

The Unacceptable Delay in Axial Spondyloarthritis Diagnosis: A Global Call to Action

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7 YEARS AVERAGE DIAGNOSIS

Background and objectives

Research shows that, globally, the average diagnostic delay in Axial Spondyloarthritis (axSpA) is 7 years. In some countries, it is much worse. Comparative figures from the previous three decades show that the time to diagnosis has not reduced at all.

This delay is clearly unacceptable when you consider the turmoil and suffering an individual must endure during the time they wait for a diagnosis. ASIF wanted to highlight this human experience to demonstrate the impact of the delay and explore the challenges we face in trying to improve it.

We set out to compile a report, underpinned by the latest research and expert testimony, that identifies recommendations to improve the situation. Our goal is to use the report as a springboard for further action, to support our members in their work, and to reach a variety of audiences to initiate conversations about how the delay can be improved.



Methods

To bring together the anecdotal evidence and human stories, we hosted two Global Forum events in the autumn of 2020. Over 45 people attended each event; patients and patient representatives; rheumatologists and other healthcare professionals; and researchers were all present. We held break-out discussions, with each table hosting a mixture of patients and HCPs, as well as a range of geographical representation. In order to compile the report, we carried out a full literature review on diagnostic delay research, reviewed the discussions from the Global Forums and sought contributions from a range of experts.

The report

On 28 June, we published our Delay to Diagnosis report. It is a blend of empirical research, expert testimony and patient stories. Predominantly it shines a light on the human burden of waiting many years for a diagnosis. It includes:

- four detailed patient case studies
- a foreword written by the Presidents of ASIF and ASAS
- 20 expert contributions from healthcare professionals and patient organisations from around the globe
- and four examples of good practice that aim to reduce the delay.

The report also sets out:

- six barriers to timely axSpA diagnosis
- and makes five recommendations for change that can improve the diagnostic delay

Barriers

The report identified six barriers to timely diagnosis, which are:

1. Limited awareness of axSpA amongst those with symptoms
2. Lack of axSpA understanding amongst the general population
3. Incorrect / misdiagnosis at first point of healthcare system contact
4. Pathway and referral challenges
5. Challenges in accessing specialist care
6. Challenges within rheumatology

Recommendations

We also set out five recommendations for change. An overview of these are:

1. Healthcare leaders and decision-makers joining national level conversations
2. Broader awareness campaigns
3. Collaborative approaches to diagnosis challenges
4. Healthcare leaders to raise awareness of best practices
5. Delay initiatives should be underpinned by robust data

Read the full report and recommendations at:
<https://asif.info/delay-to-diagnosis-report>

Average diagnosis times

1990s

2010s

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