: <http://www.arthritis.org/about-arthritis/types/rheumatoid-arthritis/what-is-rheumatoid-arthritis.php>
2. Muscular Health in Europe Summary Report. Zurich: European League Against Rheumatism; c2017 [cited 2017 Sept 5]. 191 p. Available from: <http://www.eumusc.net/myUploadData/files/Musculoskeletal%20Health%20in%20Europe%20Report%20v5.pdf>
3. The Global Burden of Disease: 2004 Update. Geneva: World Health Organization; c2008 [cited 2017 Sept 5]. 160 p. Available from: http://www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_full.pdf
4. Van der Helm-van Mil AH. Early recognition of reumatoid arthritis. Ned Tijdschr Geneesk. 2011;155(30-31):A2902.
5. American College of Rheumatology [Internet]. Atlanta: American College of Rheumatology, Association of Rheumatology Health Professionals, and Rheumatology Research Foundation; c2017. Press release, Is Treat-to-Target Really Working for People with Rheumatoid Arthritis; 2015 Nov 8 [cited 2017 Sept 5]; [about 2 screens]. Available from: <https://www.rheumatology.org/About-Us/Newsroom/Press-Releases/ID/700/Is-Treat-to-Target-Really-Working-for-People-with-Rheumatoid-Arthritis>



About the European Alliance for Patient Access

The European Alliance for Patient Access, a division of the Global Alliance for Patient Access, is a network of physicians and patients advocating for patients' access to approved medical therapies and appropriate clinical care.

To learn more, visit www.GAfPA.org.

GAfPA.org