

Delay in diagnosis of axial spondyloarthritis revealed

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The current delay to diagnosis from symptom onset represents one of the greatest challenges in axial spondyloarthritis (axSpA)—a type of inflammatory arthritis affecting the back. Research shows an average

delay of almost 7 years—and up to 15 years in some cases—during which time the condition can progress and lead to irreversible damage. Data indicates that women wait longer than men for a diagnosis, and there has been very limited progress in reducing the time to diagnosis. This delay has a hugely detrimental impact on a person's quality of life. Because the disease frequently has early onset, individuals are left untreated—or with incorrectly treated symptoms—at a formative period in their life course.

The Axial Spondyloarthritis International Federation (ASIF) set out to coordinate a comprehensive evidence-based global review of the factors influencing the current [diagnosis delay](#) in axSpA, and to produce a definitive report that shines a light on these barriers, as well as providing a resource that can ultimately empower a range of international stakeholders to reduce this delay.

At the 2021 EULAR congress, Wendy Gerhart and colleagues report the results of a full literature review and two virtual global forum events, involving patients and patient group representatives, researchers, rheumatologists, and other [healthcare professionals](#). The aim was to explore key diagnosis challenges across different healthcare systems and identify opportunities for addressing these. Break-out discussions were held, and participants were asked to identify the personal and societal effects of the diagnostic delay, the reasons it occurs, and initiatives to tackle the challenge. Alongside key stakeholder testimonies, best practices from around the world were also identified. In total, 92 stakeholders participated in the events, representing patients and healthcare professionals from 23 countries across five continents.

The findings from these activities were incorporated within a new 'Delay to Diagnosis' report, which for the first time definitively sets out the lived realities from a global perspective of the axSpA diagnosis delay. The report identified important commonalities across different countries

and healthcare systems contributing to the current average global 7-year diagnosis delay. These include: 1) poor awareness of axSpA, particularly in primary-care services; 2) complexities in diagnosing the disease; 3) poorly defined referral pathways; and 4) insufficient patient access to rheumatologists and appropriate diagnostics.

The report also highlights the significant impact this delay has on individuals and wider society, providing a foundation for future advocacy work. A series of recommendations has been identified, the implementation of which will help make tangible progress in reducing the delay.

Despite longstanding challenges, there are now clear opportunities for transforming how axSpA is diagnosed around the world. This message needs to be heard and acted upon urgently by all those involved in the management and delivery of axSpA care. The future program of work for ASIF's Delay to Diagnosis project will respond to these findings and be centered around supporting axSpA patient associations globally to take this call to action forward throughout 2021 and beyond.

Provided by European Alliance of Associations for Rheumatology

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